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Women's experience of coping with termination of pregnancy for fetal abnormality: Coping strategies, perinatal grief and posttraumatic growth

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A thesis submitted in partial fulfilment of the requirements of the University of West London for the degree of Doctor of Philosophy

June 2015

Abstract

Pregnancy termination for fetal abnormality (TFA) represents 2% of all terminations in England and Wales. In recent years, the number of TFAs has risen (3,099 in 2014 compared to 2,085 in 2009) due to technological developments in prenatal diagnosis and increased maternal age, which have led to a growing number of fetal abnormalities being identified, and this earlier in pregnancy. Research suggests that TFA can have negative, long-lasting psychological consequences for women. These include depression, posttraumatic stress disorder and complicated grief. However, at the inception of the research programme, no research had been conducted on women's coping processes when dealing with TFA despite clear evidence of a relationship between coping processes and psychological adjustment in other areas of health research. Similarly, although research indicates that some individuals experience positive growth as a result of trauma, no empirical work had been undertaken on potential positive psychological outcomes following TFA. Finally, a dearth of research on health professionals' understanding of women's coping with TFA was also identified, despite the likely impact this understanding would have upon women's experience of care and the way they cope with TFA.

This thesis aims to address these knowledge gaps in order to further our understanding of women's experience of TFA. Specifically, the research had three main objectives: 1) to gain an understanding of women's coping strategies when dealing with TFA; 2) to examine the relationship between coping and psychological outcomes, as defined by perinatal grief and posttraumatic growth; and 3) to investigate health professionals' perceptions of women's coping to identify potential disparities between health professionals' and women's accounts.

To answer these objectives, a mixed methodology was utilised and five studies were conducted: a systematic review of the qualitative evidence pertaining to women's experiences of TFA; two qualitative studies: the first one exploring women's coping strategies when dealing with TFA, and the second one investigating health professionals'

perceptions of women's coping; and, finally, two quantitative studies: the first one examining the relationship between coping strategies and perinatal grief, and the second one assessing the relationship between coping, perinatal grief and posttraumatic growth. The empirical work relating to the women was carried out online, with participants recruited from a specialist support organisation. The empirical work concerning the health professionals was conducted face-to-face, with participants recruited from three hospitals in England. Ethical approval was obtained for all studies prior to fieldwork commencing.

The research generated several important findings, which both build upon existing evidence and further our insights into women's experience of TFA. Firstly, the research clearly indicates that women regard TFA as a traumatic event, which is akin to an existential crisis and which can have negative psychological consequences. Women view TFA as a unique form of bereavement, which can be misunderstood and stigma-bearing. The research also indicates that TFA is an individual as well as a social phenomenon with women's experiences both shaping and reflecting the political and sociocultural environment within which TFA occurs.

Secondly, the research shows that coping with TFA involves four main strategies: 'support,' 'acceptance,' 'avoidance,' and 'meaning attribution' which are relevant to both the termination procedure and its aftermath. The findings also reveal that, despite mainly using coping strategies considered to be adaptive, women's levels of grief are high, and that, for some individuals, distress persists long after the termination. The research also provides evidence of a relationship between coping and psychological adjustment to TFA, with strong associations observed between several coping strategies and psychological adjustment. In particular, the research shows that coping strategies such as 'acceptance' and 'positive reframing' are closely associated with lower levels of grief, whilst 'self-blame' and 'behavioural disengagement' relate to higher grief levels.

Thirdly, the research offers new insights into the potential for personal growth following TFA. This is particularly manifest in the qualitative investigations and, although it is less evident in the quantitative study, moderate levels of growth were observed for several

growth dimensions: 'relating to others,' 'personal strengths' and 'appreciation of others.' The findings also indicate that a relationship exists between coping and posttraumatic growth, with 'positive reframing' being a significant predictor of growth.

Lastly, the findings reveal that health professionals have a valid understanding of women's short-term coping strategies when dealing with TFA, but have limited insights into their long-term coping processes. This points to a deficit in aftercare, an issue which was raised by the women in this research.

Collectively, these findings have important implications in terms of theory, practice and future research in the area of TFA, which are considered in this thesis. Among the most significant ones are the need to identify women at risk of poor psychological adjustment, the need for a truly women-centred care that continues well beyond the termination, as well as the importance of 'acceptance' and 'positive reframing' as potential protective factors against distress and of 'positive reframing' as a potential foundation for growth. A corollary of the research is the development and implementation of a psychological intervention to support women following TFA. This proposed intervention is underpinned by the reported high levels of grief, the deficit in aftercare, and the potential for growth following TFA, and represents the next step of the research programme.

Acknowledgements

I would like, first and foremost, to acknowledge both my supervisors, Professor Kathryn Mitchell and Dr Pauline Fox, for their continuing support, encouragement and guidance through this immensely stimulating and rewarding academic journey. I cannot thank them enough for the advice they have given me and for their interest in my work. For all this, I am extremely grateful. My thanks also go to my colleagues in the Psychology department and, in particular, to Lee Usher for being such an empathetic listener.

I also wish to thank Jane Fisher and Sally George from Antenatal Results and Choices (ARC) who have been extremely supportive throughout this process, not least by giving me the opportunity to interview ARC members. I would also like to express my gratitude to Helen Statham from the University of Cambridge for her support and for having shared with me her experience of conducting research in the area of pregnancy termination for fetal abnormality. Last but not least, I wish to acknowledge the generosity and openness of the participants, whose moving and humbling stories I have had the privilege to share.

Finally, I wish to express my extreme gratitude to my husband, Tris, for his unwavering support during this journey, and to my lovely children, Greta and Laszlo, who have been so patient and have refrained from asking 'when are you finishing your PhD?' I would also like to thank my close family and friends for their continuous support and encouragement, and the hours of childcare they have provided me with.

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Overview of thesis

This thesis is about women's experience of coping with termination of pregnancy for fetal abnormality (TFA). TFA is an important topic to investigate because it is a unique and complex phenomenon. TFA is similar to other perinatal losses (e.g. miscarriages, stillbirths and neonatal deaths) in that parents lose a baby before or around the time of birth. Further to the loss of the baby itself, parents also experience the loss of the hopes and dreams that accompanied the pregnancy. However, TFA is also fundamentally different from miscarriage and stillbirth in that it is self-perpetrated, and from neonatal death in that it occurs during pregnancy. It also differs from abortion for non-medical reasons in that the pregnancy is, in most cases, wanted. TFA is also unique because it results from parental choice and the decision is based upon disability-related considerations. Thus, it bears a moral and ethical dimension, which adds a level of complexity to this event. TFA is also an important topic because of its impact upon individuals. TFA can have profound long-lasting psychological consequences for those involved (including posttraumatic stress, depression and complicated grief). As a social phenomenon, TFA also impacts upon the wider society. TFA both reflects and influences the legal, political and social context within which the individual experience of TFA takes place. Finally, TFA is a growing phenomenon. The number of women facing TFA is likely to rise due to technological progresses in prenatal diagnosis and increased maternal age.

Given the current relevance of TFA to individuals and the wider society, it is important to understand women's experience of coping with TFA, particularly because coping has been shown to relate to psychological outcomes. Therefore, it is essential to understand women's use of coping strategies when dealing with TFA and how these relate to their psychological adjustment. It is also essential not to limit any investigation about TFA to its negative psychological outcomes. Research has demonstrated that following a trauma, individuals may experience positive growth, therefore, concepts such as posttraumatic growth may also be relevant to TFA. The research presented in this thesis addresses these

issues. The ultimate aim of the research is to further the understanding of women's experience of coping with TFA, with a view to translate this knowledge into practice and inform policy making, for the benefit of the women and their families.

Chapter 1 provides an introduction to the research. It outlines the context of the research in terms of the medical, legal and ethical frameworks that are relevant to TFA. It provides a review of the quantitative literature pertaining to the psychological outcomes of TFA and the factors that may be associated with it. The chapter also presents the three constructs which underpin this research's focus and are pertinent in the context of TFA: perinatal grief, coping and posttraumatic growth. The chapter concludes by presenting the rationale, aims and objectives of the research.

Chapter 2 describes the first study (Study 1), which consists of a systematic review and synthesis of the qualitative evidence of women's holistic experiences of TFA.

Chapter 3 presents the rationale for the methodological approach used in the research, namely the use of a mixed-methods approach grounded in the pragmatic paradigm, the use of a support organisation as a sampling pool and the use of mostly an online medium to gather the data. The chapter also describes the methods used to conduct the empirical work, both quantitative and qualitative.

Chapter 4 depicts the first empirical study (Study 2a), which focuses on exploring women's coping strategies when undergoing TFA. In particular, it examines the coping strategies used by women at the time of the procedure and afterwards.

Chapter 5 describes the second empirical study (Study 2b) which consists of a quantitative assessment of women's coping strategies and their relation to perinatal grief. The influence

of various factors (demographics, and termination-related variables) is examined and the predictors of grief are identified.

Chapter 6 details the third empirical study (Study 3), which focuses on health professionals' perceptions of women's coping with TFA. The women's and health professionals' accounts are compared to identify the similarities and differences between the two groups.

Chapter 7 depicts the fourth empirical study (Study 4), which centres on posttraumatic growth following TFA. In particular, it measures posttraumatic growth in the context of TFA and assess its relationship to women's coping strategies and levels of perinatal grief. The predictors of posttraumatic growth are also identified. This study also serves a confirmatory purpose as coping strategies and levels of perinatal grief are assessed for a second time. A brief longitudinal analysis is also provided.

Chapter 8 provides an overall discussion to the research. The implications of the research in terms of theory, practice and future research are discussed. The chapter also outlines the studies' strengths and weaknesses. As a corollary of the research presented in this thesis, a proposal for a psychosocial intervention to support women post termination is also described.

Chapter 1 - Introduction to the research

This chapter provides an in-depth analysis of the theoretical approaches and research which addresses the field of pregnancy termination for fetal abnormality (TFA). It outlines the context within which women experience pregnancy termination for fetal abnormality in terms of medical, legal and ethical frameworks, and presents a review of the literature on women's psychological adjustment to TFA and the factors that may be associated with it. The psychological constructs relevant to TFA i.e. perinatal grief, coping and posttraumatic growth in the context of TFA are also introduced. The chapter concludes by presenting the overarching rationale for the research, its aims and objectives.

1.1 TFA in context

1.1.1 Medical and legal frameworks surrounding TFA

1.1.1.1 The development of prenatal screening and diagnosis

TFA is intrinsically linked to the practice of prenatal screening and diagnosis. Prenatal screening and diagnosis is a relatively new phenomenon, which dates back to the early 1970s and aims to identify diseases of the fetus (Bewley, 2003; National Health Service Fetal Anomaly Screening Programme, n.d. [NHS FASP]; National Institute for Health and Care Excellence [NICE], 2008). Estimates indicate that approximately 3% of pregnancies are affected by a disorder and that congenital abnormalities are the second commonest cause of infant deaths (under one year of age) in England and Wales (Kurinczuk, Hollowell, Boyd, Oakley, Brocklehurst, & Gray, 2010). The practice of prenatal screening and diagnosis has been driven by a wish to identify fetal abnormality as early as possible in pregnancy (Nicolaidis, 2011). This is to enable reproductive choice (whether to continue or end the pregnancy), to prepare for any outcomes (termination, palliative care or postnatal treatment), to manage delivery at a specialist unit, and to enable in utero therapy (NHS FASP, n.d.; NICE, 2008).

Prenatal screening and diagnosis is the result of the collaboration between three medical technologies: amniocentesis, the ability to study human chromosomes, and obstetric ultrasound (Löwy, 2014). The first technology relates to the ability to sample the amniotic fluid. Amniocentesis, initially called amniotic tap, was developed at the end of the 19th century and was used to test for polyhydramnios, or excess of amniotic fluid, a condition associated with diabetes (Hogan, 2013). From the 1950s, amniotic fluid was used to access fetal cells to check the fetal sex and detect sex-related diseases. Renamed amniocentesis in the 1960s, the technique was seen as a great technological innovation, but health professionals also identified that it carried a risk of miscarriage and therefore, offered it sporadically (Löwy, 2014). By the 1980s, however, amniocentesis was considered the 'gold standard' of prenatal diagnosis techniques and was widely used to identify fetal disorders in the second trimester of pregnancy (Hogan, 2013).

The second technology relates to the ability to test human chromosomes. In the late 1950s, a technique was developed that enabled the identification in utero of aneuploidies (irregular number of chromosomes) such as Down's, Edwards' and Patau's syndromes. This new technique, later refined to enable the detection of chromosome structural anomalies such as deletions and translocations (Hogan, 2013), played a significant role in the development of mass screening in the mid-1990s (Löwy, 2014). In the 1980s, a new technique to collect fetal cells from the placenta was discovered. Chorionic villus sampling (CVS) enabled chromosomal analysis to be conducted from ten weeks of gestation rather than 16 weeks as indicated for amniocentesis (Evans, Andriole, & Evans, 2015; Hogan, 2013), thus moving prenatal diagnosis earlier in the pregnancy. Both CVS and amniocentesis still carry a 1-2% risk of miscarriage (NHSa, n.d.; RCOG, 2011; Weisz & Rodeck, 2009).

The third technology relates to the development of ultrasound techniques. Initially used to measure the fetus and date the pregnancy, ultrasound has been increasingly utilised in prenatal screening since the 1970s (NICE, 2008). This is particularly the case since an increase in fetal nuchal translucency was identified as a possible marker for chromosomal

defects in the 1990s (Nicolaides, Azar, Byrne, Mansur, & Marks, 1992; Russo & Blakemore, 2014). This technique has evolved to enable visual detection of complex fetal structural anomalies during the mid-pregnancy scan and fetal growth problems (NICE, 2008). It has also contributed to making CVS and amniocentesis easier, and thus safer for health professionals to carry out (Löwy, 2014).

1.1.1.2 The development of mass prenatal screening

Prenatal testing diagnosis was originally offered to women considered to be at high risk of fetal disorders. For example, Down's syndrome testing was initially offered to women over 35 years of age (Boyd et al., 2008; Löwy, 2014; Russo & Blakemore, 2014). However, the realisation that this condition affected babies born from women of various ages and without any hereditary predisposition, meant that targeting women over 35 was too restrictive. The discovery of a link between fetal nuchal translucency and Down's syndrome in the early 1990s, alongside the identification of biomarkers for Down's syndrome, underpinned the drive to extend prenatal screening to the wider population of pregnant women (Löwy, 2014; Nicolaides, 2011). Mass prenatal screening has become the norm in high-income countries, and is organised around two elements: screening and diagnosis. Screening tests aim to identify women at high risk of fetal disorders. These tests are conducted for disorders that are relatively common, and for which prenatal diagnostic tests are available. Diagnostic tests are then offered to women who have been identified at high risk of a fetal disorder by screening tests (NHS FASP, n.d.).

1.1.1.3 Prenatal screening and diagnosis in 2015 in England

Currently, pregnant women in England are offered prenatal screening tests for a range of conditions under the NHS (NHS FASP, n.d.). These include infectious diseases, inherited blood disorders, such as sickle cell disease and thalassaemia, and genetic and structural fetal anomalies. The screening tests for fetal anomalies are conducted at different gestational ages and involve different techniques (NHS FASP, n.d.; NICE, 2008. RCOG,

2010). The first test is the combined screening test. It is carried out in the first trimester of pregnancy and calculates the risk of carrying a fetus affected by Down's syndrome or trisomy 21 (Twiss, Hill, Daley, & Chitty, 2014). It has a detection rate of 85-90% (NHS FASP, n.d.; Nicolaides, Wright, Poon, Syngelaki, & Gil, 2013). Since April 2015, the combined test is also used to screen for Edwards' and Patau's syndromes (trisomies 18 and 13 [NHS FASP, n.d.]). This test is based on maternal serum biomarkers and ultrasound measurements for the nuchal translucency. Women found to be at high risk (up to a 1 in 150 chance) of having a fetus affected by any of these disorders can then undertake a diagnostic test such as CVS or amniocentesis. A second screening test, the quadruple test, is available during the second trimester for women too advanced in their pregnancy to undergo the combined test. This test only screens for Down's syndrome and its detection rate is lower at 70% (NHS FASP, n.d.). It is currently estimated that up to 74% of women opt for Down's syndrome screening (Crombag et al., 2014). The third major screening test is the mid-pregnancy ultrasound scan referred to as the anomaly scan. It screens for major structural fetal anomalies [NHS FASP, n.d.] and is conducted between 18 and 21 weeks' gestation. Following the scan, women may be offered further diagnostic tests if warranted.

Technical developments in the field of prenatal screening and diagnosis are on-going (RCOG, 2010). One of the most recent and significant ones is non-invasive prenatal testing (NIPT) for aneuploidy (Chitty, Hill, White, Wright, & Morris, 2012; Hill et al., 2014). This technique enables the testing of fragments of cell-free fetal DNA that are present in the maternal plasma for genetic disorders. The fact that the only procedure required for NIPT is a maternal blood test makes this test particularly attractive, as it reduces the risk of miscarriage associated with CVS or amniocentesis (NHS [c] Rapid project, n.d.). In this respect, NIPT has been referred to as the "holy grail of prenatal diagnosis" (Bryant, 2014, p.1). To date, NIPT has been exclusively used in a screening capacity. Its detection rate ranges from 98.6% to 100% for Down's syndrome, but is lower for other trisomies (up to 97% for trisomy 18 or Edwards' syndrome and up to 83% for trisomy 13 or Patau's syndrome [Twiss, et al., 2014]). Therefore, NIPT cannot yet be used as a diagnostic tool.

NIPT is currently available in the UK in the private sector from ten weeks' gestation, and research is under way to assess how it may be implemented into the NHS screening programme (Chitty et al., 2012; Hill et al., 2014).

Although technological developments in prenatal diagnosis have led to higher detection rates, there are still few in utero treatments for major fetal abnormalities (RCOG, 2011). Whilst some look promising (e.g. balloon tracheal occlusion technique to treat congenital diaphragmatic hernia), there remain uncertainties about the short- and long-term outcomes of these procedures (Depestre & De Coppi, 2012; RCOG, 2010). Consequently, after a prenatal diagnosis of a major abnormality, women face the decision to continue the pregnancy in the knowledge that their child may have a reduced life expectancy or a severe disability, or end the pregnancy. Most women in the UK choose the latter option when major abnormalities are diagnosed (Boyd et al., 2008; Johnson et al., 2012; Morris & Springett, 2014). For example, 90% of women opt to terminate their pregnancy after a fetal diagnosis of Down's syndrome (Morris & Springett, 2014), 83% after a diagnosis of anencephaly (partial absence of the skull and brain) and 63% after a diagnosis of spina bifida (neural tube defect resulting in a gap in the spine [Johnson et al., 2012]).

1.1.1.4 The abortion law in England

In England, Scotland and Wales, abortion is legal until 24 weeks of gestation after which the fetus is considered viable. After 24 weeks' gestation, the Abortion Act (1967, as amended in Human Fertilisation and Embryology Act, 1990, section 1[1]d), only sanctions abortions when "there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped" (clause E of the Abortion Act). There is currently no legal guidance on the definition of substantial risk and serious handicap. It is "a matter of clinical judgment and accepted practice" (British Medical Association [BMA], 2007, p.1). TFA is only lawful when two registered medical practitioners are of the opinion, formed in good faith, that the grounds for termination of pregnancy have been met (RCOG, 2010). Terminations after 22 weeks' gestation require a feticide (a

procedure to induce fetal demise through intra-cardiac or intra-amniotic injections) to be performed to ensure the baby is not alive at birth (RCOG, 2010).

1.1.2 Incidence of TFA

In England and Wales in 2014, 2% of all pregnancy terminations were carried out under clause E of the Abortion Act. This represented 3,099 pregnancies (Department of Health [DH], 2015). Most terminations were performed under 24 weeks of gestation with only 202 carried out beyond that timeframe. The main causes for termination were congenital malformations (46%), particularly defects of the nervous system (22%), and chromosomal abnormalities (37%), particularly Down's syndrome (21%). It is, however, accepted that the number of TFAs is an underestimation. Firstly, below the legal timeframe of 24 weeks of gestation, pregnancies affected by fetal abnormalities may be terminated under a different clause, most likely clause C or 'mental health' clause under which 97% of the terminations are conducted (Abortion Review, 2012; DH, 2015; Parliamentary inquiry into abortion on the grounds of disability, 2013). Secondly, a discrepancy between the number of terminations for Down's syndrome reported by the DH and that reported by the National Down's Syndrome Cytogenic Register (NDSCR) has been identified (DH, 2015; Morris, Grinsted & Springett, 2015). A matching exercise undertaken by the RCOG between the two registers using 2012 data indicated that twice as many terminations for Down's syndrome were notified to the NDSCR compared to the DH (DH, 2015). Given that the NDSCR is the only national register of fetal abnormality, the matching exercise could not be replicated for other conditions. Based on these considerations, the figure published by the DH of the number of TFAs is likely to be higher than 3,099.

Regardless of the extent of the DH's underestimation, the accurate number of TFAs is likely to remain small in absolute terms. It has, however, increased over time, from 2,085 in 2009 to 3,099 in 2014 (DH, 2010-2015). It is expected to rise further due to the recent developments in prenatal screening and diagnosis technologies (Korenromp et al., 2007a; Lewis, Hill, Silcock, Daley, & Chitty, 2014). This is compounded by the fact that more

couples delay starting a family (Loane et al., 2013), with the average maternal age now at 30 years of age compared to 28.5 in 1995 (Office for National Statistics a [ONS], 2008, 2014a). This is despite evidence that childbearing after 35 years of age is associated with complications during pregnancy and adverse pregnancy outcomes (RCOG, 2009).

1.1.3 TFA as a unique form of perinatal loss

1.1.3.1 Definition of perinatal loss

Perinatal loss is generally defined as a loss occurring during pregnancy (fetal loss) or soon after birth (neonatal loss; [Barfield, 2011]). In England, the ONS defines perinatal loss as stillbirths and deaths that occur during the first week of life, with deaths occurring between 7 and 28 days of life classified as neonatal deaths. Although miscarriage is excluded from the ONS's definition, some researchers have chosen to include it in their studies (Bennett, Litz, Lee, & Maguen, 2005; Hutti, 2005; Kersting & Wagner, 2012). Perinatal loss is a relatively common phenomenon (Black & Wright, 2012). It is estimated that one in five pregnancies ends in miscarriage (NHSb, n.d.) and in the UK, in 2013, the stillbirth and neonatal death rates were 4.7 and 2.7 per 1,000 births respectively (ONS, 2014b).

1.1.3.2 TFA in relation to other perinatal losses

1.1.3.2.1 Similarities between TFA and other perinatal losses

TFA shares several characteristics with other perinatal losses such as miscarriages, stillbirths or neonatal deaths. In all cases, parents lose a child before birth or at the very early stage of life. Evidence indicates that grief reactions following TFA are similar to those experienced after stillbirths or miscarriages (Keefe-Cooperman, 2005; Robinson, 2014; Salvesen, Øyen, Schmidt, Malt, & Eik-Nes, 1997; Wool, 2011). Similarly to other perinatal losses, TFA occurs at a time when people would, in theory, rejoice. With the loss of the baby, parents also experience the loss of their hopes and dreams (Bennett et al., 2005) and, for many, it may be the first time they experience the loss of a loved one (Black & Wright, 2012). Furthermore, although the baby may be 'very real' for the parents, particularly through

visualising images of the fetus and experiencing fetal movements, the baby may remain an abstract entity for those around them (Brier, 2008). This is particularly the case when the loss occurs early in pregnancy and the pregnancy has not yet been disclosed to others or is not clearly visible. Consequently, some parents may find it difficult to openly mourn their child (Brier, 2008; Robinson, 2014) and may feel that their grief is not recognised by society (Rowlands & Lee, 2010).

In this context, the concept of disenfranchised grief (Doka, 1989, 2002) is pertinent to TFA and other perinatal losses. Disenfranchised grief relates to losses that constitute a violation of societal norms (e.g. extramarital relationship, abortion) and/or cannot be socially sanctioned or publicly mourned (e.g. perinatal loss [Doka, 1989, 2002]). Disenfranchised grief is characterised by a difficulty to express and legitimise a loss, and a difficulty to express the drive to restore equilibrium and grow following the loss (Attig, 2004). TFA, with other perinatal losses, may be subject to disenfranchised grief as parents may find it difficult to disclose that they have chosen to end the pregnancy and publicly mourn their loss (Black, 2011; Bryar, 1997; Flenady et al., 2014; Lang et al., 2011; Leichtentritt, 2011; Maguire et al., 2015; McCoyd, 2007; Moore, Parrish, & Black, 2011; Wilson, 2014).

1.1.3.2.2 Differences between TFA and other perinatal losses

TFA differs from other perinatal losses such as stillbirths and miscarriages in that it is self-perpetrated, and differs from neonatal losses in that it occurs in pregnancy. It also differs from abortion for non-medical reasons in that the pregnancy is usually wanted (Fisher & Lafarge, 2015; McCoyd, 2010a). Furthermore, it differs from other types of bereavement in that the loss is not socially sanctioned in the same way (Doka, 1989; Wilson, 2014).

Furthermore, TFA bears a unique moral component because parents choose to terminate the pregnancy, which leads to some of them experiencing feelings of guilt (Gaudet, Séjourné, Allard & Chabrol, 2008; Geerinck-Vercammen & Kanhai, 2003; Korenromp, Iedema-Kuiper, van Spijker, Christiaens, & Bergsma, 1992; White-Van Mourik, Connor, & Ferguson-Smith, 1992; Nazaré, Fonseca, & Canavarro, 2014). The fact that the decision is

based upon disability-related considerations also adds a degree of complexity and confers an ethical dimension to TFA.

1.1.4 Ethical considerations related to TFA

1.1.4.1 *Main ethical considerations*

TFA is at the centre of many ethical considerations. It would be outside the scope of this thesis to review them all; nonetheless, it is important to examine those that are particularly pertinent to women's experiences of TFA. Bewley (2003) identified four ethical considerations pertaining to prenatal diagnosis, which are relevant to TFA. The first consideration relates to whether the rights of the fetus should take precedence over the rights of the mother, and whether the fetus' right to life should be protected regardless of the disorder he/she may be affected by. The second consideration concerns the level of risk attached to the treatment of fetal abnormality in utero, and at which point this risk becomes unacceptable. Few in utero treatments for fetal abnormality exist and further research is needed to establish their short- and long-term effectiveness (RCOG, 2010).

The third consideration centres on the timeframe and fetal conditions for which TFA can be performed. This relates to questions about the viability of the fetus, the definition of 'substantial risk' and 'severe handicap' in clause E of the Abortion Act (1967) and whether some conditions may be considered 'worse' than others. The final consideration relates to the implications of TFA for people with disabilities. TFA raises questions about the perceived value of a life with disability and, in doing so, may be regarded as discriminatory to people living with a disability. These ethical considerations have profound implications at both micro (individual level) and macro (legal and political) levels, and are discussed in the subsequent sections.

1.1.4.2 *Ethical considerations at a micro level*

Ethical considerations occur at an individual level for the women and their families, and the health professionals involved in their care.

1.1.4.2.1 Women's ethical considerations

Women who choose to end their pregnancy may morally struggle with their decision. Existing literature has shown that taking the decision to end the pregnancy is complex and painful (Gaudet et al., 2008; McCoyd, 2007; Sandelowski & Barroso, 2005). A review of qualitative studies on the decision-making process in the context of TFA (Sandelowski & Barroso, 2005) indicates that this experience is akin to an existential crisis in that parents have to make a life or death decision. Parents report feelings of ambivalence in the decision-making process and being torn between the natural desire to bring their child into the world, doubts about their ability to bring up a child with an impairment, and the wish to spare their unborn child a life of suffering. This ambivalence creates intra and interpersonal tensions that generate distress. Sandelowski and Barroso (2005) also suggested that the decision-making process involves considerations about the impact the birth of a child with impairment may have upon the parental relationship and family life. In the TFA literature the decision-making process is often described as “a Sophie’s choice” (or a non-choice [Chandler & Smith, 1998]), a “travesty of choosing”, “chosen loss and lost choices” (Sandelowski & Barroso, 2005).

Evidence also shows that among women who opt to terminate their pregnancy, feelings of guilt related to the decision are common (Gaudet et al., 2008; Geerinck-Vercammen & Kanhai, 2003; Korenrump et al., 1992; Nazaré et al., 2014; White-Van Mourik et al., 1992). Guilt is generally directed towards the unborn child as the parents deny him/her a chance to live, but can also be directed towards a child in the family affected by the same disorder diagnosed in the baby (Korenrump et al., 1992). The decision-making process is also complicated by the fact that some women are fearful of being judged and often choose to keep their decision secret (Bryar, 1997; France, Hunt, Ziebland, & Wyke, 2013; McCoyd, 2007).

1.1.4.2.2 Health professionals' ethical considerations

Evidence also indicates that health professionals may struggle with their own moral dilemmas (Garel, Gosme-Seguret, Kaminski, & Cuttini, 2002; Garel, Etienne, Blondel, & Dommergues, 2007). One dilemma centres on whether health professionals' moral obligation is towards the mother or the fetus (Chervenak, McCullough, Skupski, & Chasen, 2003; Malhotra, Menahem, & Gillam, 2010). Chervenak et al. (2003) suggested that two ethical principles guide the doctor-patient relationship in cases of fetal abnormality: beneficence to the patient and respect for autonomy. They argued that although the fetus cannot have autonomy, once it reaches viability, it becomes a patient in its own right. This implies that health professionals have "beneficence-based obligations" towards it. This is particularly challenging when beneficent-based obligations towards the fetus differ from those towards the mother. To address this issue, Malhotra et al. (2010) recommended that autonomy should underpin practice and that the woman's view of the fetus (as a patient or not) should lead clinical practice.

Another ethical dilemma experienced by health professionals focuses on their ability to claim conscientious objection and the extent to which this right is respected. Although the Abortion Act (1967) allows health professionals to opt out of participating in abortion treatment on ethical grounds, reports into how this right is implemented show mixed results. In a review of the law and ethics of abortion, the BMA (2007) indicated that both the doctors claiming conscientious objection and those performing abortions experienced harassment and discrimination. The status of conscientious objectors also covers medical students who can opt out of witnessing abortions (BMA, 2007). A study of British medical students identified that up to 22% oppose abortion for congenital abnormality (Strickland, 2012).

The ethical debates taking place at a micro level have legal, political and clinical implications, which directly impact upon the care provided to women and influence their experience. These debates also reflect ethical considerations relating to the wider issues of abortion and eugenics that occur at a macro level.

1.1.4.3 Ethical considerations at a macro level

1.1.4.3.1 TFA and the wider abortion debate

Due to its classification as a type of abortion, TFA is linked to the wider abortion debate (pro-life vs. pro-choice) and whether abortion harms women's mental health (Coleman, 2011; Major et al., 2009). Reviews on the impact of abortion upon women's mental health have shown contrasting results (Bellieni & Buonocore, 2013; Charles, Polis, Sridhara, & Blum, 2008; Coleman, 2011; Major et al., 2009; National Collaborating Centre for Mental Health [NCCMH], 2011). A systematic review by Charles and colleagues (2008) based on 21 studies suggested that studies that use robust methodologies such as using appropriate control groups and controlling for confounding variables, did not provide evidence of a negative impact of abortion upon women's mental health. This finding was supported by a review conducted by the American Psychological Association (Major et al., 2009), which concluded that women who have an abortion are at no greater risk of mental health issues than those who deliver an unplanned pregnancy. Similarly, in the UK, the report by the NCCMH published by the Royal College of Psychiatrists (2011), indicated that a history of mental health issues and the fact that the pregnancy is not wanted were factors more closely associated with mental ill-health than abortion itself.

Conversely, some reviews have pointed to a negative impact of abortion upon women's mental health. A meta-analysis by Coleman (2011) concluded that women who had an abortion experienced an 81% increased risk of mental health problems, and that as much as 10% of the incidence of mental health issues among women could be attributed to abortion. Similarly, a review by Bellieni and Buonocore (2013) suggested that abortion is a risk factor for women's psychological wellbeing above and beyond other types of loss such as miscarriage. The review concluded that, following abortion, women are at greater risk of developing anxiety disorder and/or depression, using and/or abusing substances and experiencing a loss of self-esteem, than those who miscarried or carried an unplanned pregnancy to term.

The debate about whether abortion is detrimental to women's mental health or not has been blurred with methodological arguments about the quality of studies included in the reviews. In their review, Charles et al. (2008) argued that the studies suggesting a negative impact of abortion were methodologically flawed because they either failed to use appropriate control groups or control for confounding variables such as pre-existing mental health issues. For example, one of the studies they considered to be of poor quality compared a group of women who had an abortion with another group comprising women who had miscarried, women who had carried a pregnancy to term, women who were pregnant/not pregnant at the time of data collection. Similarly, Steinberg, Trussell, Hall and Guthrie (2012) re-visited the reviews by Coleman and the NCCMH (both 2011) and concluded that Coleman's meta-analysis was flawed because of the inclusion in her review of 'poor quality' studies, which the NCCMH had chosen to exclude because that they had not included a control group or controlled for confounding variables.

The debate about abortion generates polarised views as is regularly evidenced in the British national press (The Guardian, 2011, 2014; The Sunday Times, 2014; The Telegraph, 2011, 2015) and in the debates between pro-choice (e.g. British Pregnancy Advisory Service [Bpas]) and pro-life (e.g. Prolife) organisations. It has important implications upon the laws, policies and clinical practices (Parliament Publications, 2008a, 2011, 2014a, 2014b), which in turn may influence women's reproductive experiences. The various proposed amendments to the abortion law also reflect the divergence in opinions about abortion. One such amendment, proposed to the House of Parliament in 2008, aimed to reduce the legal limit for abortion from 24 to 22 weeks on the basis of evidence suggesting that fetuses may be viable from 23 weeks of gestation (Parliament Publications, 2008a). Another amendment, filed in 2011, aimed to prevent independent abortion providers such as Bpas and Marie Stopes offering pre-abortion counselling to women, on the grounds that the counselling they offer may be biased towards their services (Parliament Publications, 2011). This amendment had potentially significant implications given that the independent sector is responsible for carrying out 67% of all abortions for non-medical reasons under NHS contract (DH, 2015).

Other recent debates have focused on sex-selection abortion or on the legal requirements for two health professionals to sanction abortion (Parliament Publications, 2014a, 2014b). Collectively these debates are evidence of the intensity of the debate surrounding abortion.

TFA, being categorised as a form of abortion, is not exempt from polarised views. The fact that the pregnancy is terminated on the grounds of fetal abnormality also results in TFA being linked to the eugenics debate (Asch, 1999; Harris, 2001; Shakespeare, 1998, 2011; Ville, 2011; Wertz, 1998).

1.1.4.3.2 TFA and the eugenics debate

The debate about TFA within the wider eugenics debate is underpinned by the coexistence of prenatal diagnosis, which could be regarded as aiming to prevent disability, and the drive for social integration of people with disability (Ville, 2011). Fundamentally, it raises the issue of whether prenatal diagnosis and pregnancy termination on the ground of fetal abnormality is discriminatory towards people with disability (Asch, 1999; Shakespeare 2011). This questioning is manifest in: the Jepson court case; the various attempts to change the abortion law, in particular the component relating to the concept of impairment; the publication by the DH of the list of pathologies for which TFA are conducted post-24 weeks; and the creation of an independent parliamentary inquiry into the interaction between the Abortion and the Equality Acts (1967, 2010).

The Jepson case (*Jepson v The Chief Constable of West Mercia Police Constabulary*, High Court of England and Wales [EWHC] 3318, 2003) rose from the identification in the 2001 abortion statistics of a case of pregnancy termination for bilateral cleft lip and palate conducted post-24 weeks (EWHC 3318, 2003; Statham, Solomou, & Green, 2006). Jepson argued that this termination violated the Abortion Act (1967) as cleft lip and palate do not meet the criteria for serious handicap. The case was dismissed but Jepson was granted a judicial review on appeal. After further investigation, the case was definitively closed in 2005 and none of the doctors were prosecuted (Fisher, 2008; Statham et al., 2006; The Crown Prosecution Service, 2005). Despite the absence of conviction, the

case generated some questioning among health professionals about their professional practice (Fisher, 2008). It may also account, in part, for the health professionals' increased reluctance to offer terminations beyond 24 weeks of gestation for conditions such as Down's syndrome or achondroplasia (a form of dwarfism; [Fisher, 2008; Statham et al., 2006]). This reluctance may relate to a fear of liability and/or to the fact that the fetus is increasingly regarded as a patient in its own right (Statham et al., 2006).

Further evidence of the debate about TFA within the wider eugenics debate can be found in the proposed amendments to the abortion law, which have been submitted to the House of Parliament. In 2007, a group of Members of Parliament (MPs) proposed that terminations should not be carried out beyond 24 weeks' gestation because it discriminates against fetuses affected by a severe disorder (Parliament Publications, 2007). A second proposal intended to explicitly define the concepts of 'substantial risk' and 'serious handicap' (Parliament Publications, 2008b). The aim of the third proposal was to reduce the scope of medical conditions for which late terminations (post-24 weeks) can be performed. It recommended the exclusion of conditions such as cleft palate or congenital talipes equinovarus (club foot) on the basis that these were not life threatening. This proposal was highly disputed by pro-choice organisations (Antenatal Results and Choices [ARC]) who argued that it would result in creating a hierarchy of impairments, in some conditions being stigmatised and the severity of other conditions being underestimated (ARC, 2008). Although none of these proposals were adopted, they reflect the wider political debate surrounding abortion, whether it is conducted on the ground of fetal abnormality or not.

More recently, the publication by the DH of the figures on terminations occurring after 24 weeks' gestation alongside a list of pathologies has also been contentious. Until 2011, the DH only published this information for groups of abnormalities (e.g. chromosomal abnormalities), on the basis that releasing information about each condition could lead to some women being identified (RCOG, 2010). This decision was overruled in 2011 following lobbying by some MPs and pro-life organisations (BBC, 2011). Since then, the DH is

required to publish the list of conditions for which TFAs have been sanctioned, including those conducted post-24 weeks.

Finally, in 2013, a parliamentary inquiry was set up to examine the interaction between the Abortion Act (1967) and the Equality Act (2010), which aims to prevent the discrimination of individuals with disability. The aim of this inquiry was to evaluate the impact of the policy allowing termination for fetal abnormality upon the rights of people with disabilities, with a view to protect these rights and prevent discrimination. This inquiry, chaired by an MP open about her pro-life views, concluded that “allowing abortion up to birth on the grounds of disability is discriminatory, contrary to the spirit of the Equality Act, and does affect wider public attitudes towards discrimination” (Parliamentary inquiry into abortion on the grounds of disability report, 2013, p.3). It remains to be ascertained whether this inquiry will have any impact upon the abortion law. Nonetheless, this inquiry is further evidence of the on-going debate about TFA in relation to eugenic considerations.

Collectively these ethical considerations not only reflect the legal and political environment in which TFA is conceptualised, but also contribute to shaping the context within which women experience TFA.

1.1.5 TFA in practice

In Great Britain, the practice of TFA is ‘indication-based’ (Schmitz, 2012). This implies that the decision-making is primarily based upon the severity of the fetal condition and its potential negative impact on the mother, and on the fact that health professionals play a major role in the decision-making process (Schmitz, 2012). However, there is no clear definition or consensus as to what constitutes a ‘substantial risk’ and ‘a severe handicap’ in the Abortion Act (1967 [Dommergues, Mandelbrot, Mahieu-Caputo, Boudjema, Durand-Zaleski, & ICI Group-Club de medecine foetale, 2010; Savulescu, 2001; Statham et al., 2006]). Therefore, working within the existing legal framework presents several challenges to health professionals responsible for making decisions about the management of pregnancies affected by a fetal abnormality. Indeed, in many cases, the exact postpartum

outcome is not known, unless the condition is incompatible with life (Schmitz, 2012).

Furthermore, non-lethal conditions, such as Down's syndrome, can vary significantly in their degree of severity, and it is not always known whether they are associated with other anomalies (Dommergues et al., 2010; Statham et al., 2006).

In the absence of specific guidelines, clinical practice is driven by consensus among clinical teams and peers (for example within multidisciplinary meetings), with decisions being made on a case-by-case basis rather than being based upon pre-defined protocols and criteria (Dommergues et al., 2010; Garel et al, 2002; Statham et al., 2006). In a study of professionals in four fetal medicine units, Statham and colleagues (2006) found little interest for a list of conditions for which pregnancies could be terminated beyond 24 weeks of gestation. Whilst most participants, in this study, welcomed clearer guidance, the majority considered a pre-defined list to be disadvantageous. Rather, health professionals acknowledged that there are advantages in working within a legal framework that is not prescriptive, allows TFA without gestational limits and enables them to use their clinical judgement.

Health professionals working in the areas of fetal medicine or antenatal screening endeavour to act within the law, in part because they may be liable to prosecution (see the Jepson case; Fisher 2008; Statham et al., 2006). However, as highlighted in section 1.1.4.2.2, they are also subjected to ethical self-questioning and have to balance their own moral values with their clinical practices (Farsides, Williams, & Alderson, 2004). Evidence shows that many health professionals are ambivalent towards the type of conditions that justify a late termination (Janvier, Couture, Deschenes, Nadeau, Barrington & Lantos, 2012; Statham et al., 2006) and that they find it challenging to terminate pregnancies in cases of relatively minor anomalies such as cleft lip palate or Klinefelter syndrome (a genetic disorder affecting male fetuses, which can translate into physical symptoms resulting from low levels of testosterone and into learning and social difficulties [Garel et al, 2003; Janvier et al., 2012]). Regarding clinical practices that may be considered morally controversial (e.g. abortion), several demographic variables have been shown to relate to health professionals'

approaches to patient management. These include age, gender, ethnicity, political affiliation and religion (Brown et al., 2014). For example, a study by Curlin, Lawrence, Chin and Lantos (2007) among American health professionals showed that physicians who were male and had strong religious beliefs were less willing to make services available or refer patients to services deemed morally controversial than those who were female and/or were less religious.

Professional speciality may also impact upon the way health professionals regard TFA and manage pregnancies. In a study comparing maternal-fetal medicine and fetal-care paediatric professionals, Brown and colleagues (2014) found that maternal-fetal medicine professionals were more likely than their counterparts to consider the presence of a fetal abnormality, the effect that the birth of a child with an impairment may have upon the family and the costs of future healthcare for a child with a disability, as appropriate reasons to terminate a pregnancy. These professionals were also more likely to view their clinical responsibility as being primarily towards the woman rather than the fetus. Finally, gestational age (and the legal framework relating to it) may also impact upon clinical judgements. A study by Savulescu (2001) suggested that among professionals working in the field of genetics and obstetrics, fewer supported TFA at 24 weeks compared to 13 weeks of gestation for a range of conditions, in particular those considered to be relatively minor.

Whilst there is a consensus that personal beliefs should not impact upon care delivery (General Medical Council, 1997; Janvier et al., 2012; Savulescu, 2006), one may question the concept of non-directive counselling which underpins clinical management of pregnancies affected by a fetal abnormality (RCOG, 2010). Indeed, it is debatable whether health professionals with moral objections to some aspects of TFA (e.g. type of conditions for which a termination can be sanctioned or gestational age) may be in a position to offer truly non-directive care to patients. This is particularly important because non-directive counselling not only dissociates clinical practices from eugenic considerations, but also protects health professionals from potential law suits (Farsides et al., 2004). In practice, however, research shows that non-directive counselling is not always utilised, with some

patients reporting feeling pushed towards termination, particularly when abnormalities are incompatible with life (e.g. trisomies 13 and 18; Guon, Wilfond, Farlow, Brazg, & Janvier, 2014).

Collectively, the evidence suggests that although the law enables health professionals to use their clinical judgment and discretion to manage pregnancies affected by a fetal abnormality, it also leaves them with a lack of clear guidance and prone to self-questioning. This may have direct impact on the care they provide to women, the extent to which they deliver non-directive counselling, which in turn, may impact upon women's experiences of TFA.

1.1.6 Summary - TFA in context

TFA is a relatively new phenomenon, intrinsically linked to the development of prenatal screening and diagnosis. The technological developments in prenatal screening and diagnosis in the past 40 years have resulted in more women being diagnosed with fetal abnormalities and this, progressively earlier in the pregnancy (Nicolaidis, 2011). In turn, this has resulted in more women ending their pregnancy because of fetal abnormality (DH 2010-2015; Lewis et al., 2014). TFA is a unique and complex phenomenon. It shares many characteristics with other perinatal losses such as miscarriages, stillbirths and neonatal deaths (Black & Wright, 2012). However, it also fundamentally differs from them. TFA generates ethical considerations because it results from parental choice and the decision is based upon disability-related considerations. These ethical considerations are manifest at a micro level for the women themselves (e.g. decision making, feelings of guilt [Sandelowski & Barroso &, 2005]) and the health professionals involved in their care (Garel et al., 2002; 2007). They are also manifest at a macro level (i.e. legal and political context) through the debate about abortion and whether it impacts on women's mental health (Coleman, 2011; NCCMH, 2011) and the eugenics debate about the impact of termination for fetal abnormality upon people with disabilities (Shakespeare, 2011; Ville, 2011). These ethical considerations reflect and shape the context within which women experience TFA and

influence the way they adjust to it. In practice, managing pregnancies affected by a fetal abnormality is a complex process. Whilst the law provides health professionals with some degree of clinical freedom, it also generates questions health professionals may find challenging to address. This, in turn, may influence the care they provide to women and ultimately, women's experiences of TFA.

1.2 Women's psychological adjustment to TFA

As part of the conceptualisation of this research, a review of the literature on women's psychological adjustment to TFA was undertaken to identify existing research in women's coping with TFA. This review included both qualitative and quantitative literature.

1.2.1 Overview of the literature review

1.2.1.1 Methods

A literature review was conducted at the inception of the research programme in October 2011, and has been updated on an on-going basis. Although not a systematic review, several steps were taken to maximise literature coverage. Searches were conducted using the following databases: Academic Elite Search, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Google Scholar, PsycARTICLES, PsychINFO, PubMed, and ISI Web of Knowledge. A manual search of the reference sections of retrieved articles, monographs on fetal medicine, bereavement, and prenatal diagnosis was also conducted. Renowned experts in the field of TFA were consulted for additional materials (H. Statham, personal communications, 2011, 2012).

The search terms used included: termination of pregnancy, fetal abnormality(ies), fetal anomaly(ies), congenital anomaly/abnormality; third trimester abortion, second trimester abortion, late abortion; adaptation, adjustment, sequelae; coping, coping strategies, coping processes. No time limit was put on the searches but the large majority of the literature is dated post-1970, which corresponds to the introduction of prenatal diagnosis. Research

alerts from PubMed and Google Scholar were also used to keep up to date with new research. The literature review identified qualitative and quantitative studies about women's experience of TFA and their psychological adjustment. An overview of each body of knowledge is presented in the subsequent sections.

1.2.1.2 Overview of the qualitative evidence

Qualitative research on TFA has been mainly concerned with: 1) the process of making the decision to end the pregnancy including information given to women and the concept of informed choice (Benute et al., 2012; Chandler & Smith, 1998; France, Locock, Hunt, Ziebland, Field, & Wyke, 2011; Gawron, Cameron, Phisuthikul, & Simon, 2013; McCoyd, 2008; Sandelowski & Barroso, 2005); 2) women's experience of the diagnosis of fetal abnormality (Black, 2011; Lalor, Begley, & Galavan, 2009; Sommerseth & Sundby, 2010); 3) women's experiences of TFA (Bryar, 1997; Chaloumsuk, 2013; Gammeltoft, Tran, Nguyen, & Nguyen, 2008; Koponen, Laaksonen, Vehkakoski, & Vehmas, 2013; McCoyd, 2007; Rillstone & Hutchinson, 2001); 4) women's experience of specific elements of the termination such as feticide (Graham, Mason, Rankin, & Robson, 2009; Leichtentritt, 2011); and 5) more recently, women's experiences of care (Asplin, Wessel, Marions, & Georgsson Öhman, 2014; Fisher & Lafarge, 2015). Although there is a plethora of evidence on each of these areas, at the inception of this research, no attempt had been made to synthesise this body of knowledge. This observation informed the research's first objective (section 1.4.2.1), which is to conduct a systematic review and synthesis of the qualitative evidence on women's experiences of TFA. This study (Study 1) is presented in chapter 2.

1.2.1.3 Overview of the quantitative evidence

Alongside clinical research into TFA and the different methods of termination (Bryant, Grimes, Garrett, & Stuart, 2011; Burgoine et al., 2005; Fisher, Lohr, Lafarge, & Robson, 2015), the quantitative literature has mainly focused on the psychological outcomes of TFA (Iles & Garth, 1993; Kersting et al., 2005, 2007, 2009; Korenromp et al., 2005a, 2005b,

2007a; Korenromp, Page-Christianses, van den Bout, Mulder, & Visser, 2009; Mirlesse, Perrotte, Kieffer & Ville, 2011; Nazaré, Fonseca & Canavarro, 2012; Salvesen et al., 1997; Statham, Solomou & Green, 2001). In 2011, two systematic reviews on women's psychological adjustment to TFA were published (Steinberg, 2011; Wool, 2011), which rendered another systematic review of the quantitative evidence relating to psychological outcomes redundant in relation to the timescale of the thesis.

The literature review also revealed a dearth of research in the area of coping in the context of TFA, i.e. on the coping strategies involved in dealing with TFA, despite the fact that coping has been shown to be associated with psychological outcomes (Carver & Connor-Smith, 2010; Lazarus & Folkman, 1984). The paucity of research on coping in the context of TFA informed the research's second objective (section 1.4.2.2), which is to investigate women's coping strategies when dealing with TFA and their relationship with psychological adjustment. The review also highlighted that research on the psychological adjustment to TFA remains exclusively focused on negative outcomes, despite evidence that some individuals experience growth as a result of a difficult experience or trauma (Bonanno, 2004; Joseph, 2011; Tedeschi & Calhoun, 2004). The lack of research into potential positive outcomes of TFA informed the research's fourth objective (section 1.4.2.4), which is to investigate whether positive psychological outcomes occur in the context of TFA and how these relate to coping.

The systematic review and synthesis of the qualitative evidence (Study 1) is fully reported in chapter 2, therefore, the remainder of this section focuses on the review of the quantitative literature pertaining to women's psychological adjustment to TFA, with a view to inform our understanding of how they may cope with it.

1.2.2 Women's psychological adjustment to TFA

1.2.2.1 Psychological outcomes

Section 1.1.4.3.1 outlined discussions about the impact of abortion upon women's psychological wellbeing. Systematic reviews based on robust methodological techniques,

such as using appropriate control groups and controlling for confounding variables (e.g. pre-existing mental health or socioeconomic status) suggest no difference in mental wellbeing between women who had an abortion and those who had not (Charles et al., 2008; Major et al., 2009; NCCMH, 2011; Steinberg et al., 2012). However, a different conclusion may be reached in the context of TFA. Two reviews of the quantitative evidence on psychological outcomes following TFA (Steinberg, 2011; Wool, 2011) reached contrasting conclusions. Steinberg's review (2011) focused on late abortion (from second trimester) and mental health. It reviewed quantitative studies of women who had undergone TFA but excluded any studies which did not include a comparison group. The review concluded that women terminating their pregnancy did not exhibit worse mental health than women who had suffered other perinatal loss or had adverse perinatal outcomes (e.g. first-trimester TFA, giving birth to children with heart malformations, or preterm infants). However, it can be argued that the fact that all groups displayed similar levels of anxiety, depression, grief and posttraumatic stress does not signify that women did not experience psychological distress in the first place. Indeed, given that the comparison groups deemed appropriate by Steinberg comprised women whose pregnancies also resulted in negative outcomes, the fact that no difference in levels of mental wellbeing between study and comparison groups was observed is not surprising.

The review by Wool (2011) looked at parental psychological outcomes after diagnosis of fetal anomaly. It covered diagnosis, decision making, grief reactions as well as experience of palliative care (as some studies included women who continued with their pregnancy). The review concluded that TFA can be traumatic, with grief levels similar to those experienced following other perinatal losses. Both terminating and continuing the pregnancy were associated with psychological difficulties. This is in keeping with studies looking at the experiences of women who continue the pregnancy after a diagnosis of fetal abnormality, which highlight women's emotional difficulties such as the experience of shock and despair at the diagnosis, and ambivalence towards the pregnancy and the baby (Jones, Statham, & Solomou, 2005; Lalor et al., 2009).

Much of the quantitative literature indicates that TFA can have profound psychological consequences for women (Kersting et al., 2007, 2009; Korenromp et al., 2005a, 2009). A study by Korenromp and colleagues (2009) showed that four months post-TFA, 46% and 28% of women displayed pathological levels of posttraumatic stress and depression respectively. Similarly, a study by Kersting et al. (2009) suggested that two weeks post-TFA, 22% of women were diagnosed with a psychiatric disorder (e.g. depression and anxiety). The psychological consequences of TFA have been well documented in the literature and include symptoms of depression and posttraumatic stress (Fisher & Statham, 2009; Green & Statham, 2007; Iles & Garth, 1993; Kersting et al., 2005, 2009; Korenromp et al., 2007a; Mirlesse et al. 2011; Salvesen, et al., 1997; Statham et al., 2001). Complicated grief has also been used as an outcome measure (Kersting et al., 2007; Nazaré, Fonseca, & Canavarro, 2013; Zeanah, Dailey, Rosenblatt, & Saller, 1993). Feelings of guilt with regards to ending the pregnancy have also been observed (Geerinck-Vercammen & Kanhai, 2003; Korenromp et al., 1992; Nazaré et al., 2014; White-Van Mourik et al., 1992). However, research also shows that very few women regret the decision to terminate (Kersting et al., 2005; Korenromp, 2006; White-Van Mourik et al., 1992; Zeanah et al., 1993). In a study of 217 women who had experienced TFA, Korenromp et al (2007a) indicated that only 2% of women regretted their decision. The evidence also points to some women experiencing a loss of self-esteem following TFA (Korenromp et al., 1992; White-Van Mourik et al., 1992).

1.2.2.2 Psychological adjustment over time

Research suggests that women experience high levels of grief immediately after the termination and that these subside in time. However, some women still display symptoms of grief or posttraumatic stress years afterwards (Green & Statham, 2007; Kersting et al., 2009; Korenromp et al., 2005a, 2009). The study by Korenromp and colleagues (2009) showed that 16 months post-TFA, 20% and 13% of women still displayed pathological levels of posttraumatic stress and depression respectively. Similarly, the study by Kersting et al (2009) found evidence of psychiatric disorder 14 months post termination in 17% of women.

Given its long-term effect, TFA has been referred to as a “trauma rather than a loss” (Korenromp et al., 2005a, p.259). Research also indicates that women who display high levels of distress immediately after TFA are at higher risk of long-term psychological complications than those who exhibit lower levels of distress (Korenromp, 2006).

TFA may also impact upon future pregnancies. Women who have suffered a perinatal loss have been shown to experience emotional difficulties in subsequent pregnancies, including anxiety, ambivalence towards the pregnancy, doubts, and insecurities (Blackmore et al., 2011; Côté-Arsenault, 2003, 2007; Lamb, 2002; McCarthy et al., 2015). These issues have also been reported in the context of TFA, although more so in the qualitative literature (Rillstone & Hutchinson, 2001).

In summary, the evidence relating to the psychological outcome of TFA suggests that TFA can have profound psychological consequences for women. It also highlights that a significant proportion of women struggle to adjust to their loss and that these difficulties may be manifest long after the termination. It is, therefore, important to understand which factors may be implicated in women’s psychological adjustment to TFA and to what extent these relate to women’s mental health.

1.2.3 Factors associated with psychological adjustment to TFA

Understanding the factors associated with psychological adjustment following TFA is relevant for two reasons. Firstly, this understanding may inform practice through enabling the identification of women at risk of psychological complications following TFA. Secondly, the factors related to women’s psychological adjustment to TFA may also be associated with women’s use of various coping strategies. The literature points to several factors linked to women’s psychological adjustment to TFA (Davies, Gledhill, McFadyen, Whitlow, & Economides, 2005; Geerinck-Vercammen & Kanhai, 2003; Kersting et al., 2005; 2009; Korenromp et al., 1992, 2005a, 2005b; Korenromp, 2006; Korenromp, Page-Christiaens, van den Bout, Mulder, & Visser, 2007b; Nazaré et al., 2012, 2013; Statham et al., 2001; White-Van Mourik et al., 1992; Zeanah et al., 1993). These include: 1) clinical factors linked to the

terminated pregnancy (e.g. gestational age, abnormality prognosis, method of termination, etc.) and women's obstetric history (e.g. first pregnancy, number of living children at the time of the TFA); 2) demographic factors (e.g. age, levels of education) and individual characteristics (e.g. self-esteem; religious beliefs); 3) women's experience of care; and 4) couple congruence. These factors are explored in the subsequent sections.

1.2.3.1 Clinical factors

1.2.3.1.1 Factors related to the terminated pregnancy

Factors related to the terminated pregnancy include: time elapsed since the termination, gestational age at the time of termination, the abnormality prognosis, method of termination and how women feel about their decision to terminate the pregnancy.

Research shows contrasting findings regarding the relationship between time elapsed since TFA and women's psychological adjustment (Geerinck-Vercammen & Kanhai, 2003; Kersting et al., 2007; Statham et al., 2001; Statham 2002). Some research indicates that women whose loss was more recent display higher levels of grief than those whose loss was less recent (Statham et al., 2001; Statham, 2002). However, in a study involving 89 couples, Geerinck-Vercammen and Kanhai (2003) indicated that psychological difficulties (e.g. anxiety, feeling of doubt, guilt and shame) had abated six months post termination. Other evidence suggests that despite a decrease in levels of distress over time, signs of grieving are still manifest, sometimes years after the termination (Green & Statham, 2007; Kersting et al., 2005, 2009; Korenrump et al., 2009). A study by Kersting et al. (2005) found no difference in levels of distress between women two to seven years post-TFA, concluding that there is no decrease in levels of distress over time.

Another factor associated with women's psychological adjustment to TFA is gestational age. Similarly to the evidence on time elapsed since TFA, research on the relationship between gestational age at the time of TFA and women's psychological adjustment is inconclusive. Several studies (Korenrump et al., 1992; Statham et al., 2001; Zeanah et al., 1993) have found no significant effect of gestational age on women's levels of

distress. By contrast, a study by Davies et al. (2005) suggested that the levels of distress shortly after the termination are higher among women who undergo TFA in the second trimester than in the first trimester, although this difference subsides over time. Korenromp et al. (2005a) also indicated that there is a relationship between higher levels of distress following TFA and more advanced gestational age, although the effect of the relationship was modest.

Abnormality prognosis has also been shown to relate to women's adaptation, but again, research findings vary significantly (Korenromp et al., 2005a; Statham et al., 2001; Zeanah et al., 1993). A study by Korenromp et al. (2005a) suggested that there is a relationship between high levels of distress and a prognosis compatible with life. However, studies by Statham et al. (2001) and Zeanah et al. (1993) did not find any evidence of an association between the severity of prognosis and women's psychological adjustment.

The potential association of the method of termination and women's psychological adjustment has been less commonly evaluated in the context of TFA, given that the method of termination is dependent on gestational age. Surgical terminations are generally conducted up to 14 weeks' gestation in NHS settings despite evidence that, in the second trimester, surgical terminations may be safer than medical ones because of lower rates of retained tissue (Luys, Robson, Parsons, Fisher, & Cameron, 2013). The method of termination in itself, whether surgical or medical, does not appear to be related to women's psychological adjustment to TFA as no difference in levels of grief or depression were observed by type of method (Burgoine et al., 2005; Statham et al., 2001; Zeanah et al., 1993).

Lastly, research has indicated that the way women feel about the decision to terminate the pregnancy relates to their psychological adjustment (Korenromp et al., 1992, 2005a, 2007a, 2009). In particular, the way women feel about their decision may relate to the abnormality prognosis. A study by Korenromp et al. (1992) suggested that women for whom the fetal prognosis is incompatible with life (e.g. anencephaly or bilateral renal agenesis [absence of kidneys]) are more likely to regard their decision as the right one,

compared to women for whom the fetal prognosis is compatible with life (e.g. Down's syndrome or achondroplasia). Women facing a fetal prognosis compatible with life may question their decision to a greater extent and consequently, experience more adverse psychological outcomes (Korenromp et al., 2005a, 2007a, 2009).

1.2.3.1.2 Obstetric history

The research to date shows that whether the terminated pregnancy was a first pregnancy or not does not appear to have a bearing on women's psychological adjustment (Statham et al., 2001), nor does the existence of children at the time of TFA (Korenromp et al., 2005a). By contrast, research indicates that having children subsequently to the termination may promote better adaptation (Statham et al., 2001).

In summary, the evidence of a relationship between obstetric and termination-related factors and women's psychological adjustment is inconclusive. Wide variations were observed regarding the degree of association between these variables and women's mental health post-TFA. Therefore, it would be helpful to include these factors in the empirical work to be conducted as part of this research, to establish how these factors relate to women's psychological adjustment and their use of coping strategies.

1.2.3.2 Demographic factors and individual characteristics

Another set of factors which may be associated with women's psychological adjustment to TFA are demographics and individual characteristics (Korenromp et al., 2005a, 2005b; Mirlesse et al., 2011; Statham et al., 2001; White-Van Mourik et al., 1992; Zeanah et al., 1993). Evidence suggests that there is a relationship between maternal age and women's psychological adjustment to TFA, with younger women displaying higher levels of distress (Korenromp et al., 2005b; Statham et al., 2001; White-Van Mourik et al., 1992; Zeanah et al., 1993) and being more vulnerable to depression (Mirlesse et al., 2011) than older ones. The evidence is less consensual regarding women's level of education. Indeed, although level of education has been shown to relate to women's distress, with women with lower level of

education exhibiting more adverse emotional reactions (Korenromp et al., 2005a; Statham et al., 2001) than those with a higher level of education, the opposite has also been observed (Zeanah et al., 1993).

Individual characteristics such as self-efficacy or self-esteem are also thought to be related to women's adjustment to TFA. Korenromp et al. (2007a, 2009) suggested that low levels of self-efficacy are associated with adverse emotional outcomes (e.g. depression). Individual beliefs, such as religiosity, have also been shown to relate to women's adjustment to TFA, with higher religiosity associated with more negative psychological outcomes (Korenromp et al., 2007a; Statham et al., 2001). However, the opposite effect was also observed (Kersting et al., 2007).

Similarly to the evidence on obstetric and termination-related factors, research is somewhat inconclusive regarding the nature and degree of association between demographic factors and individual characteristics, and women's adjustment to TFA. This also warrants further examination.

1.2.3.3 Women's experience of care

Women's experience of the care they receive may also relate to their psychological adjustment post-TFA. In England, guidelines on what constitutes good care in the context of TFA are available to health professionals. The RGOG (2010) stated that TFA management should include providing women with a choice of termination method, non-judgemental and supportive care from staff, and well-organised follow-up care. Research indicates that, in England, these guidelines are not systematically followed (Fisher et al., 2015; Luys et al., 2013). There is, however, a dearth of research on women's experience of care when undergoing TFA and how this may relate to their mental wellbeing post-TFA (Statham et al., 2001; Statham, 2002). Nevertheless, Statham et al. (2001) found that women who perceived the care they received as being insensitive, particularly towards their baby, had lower emotional wellbeing post termination. The importance of sensitive and compassionate care has, more recently, been highlighted in the TFA qualitative literature (Asplin et al., 2014;

Fisher & Lafarge, 2015; McCoyd, 2009a), with women reporting this element as being helpful in coping with the termination.

The importance of care, and in particular of compassionate care, has been highlighted in the context of other perinatal losses (Geller, Psaros, & Kornfield, 2010; Gold, 2007; Kelley & Trinidad, 2012; Rowlands & Lee, 2010). A systematic review by Gold (2007) on experiences of care following unplanned pregnancy loss indicated that parents greatly value the emotional support they receive from health professionals and are particularly grateful when sensitivity is displayed towards the mother and the baby. These findings were supported by a study by Rowlands and Lee (2010) and a review conducted by Geller et al. (2010), which also emphasised the importance of compassion towards women following miscarriage. The review by Geller et al. (2010) also underlined the importance of the congruence between women and health professionals regarding the perceived importance of the miscarriage. Women who felt that health professionals failed to understand how important the miscarriage was to them, were more dissatisfied with the care they received. Similarly, a study by Kelley and Trinidad (2012) into women's experiences of care following a stillbirth also showed that women value staff who are empathetic towards their situation and enable them to see/spend time with their baby.

1.2.3.3.1 Compassionate care and factors underpinning its provision

The topic of compassionate care has gained prominence since the publication of the Francis report (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) and the ensuing impetus within the NHS to develop a model of care based on compassion and respect. Compassionate care is particularly relevant to TFA given the sensitivity of the issues it raises, and because women's experience of care is likely to influence the way they adjust to TFA. Research has shown that compassionate care is important to women in the context of TFA (Asplin et al., 2014; Fisher & Lafarge, 2015; McCoyd, 2009a; Statham et al., 2001; Statham, 2002). Therefore, it is important to understand the factors that may underpin health professionals' ability to provide such care.

It is reasonable to assume that providing compassionate care in the context of TFA may be based on health professionals' understanding of TFA, the complexity of the decision-making process and the coping processes involved in dealing with this event. There is, however, a paucity of research in this area. The literature review identified several studies focusing on health professionals' experience of caring for women in various contexts such as providing abortion (Nicholson, Slade, & Fletcher, 2010) and working in fetal medicine (Menezes, Hodgson, Sahhar, & Metcalfe, 2013). Only a few relate specifically to TFA (Garel et al., 2002, 2007), and all are of a qualitative nature. Nevertheless, collectively these studies indicate that caring for parents in these contexts may be challenging. Firstly, health professionals may struggle with their own moral dilemmas (as detailed in section 1.1.4.2.2). Secondly, they may struggle with the intensity of the emotions displayed by patients (Menezes et al., 2013). Research has also indicated that health professionals may find some specific duties such as breaking bad news difficult to carry out (Fallowfield & Jenkins, 2004; Guerra, Mirlesse, & Baião, 2011; Lalor, Devane, & Begley, 2007). Furthermore, it is possible that due to the stressful nature of TFA, some women may feel unsatisfied with the care they received, however well managed (Fisher et al., 2015). Finally, health professionals may find it difficult to make a decision of whether to offer a termination or not depending on the severity of the fetal abnormality and gestational age (Garel et al, 2003; Janvier et al., 2012; Savulescu, 2001; see section 1.1.5)

However, evidence also suggests that despite the challenges of caring for women, health professionals have some understanding of the emotional difficulties that women experienced in the context of perinatal loss (Geller et al., 2010; Gold, 2007; Kelley & Trinidad, 2012; Menezes et al., 2013; Nicholson et al., 2010; Rowlands & Lee, 2010). Nevertheless, no study has, so far, investigated this question specifically, nor has any study examined health professionals' perceptions of women's coping with TFA. This level of understanding is, nevertheless, essential for health professionals to deliver compassionate care. The dearth of research in this area informed the research's third objective (section 1.4.2.3), which is to examine health professionals' perceptions of women's coping with TFA.

1.2.3.4 Couple congruence

Research indicates that couple congruence may also impact upon women's adjustment to TFA, with women's grief levels being higher when they perceive their relationship to be incongruent (Korenromp, 2006; Nazaré et al., 2012, 2013). Studies about men's emotional adjustment to TFA suggest that men may also experience psychological difficulties following TFA (Korenromp et al., 1992, 2005b; Lafarge & Fox, 2013a; Robson, 2002; Suslak, Scherer & Rodriguez, 1995). Research also shows that men and women grieve differently and that women experience more intense grief than men after TFA (Korenromp et al., 2005b; Korenromp, 2006; Nazaré et al., 2013, 2014), but this difference subsides over time (Korenromp et al., 2005b). The discrepancy between partners is attributed to the physicality of the pregnancy with women experiencing a physical as well as an emotional loss (Nazaré et al., 2012, 2013). This has also been documented in the context of other perinatal losses such as miscarriages (Brier, 2008).

Although both the potential for distress in both genders and the possible impact of couple congruence upon women's psychological adjustment to TFA have to be acknowledged, the fact that women display higher and longer-lasting levels of grief following TFA than men underpins the research's focus on women's experience. In addition, examining couple congruence in coping with TFA would significantly alter the research's orientation. Given that, at the inception of the research programme, no research had been conducted on coping with TFA, it was deemed essential for the research to concentrate on those most concerned by the experience of TFA; in the first place, the women. Based on these considerations, whilst remaining cognisant of the potential importance of couple congruence on women's adjustment to TFA, the decision was made not to investigate this factor as part of the research reported in this thesis.

1.2.4 Summary of the literature review

The literature review on women's psychological adjustment to TFA indicates that TFA is a traumatic event that can have long-term negative psychological consequences for women and their partners, including during subsequent pregnancies. These consequences have been well documented and include complicated grief, depression and posttraumatic stress (e.g. Kersting et al., 2005, 2007; Korenromp et al., 2005a, 2007a; Mirlesse et al., 2011; Statham et al., 2001; Zeanah et al., 1993). Psychological adjustment to TFA has been associated with various factors. These include: clinical factors related to the terminated pregnancy and obstetric history, demographics and individual characteristics, women's experience of care, and couple congruence (e.g. Davies et al., 2005; Kersting et al. 2005, 2007, 2009; Korenromp et al., 2005a, 2007a; 2009; Mirlesse et al. 2011; Statham et al., 2001). However, much of the literature is either limited (e.g. women's experience of care) or contrasted (e.g. the degree of association between various obstetrics, termination-related or demographic factors and women's psychological adjustment to TFA). Therefore, investigating which factors and to what degree they may be associated with women's psychological adjustment and their use of coping strategies is important.

Importantly, the literature review has identified several important knowledge gaps. These comprise: 1) the absence of a synthesis of the qualitative evidence on women's holistic experience of TFA; 2) a lack of research on women's coping strategies when dealing with TFA; 3) a dearth of research on health professionals' perceptions of women's coping with TFA; 4) a paucity of research on potential positive psychological outcomes following TFA such as posttraumatic growth. These knowledge gaps informed the research's overarching rationale, aims and objectives, which are detailed in section 1.4. The next section focuses on the constructs identified as being relevant to TFA and which underpin the focus of the research programme: coping, perinatal grief and posttraumatic growth.

1.3 Coping, perinatal grief and posttraumatic growth in the context of TFA

The literature review identified that, as a form of bereavement, one key psychological outcome of TFA is grief (e.g. Kersting et al., 2007; Nazaré et al., 2013, 2014; Zeanah et al., 1993). The review also identified that the process of coping with TFA and the potential positive psychological outcomes have not yet been assessed in the context of TFA, despite the contribution that these concepts could make in deepening our understanding of women's experience and adjustment to TFA. The subsequent sections focus on the three psychological constructs of coping, perinatal grief and posttraumatic growth in relation to TFA.

1.3.1 Coping with TFA

1.3.1.1 *Defining coping*

Interest in coping originates from the realisation that people who face similar stressful events adjust in different ways, and that coping processes influence psychological outcomes (Carver & Connor-Smith, 2010; Lazarus & Folkman, 1984). Whilst personality traits and situational factors are involved in the way people adjust to any event, several cognitive and behavioural factors are also believed to be implicated. Coping was a relatively neglected field of research until the work by Lazarus and Folkman (1984) on the cognitive stress theory in the early 1980s, which aimed to define, conceptualise and instrumentalise coping processes. Coping is now widely used in the field of Psychology and, in particular, in health psychology to understand individuals' management and adaptation to a range of conditions (e.g. Cartwright, Endean, & Porter, 2009; Duangdao & Roesch, 2008; Moskowitz, Hult, Bussolari, & Acree, 2009).

Lazarus and Folkman (1984) defined coping as: "cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.141). In other words, coping is a series of psychological processes that takes place when one is faced with a stressful event. It consists of appraising the threat to reduce its magnitude and subsequent impact upon the individual (Carver &

Connor-Smith, 2010). These psychological processes involve threat appraisal (perception and evaluation of the threat) and coping *per se* (resources involved in managing the problem). This theory, therefore, suggests that coping is contextual and situation dependent and varies according to the type of stressor and the individual's situation. Given the many ways to appraise and manage a stressful situation, much research has focused on categorising these processes (Carver, Scheier, & Weintraub, 1989; Carver 1997; Carver & Connor-Smith, 2010; Carver & Vargas, 2011; Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984; Pargament, Smith, Koenig, & Perez, 1998; Roth & Cohen, 1986; Skinner, Edge, Altman, & Sherwood, 2003).

1.3.1.2 Categorising coping processes

The first classification of coping processes was articulated around two dimensions: approach and avoidance coping (Roth & Cohen, 1986), with the former representing approaching or engaging with the identified threat and the latter, avoiding it. Approach coping has been considered to be more beneficial to individuals' long-term wellbeing than avoidance coping. However, avoidance coping has also been shown to be helpful in the initial stage of a trauma or when the situation is deemed uncontrollable (Roth & Cohen, 1986). With the publication of the Ways of Coping questionnaire (Lazarus & Folkman, 1984), the field moved away from the approach-avoidance classification to a problem solving and emotional coping paradigm. Problem solving coping is aimed at the stressor and may involve steps such as actively trying to remove the stressor or avoid its negative impact. By contrast, emotion coping is aimed at managing the emotional responses to the stressor and may involve steps such as distraction and emotional support (Carver & Vargas, 2011).

Later, the work by Carver and colleagues (Carver et al., 1989; Carver 1997) gave rise to a multi-dimensional approach to coping, which they argued better reflected the complexity of coping processes. They posited that the coping categories traditionally used were too broad, too simplistic and often ill-defined. For example, some coping strategies such as using social support could serve both a problem solving and an emotional function (Carver &

Vargas, 2011). Therefore, Carver and colleagues introduced new scales to measure coping processes (the COPE inventory [Carver et al., 1989], and later, a shortened version, the Brief COPE [Carver, 1997]), which they claimed offer a more granular approach to coping. They further argued that the new scales led to a clearer differentiation between aspects of coping and enabled the identification of less helpful coping strategies, which may hinder the active process of coping.

A review by Skinner et al. (2003) of over 100 studies on coping, identified five core categories of coping: problem solving, support seeking, distraction, avoidance, and positive restructuring. Other categories have also been discussed e.g. accommodative, emotional approach, meaning-focused, and proactive coping (Aspinwall & Taylor, 1997; Carver & Connor-Smith, 2010; Carver & Vargas, 2011; Folkman, 1977; Skinner et al., 2003; Stanton et al., 2000).

1.3.1.3 Relevance of coping

Regardless of how coping processes are categorised, the relationship between the way individuals cope with an event and the way they adjust to it is clearly established (e.g. Carver 1997; Carver & Connor-Smith, 2010, Skinner et al., 2003). Many studies have highlighted the role of coping in adjusting to stressful situations among various populations, although none have addressed this in the context of TFA. Studied populations include individuals with diabetes (Duangdao & Roesch, 2008), human immunodeficiency virus (HIV [Moskowitz et al., 2009]), alopecia (Cartwright et al., 2009), individuals who have experienced severe injury and violence (Littleton, Horsley, John, & Nelson, 2007), or natural disasters (Glass, Flory, Hankin, Kloos, & Turecki, 2009). The aforementioned studies show associations, although some of them modest, between avoidance or disengagement coping and distress. Better psychological outcomes have also been observed when active coping and positive reframing are utilised (Moskowitz et al., 2009). A more contrasted picture emerges from cancer research, with little evidence of the impact of any particular coping style upon survival rates or recurrence of the disease (Petticrew, Bell, & Hunter, 2002). Carver & Connor-Smith

(2010) further suggested that coping may be more strongly associated with psychological than physical wellbeing and that coping may be influenced by the type, the duration and how controllable the stressor is. For example, when the stressor is uncontrollable, an engaged and active approach may, to some extent, backfire and generate distress. Similarly, an avoidant approach in a situation where the stressor is controllable may further the distress experienced.

Thus far, the evidence demonstrates that coping relates to the way individuals adapt to a range of health stressors. It remains to be ascertained whether this phenomenon would also be observed in the context of bereavement and perinatal loss.

1.3.1.4 Coping with bereavement and perinatal loss

The relationship between coping and psychological adjustment has also been documented in the context of bereavement and perinatal loss (Harper, O'Connor, & O'Carroll, 2014a; Schnider, Elhai, & Gray, 2007). Studies about coping with bereavement indicate strong relationships between coping strategies and adjustment to the loss. A study by Schnider et al. (2007) among students who had suffered a loss, shows that coping strategies predict complicated grief. In particular, emotional avoidant coping was linked to higher levels of distress. Similarly, a study among bereaved parents indicates a relationship between avoidance-focused coping, lower levels of cognitive restructuring, and higher levels grief (Harper et al., 2014a).

Studies on coping with perinatal loss are sparse. One qualitative study conducted among African American women following involuntary pregnancy loss (Van & Meleis, 2003) showed that women use a range of coping strategies. These include: talking about the baby, seeking support from organisations, internalising the loss, avoiding thinking about it, praying, keeping memorabilia and dealing with anxiety in subsequent pregnancies. Another qualitative study by Abboud and Liamputtong (2005) suggests that social support and positive interactions with health professionals were essential to women's coping with spontaneous loss. Other studies have focused on the coping strategies used by pregnant

women who have experienced perinatal loss previously (Bergner, Beyer, Klapp, & Rauchfuss, 2008; Côté-Arsenault, 2007). The study by Bergner et al. (2008) suggested that women who exhibit more 'depressive coping' than others are more likely to experience higher levels of anxiety and depression in the first trimester of their pregnancy. Similarly, Côté-Arsenault (2007) proposed that pregnancy subsequent to loss is perceived as a threat, which in turn, increases anxiety during pregnancy.

The literature review demonstrates that despite the link between coping and psychological adjustment to life stressors, research into coping in the context of bereavement and perinatal loss is limited. At the inception of the research programme, no studies on women's coping strategies when undergoing TFA had been identified, nor on the relationship between coping strategies and women's psychological adjustment. This observation informed the research's second objective (section 1.4.2.2).

1.3.2 Perinatal grief following TFA

1.3.2.1 Bereavement and grief theories

Some of the most influential grief theories have used a phase or stage model (Bowlby & Parkes, 1970; Kübler-Ross, 1969) to explain adaptation to bereavement. These theories posit that bereaved individuals have to progress through each phase in sequential order to successfully adjust to their loss (Hall, 2014). The concept of 'grief work,' introduced by Freud in 1917, has also been influential in emphasising the importance of emotional detachment from the deceased to adjust to a new life and build new relationships (Hall, 2014; Wilson 2014). These phase/stage theories and the concept of 'grief work' have, however, been criticised for being too rigid and not reflecting the complexity and idiosyncrasies of the experience of bereavement (Hall, 2014).

Several theories have since offered a more nuanced perspective on grief (Hall, 2014). These theories may provide a more appropriate framework to conceptualise the experience of bereavement in the context of TFA. The first theory is the continuing bonds theory (Klass, Silverman, & Nickman, 1996). This theory questions the effectiveness of

severing emotional bonds to the deceased. It posits that the purpose of grieving is not to relinquish bonds with the deceased but to maintain them and allow them to coexist with other relationships, whether these are on-going or new relationships. Consequently, continuing bonds are seen as promoting adaptation to a new world without the deceased (Wilson, 2014).

Later, Stroebe and Schut (1999) introduced the dual process model of coping with grief. This model was born from the limitations of coping theories, including Lazarus and Folkman's theory (1984), which focus on individuals' reaction to a single stressor (Meij et al., 2008). The model proposes that two types of stressors exist in the context of bereavement, those linked to the loss itself and those related to the changes that occur as a result of the loss (Stroebe & Schut, 1999). These two stressors require different coping processes: loss-orientated and restoration-orientated coping. Loss-orientated coping involves confronting and processing the loss, grief work and oscillation between relinquishing and continuing bonds. In comparison, restoration-orientated coping consists of attending to life changes, distraction from grief and working through new roles and identities. Both types of coping encompass emotion and problem-focused strategies (Stroebe & Schut, 1999). The dual process model suggests that bereaved individuals face both types of stressors and thus, oscillate between the two coping processes. Grief is conceptualised as an oscillatory process in which bereaved individuals alternately experience and avoid suffering, contemplate their loss and engage in reconstruction activities, with both coping processes needed to adjust psychologically (Stroebe & Schut, 1999). The model accounts for the coexistence of high levels of distress and functionality in daily life. In doing so, it offers a more nuanced and idiosyncratic perspective on grief.

The theory of 'finding meaning' (Niemeyer, 2001) may also be relevant to TFA. This theory suggests that bereaved individuals are "faced with a crisis of meaning" (Keesee, Currier & Niemeyer, 2008, p.1147), and that following the death of a loved one, they need to engage in the task of reconstructing meaning in a way that is congruent with their new situation and experience. The concept of 'finding meaning' is underpinned by the assumption

of 'shattered world' proposed by Janoff-Bulman (1992). It encompasses two elements: making sense of the death and benefit finding, and is closely related to posttraumatic growth. This model posits that psychological difficulties arise when individuals fail to impart meaning to their experience, either to fit with their existing world views or to assist in the creation of new frames of reference (Keesee et al., 2008; Niemeyer, Burke, Mackay, & van Dyke Stringer, 2010).

Collectively, the more recent bereavement and grief theories provide a more nuanced, idiosyncratic perspective on grief than the stage/phase models of bereavement (Bowlby & Parkes, 1970; Kübler-Ross, 1969). The theory of continuing bonds challenges the assumption that the outcome of grief is to sever the bonds with the deceased, the dual process model provides a more nuanced and pluralistic view of the process of coping with grief, whilst the model of finding meaning offers a more interpretative representation of grief (Hall, 2014; Stroebe, Schut, & Stroebe, 2007; Wilson 2014).

1.3.2.2 Relevance of perinatal grief to TFA

Many studies have examined the psychological outcomes of TFA in terms of depression and posttraumatic stress, but several have also used grief as an outcome of TFA (e.g. Kersting et al., 2009; Statham et al., 2001; Zeanah, 1993). Grief is a normal reaction following a loss and most individuals are believed to resume normal functioning within a year (Gupta & Bonanno, 2011; Kersting & Wagner, 2012). However, for some (10-15%) it can result in prolonged or complicated grief (Gupta & Bonanno, 2011). Complicated grief is characterised by an atypical intensity and duration of symptoms, and a high level of impairment on social and occupational functioning (Boelen & Prigerson, 2013; Stroebe, Schut, & van der Bout, 2013). This disorder has recently been added to the *Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-V, American Psychiatric Association [APA], 2013)*. In a literature review on complicated grief after perinatal loss, Kersting and Wagner (2012) suggested that perinatal bereavement differs from other significant losses and that several factors may contribute to this difference. These include: feelings of guilt and self-blame, loss

of reproductive self-esteem, limited experience of contact with the fetus, and the fact that the grief may be disenfranchised. In the case of TFA, women face all the aforementioned issues but they also have to decide whether to hold/see the baby, which some may find traumatic (Kersting & Wagner, 2012). A study by Kersting et al. (2007) showed that 14 months after TFA, a significant number of women (13.7%) displayed symptoms of complicated grief. This was comparable to a study by Korenromp et al. (2009) which indicates that up to one year after the termination, 20% of the women displayed symptoms compatible with a diagnosis of complicated grief. Together the aforementioned studies show that a significant proportion of women experiencing TFA develop complicated grief. This underlines the relevance of the concept of perinatal grief in the context of TFA and supports the rationale for examining it empirically.

1.3.3 Posttraumatic growth following TFA

Another area relevant to the experience of, and adjustment to, TFA is the potential for positive psychological outcomes. This phenomenon has been referred to as benefit finding (Helgeson, Reynolds, & Tomich, 2006), or thriving (Carver, 1998), but the more commonly used terminology for it is posttraumatic growth (Tedeschi & Calhoun, 2004). In the past 15 years, a growing body of evidence has indicated that people who endure traumatic events may experience stress-related growth (Bonanno, 2004; Linley & Joseph, 2004; McMillen, Smith, & Fisher, 1997; Tedeschi & Calhoun, 1996, 2004). The literature review has revealed that despite being highly relevant to TFA, posttraumatic growth has not yet been examined in this context.

1.3.3.1 Defining posttraumatic growth

The idea that people facing adversity may experience growth as a result is not new, and has foundations in ancient philosophies and Eastern religions (Joseph, 2011; Seligman, 2011). This concept enjoyed a renewed interest in the late 19th century with the philosophy of Nietzsche (1844-1900) and his famous aphorism: "*What does not kill me makes me*

stronger.” In the 20th century, the concept of growth underpinned the Humanist and Existentialist traditions (Frankl, 1959; Maslow 1962; Yalom & Liberman, 1991), with concepts such as self-actualisation, autonomy and meaning making. The rising popularity of Positive Psychology (Seligman & Csikszentmihalyi, 2000) since the beginning of the 21st century has, once again, put posttraumatic growth at the forefront of psychological research, in particular in the area of trauma.

Posttraumatic growth refers to “the experience of individuals whose development, at least in some areas, has surpassed what was present before the struggle with crises occurred” (Tedeschi & Calhoun, 2004, p.4). It corresponds to a new way of functioning and involves changes on personal, philosophical and relationship levels (Joseph, 2011). Personal changes encompass finding new strengths, compassion and empathy for others. Philosophical changes centre on gaining a sense of meaning and purpose in life and a change in life priorities. Relationship changes involve adopting a new approach to close relationships and a renewed sense of intimacy (Joseph, 2011; Seligman, 2011).

1.3.3.2 Main characteristics of posttraumatic growth

Posttraumatic growth has three main characteristics: it differs from resilience, coexists with distress and involves high cognitive processing. Posttraumatic growth differs from resilience in that the latter describes the return to normal functions following adversity. Thus, resilience can be considered as a recovery process, whereas posttraumatic growth is a “transformation” (Joseph, 2011; Tedeschi & Calhoun, 2004). Research has shown that people who score high on resilience may actually experience little posttraumatic growth (Joseph, 2011). This underlines an essential characteristic of posttraumatic growth; that it coexists with distress (Tedeschi & Calhoun, 2004).

The concept of posttraumatic growth is underpinned by Janoff-Bulman’s shattered assumptions theory (1992). This theory suggests that three assumptions shape the way we see the world: the world is benevolent, meaningful and worthy. A traumatic event has the potential to shatter these assumptions, and permanently alter the way one sees the world,

causing distress in the process. Hence, distress becomes a necessary component of posttraumatic growth. Once the world assumptions have been shattered, individuals have to build a new vision of the world congruent with their experience. This new vision may become richer, more meaningful, and more conducive to growth, despite also encompassing feelings of vulnerability (Joseph, 2011).

The process of building a new vision of the world is associated with intense cognitive activity (Tedeschi & Calhoun, 2004), a process sometimes referred to as rumination (Allbaugh, 2013). Rumination can be linked to personality predisposition (trait-related rumination) or a particular event (event-related rumination), with the latter more closely associated with posttraumatic growth (Cann et al., 2011). Event-related rumination is itself split into two categories: intrusive rumination (repetitive, negative, and unwanted thoughts) and deliberate rumination (repetitive, purposeful thoughts focusing on specific components of the difficult elements of the event; [Calhoun, Cann, Tedeschi, & McMillan, 2000; Calhoun and Tedeschi, 2006; Cann et al., 2011; Taku, Calhoun, Cann, & Tedeschi, 2008; Treynor, Gonzalez, & Nolen-Hoeksema, 2003]). Deliberate rumination is considered as a key mechanism in processing a traumatic event, which may lead to resolution and deriving meaning, with meaning relating to greater positive change (Joseph, 2011). By contrast, intrusive event related rumination is thought to generate higher levels of distress (Allbaugh, 2013; Taku et al., 2008; Triplett, Tedeschi, Cann, Calhoun, & Reeve, 2012).

Thus, posttraumatic growth can be described as a transformation that follows a traumatic event, which shakes individuals' world assumptions, is accompanied by distress and is facilitated by intense cognitive processing. This phenomenon has been documented in a number of populations and settings, leading to the consideration of its relevance to TFA.

1.3.3.3 Relevance of posttraumatic growth

Linley and Joseph (2004) estimated that positive changes are experienced by 30-75% of those experiencing trauma. Therefore, posttraumatic growth is a common phenomenon. It is also linked to higher wellbeing as evidenced by a meta-analysis by Helgeson et al. (2006),

which suggested that benefit finding (or posttraumatic growth) is associated with lower depression and higher levels of wellbeing. Posttraumatic growth has also been observed in the context of life threatening illnesses (Hefferon, Grealy, & Mutrie, 2009), survivors of cancer (Lelorain, Bonnaud-Antignac & Florin, 2010; Schroevers & Teo, 2008), and individuals living with HIV (Milam, 2006), and multiple sclerosis (Pakenham, 2005).

Joseph (2011) also proposed that the concept of posttraumatic growth is clinically useful as it enables health professionals to investigate emotional distress (e.g. posttraumatic stress) from a non-medical perspective, and as a process. This concept also provides insights into the spectrum of experiences following a traumatic event, not just the negative ones (Joseph, 2011). In the tradition of Positive Psychology, it also enables professionals to “change the focus of psychology from preoccupation only with repairing the worst things in life to also building positive qualities” (Seligman & Csikszentmihalyi, 2000). Promoting psychological wellbeing, therefore, involves targeting distress as well as encouraging individuals to adopt a richer and more meaningful view of their life.

1.3.3.4 Posttraumatic growth following bereavement and perinatal loss

Posttraumatic growth has been reported in the context of bereavement (Calhoun, Tedeschi, Cann, & Hanks, 2010; Taku, Tedeschi, & Cann, 2015) and parental bereavement (Engelkemeyer & Marwit, 2008; Riley, La Montagne, Hepworth, & Murphy, 2007). Some studies have also linked coping to posttraumatic growth. For example, the study by Riley et al. (2007) suggests that bereaved mothers who are more optimistic and make more use of coping strategies such as active coping and positive reframing, suffer less intense grief reactions and experience higher levels of posttraumatic growth. Thus, in this instance, coping was related to posttraumatic growth as well as psychological adjustment.

Research on posttraumatic growth in the context of perinatal loss is in its infancy but Black and Wright’s literature review (2012) suggests that individuals who experience perinatal loss report various positive changes as a result of their loss. These include: changes in priorities, strengthening of marital bonds, renewed appreciation for existing

relationships, renewed empathy and compassion for others and the ability to identify new possibilities in life (Black & Sandelowski, 2010). Similarly, Thomadaki (2012) conducted a qualitative study about growth following perinatal loss, which shows that women experience a range of positive transformations; firstly at an intrapersonal level through increased self-worth and self-efficacy, a change in perspectives and life priorities; secondly at an interpersonal level through renewed empathy towards others and a sense of companionship. To date, only one study has examined posttraumatic growth in the context of fetal abnormality (Black & Sandelowski, 2010). This qualitative study investigated the experience of posttraumatic growth following a diagnosis of severe fetal abnormality from the perspective of the five domains of the Posttraumatic Growth Inventory (PTGI; [Tedeschi & Calhoun, 1996]). These include: relating to others, new possibilities, spiritual change, appreciation of life and personal strength. The study found evidence of posttraumatic growth, particularly in the area of 'relating to others.' However, the sample in this study mainly comprised women who had continued with the pregnancy following the diagnosis, therefore further research, specifically in the context of TFA, is needed.

The literature review on posttraumatic growth shows that it is a common phenomenon and that it is highly relevant to perinatal loss. The fact that no studies have been conducted in the area of TFA informed the research's fourth objective (section 1.4.2.4).

1.3.4 Summary of the psychological constructs relevant to TFA

The review of the literature clearly demonstrates that perinatal grief is a construct highly relevant to TFA and that it has been used as an outcome measure for TFA (e.g. Kersting et al., 2007; Nazaré et al., 2013, 2014; Statham et al., 2001; Zeanah et al., 1993). The evidence also indicates that coping impacts upon psychological outcomes (e.g. Carver & Connor-Smith, 2010) and that avoidance coping may hinder psychological adjustment long-term (e.g. Moskowitz et al., 2009). Research also suggests that a significant proportion of individuals who face a traumatic event can experience a range of positive outcomes, including growth, as a result (Joseph, 2011). This process is generally accompanied by

distress and is facilitated by cognitive processes, which enable individuals to process the loss and build a new vision of the world that is congruent with their experience (Tedeschi & Calhoun, 2004). At the inception of the research, neither coping nor posttraumatic growth had been investigated specifically in the context of TFA despite their relevance to the area of bereavement and trauma. Furthermore, the role of coping strategies, and indeed perinatal grief, in the experience of posttraumatic growth following TFA remains to be ascertained. These observations informed the research's second and fourth objectives (sections 1.4.2.2 and 1.4.2.4).

1.4 Rationale, aims and objectives of the research

1.4.1 Rationale and aims of the research

The review clearly highlights that TFA is an important topic to investigate for four reasons. Firstly, TFA is a unique and complex phenomenon, which may be stigma-bearing and subject to misunderstandings (Black, 2011; McCoyd, 2007, 2010a). TFA is similar, yet also fundamentally different from other perinatal losses (Fisher & Lafarge, 2015; Keefe-Cooperman, 2005; Robinson, 2014). It bears a moral and ethical dimension because it results from parental choice and the decision to terminate the pregnancy is based upon disability-related considerations (Sandelowski & Barroso, 2005; Shakespeare, 2011; Ville, 2011). This adds a level of complexity to a reproductive event that many women consider as life changing.

TFA is also an important topic because of its impact upon individuals. Evidence suggests that taking the decision to terminate a pregnancy termination for fetal abnormality is complex and painful (Sandelowski & Barroso, 2005) and that TFA can have profound psychological consequences including symptoms of complicated grief, depression and posttraumatic stress (Kersting et al., 2005, 2009; Korenrump et al., 2009; Mirlesse et al., 2011; Statham et al., 2001). As a potentially traumatic event, TFA does not however impact solely upon the women who experience it. It also affects women's partners (Korenrump,

2006; Nazaré et al., 2012, 2013), their family and the health professionals caring for them (Garel et al., 2002, 2007; Menezes et al., 2013; Nicholson et al., 2010). Furthermore, the impact of TFA is not time limited and can often be felt long after the termination, including during subsequent pregnancies (Blackemore et al., 2011; Côté-Arsenault, 2003, 2007).

Defined as a type of abortion, TFA also impacts upon the wider society. It influences the entities that care for and/or provide support to women undergoing TFA, whether fetal medicine units, abortion service providers, or support organisations (e.g. Antenatal Results and Choices [ARC]). As a social phenomenon, TFA both reflects and influences the legal, political and social context within which the individual experience of TFA takes place. Thus, it can be argued that TFA has significant repercussions on society as a whole.

Finally, TFA is a growing phenomenon and the number of women facing TFA is likely to rise further due to technological progresses in prenatal diagnosis (Hill et al., 2014; Lewis et al., 2014) and increased maternal age which is associated with obstetric complications and adverse pregnancy outcomes (Loane et al., 2013; RGOG, 2009).

Based on these considerations, it is important to understand women's experience of coping with TFA because coping has been shown to relate to psychological outcomes (Carver & Connor-Smith, 2010). Therefore, it is important to understand women's use of coping strategies when dealing with TFA and how these relate to their psychological adjustment. It is also important not to restrict the consideration of psychological outcome to perinatal grief and to include positive outcomes such as posttraumatic growth, as research has demonstrated that individuals may experience growth as a result of a trauma. The research presented in this thesis addresses these issues. The ultimate aim of the research is to further the understanding of women's experience of coping with TFA, with a view to translate this knowledge into practice and inform policy making, for the benefit of the women and their families.

1.4.2 Knowledge gaps and research objectives

The literature review identified four knowledge gaps. These are: 1) the absence of a synthesis of qualitative studies on women's holistic experience of TFA; 2) a lack of research on women's coping strategies when dealing with TFA; 3) a dearth of research on health professionals' perceptions of women's coping with TFA; 4) a paucity of research on potential positive psychological outcomes, such as posttraumatic growth, following TFA. These four knowledge gaps underpin the focus of the research programme and are addressed by the four research objectives.

1.4.2.1 Objective 1: To synthesise the qualitative evidence of women's holistic experience of TFA

The current literature shows a strong quantitative focus on psychological adaptation to TFA. There are, however, several qualitative studies on women's experience of TFA but no synthesis of this body of knowledge (see section 1.2.1.2). As a complex event, TFA needs to be examined as a holistic experience. This implies going beyond the quantitative measurement of psychological outcomes of TFA to enable women's voices to be heard. The aim of this synthesis is to complement existing evidence of women's experience of TFA and provide novel insights into what coping with TFA may encompass. This knowledge gap informs the research's first objective which is to conduct a systematic review and synthesis of the qualitative evidence of women's holistic experience of TFA (Study 1, chapter 2).

1.4.2.2 Objective 2: To explore women's coping strategies when dealing with TFA and assess their relationship with perinatal grief

At the inception of this research programme, no research had been conducted on the actual process of coping with TFA. Nevertheless, evidence shows that coping impacts upon psychological adaptation to difficult events (Carver & Connor-Smith, 2010; Lazarus & Folkman, 1984). This knowledge gap informs the research's second objective, which is twofold: firstly, to explore women's coping strategies used at the time of the termination and

afterwards (Study 2a, chapter 4); secondly, to assess the relationship between coping strategies and perinatal grief (Study 2b, chapter 5).

1.4.2.3 Objective 3: To explore health professionals' perceptions of women's coping with TFA and assess to what extent these perceptions are congruent with women's accounts

At the time of writing, no research had been conducted to ascertain health professionals' perceptions of women's coping with TFA. If health professionals are to provide optimum care to women, it is important to assess how congruent health professionals' perceptions of women's coping are with women's accounts. This knowledge gap informs the research's third objective, which is to examine health professionals' perceptions of women's coping and compare them with women's accounts to identify similarities and differences between the two groups (Study 3, chapter 6).

1.4.2.4 Objective 4: To measure posttraumatic growth following TFA and assess its relationship with women's coping strategies and levels of perinatal grief

There is a strong focus in the literature on negative psychological outcomes to TFA. However, research suggests that some individuals experience growth as a result of a traumatic event (Joseph, 2011; Tedeschi & Calhoun, 2004). This knowledge gap informs the research's fourth objective, which is twofold: firstly, to ascertain whether women experience posttraumatic growth as a result of TFA; secondly, to examine the relationship between posttraumatic growth, coping strategies and perinatal grief (Study 4, chapter 7).

To answer these four objectives, five studies have been conducted: 1) a systematic review and synthesis of the qualitative evidence about women's holistic experience of TFA; (chapter 2); 2) a qualitative exploration of women's coping strategies when dealing with TFA (chapter 4). 3) a quantitative assessment of women's coping strategies when dealing with TFA and their relationship with women's levels of perinatal grief (chapter 5); 4) a qualitative

exploration of health professionals' perceptions of women's coping with TFA (chapter 6); and 5) a quantitative assessment of posttraumatic growth following TFA and the relationship between coping, perinatal grief and posttraumatic growth (chapter 7).

Prior to undertaking the empirical work on women's coping with TFA, it was deemed necessary to understand the holistic experience of TFA from the women's perspective. The systematic review and synthesis of the qualitative evidence, presented in the next chapter (chapter 2), addresses this first research objective.

1.5 Conclusions and implications for the thesis

This chapter outlined the context within which women experience TFA from medical, legal, political and ethical perspectives. Based on the evidence, TFA can be defined as a unique and complex type of perinatal loss. The literature review has indicated that TFA can be seen as a traumatic event, which may have long-lasting psychological consequences for those involved. A number of factors have been shown to be associated, to various degrees, with women's psychological adjustment to TFA. These include clinical factors related to the terminated pregnancy, obstetric history, demographics and individual characteristics, women's experience of care and couple congruence. The literature review also emphasised the relevance of the psychological constructs (coping, perinatal grief and posttraumatic growth) underpinning the focus of the research programme, in the context of TFA.

The next chapter reports the systematic review and synthesis of the qualitative evidence about women's holistic experience of TFA.

Chapter 2 - Pregnancy termination for fetal abnormality: A systematic review and synthesis of women's experiences

*The literature review in chapter 1 identified the need to gain a deeper understanding of women's holistic experience of TFA. This knowledge gap informed the research's first objective, which is to synthesise the qualitative evidence on this topic. This chapter presents a systematic review and synthesis of women's experiences of TFA. A discussion of the review's main findings is presented at the end of the chapter alongside an evaluation of its limitations. This review generated a research article (Lafarge, Mitchell, & Fox. [2014] *Pregnancy termination for fetal abnormality: A meta-ethnography of women's experiences*), which has been published in the peer-reviewed journal *Reproductive Health Matters*.*

2.1 Introduction

The literature review presented in chapter 1 indicated that TFA is a unique and complex phenomenon, which can have significant long-term psychological consequences. Two systematic reviews on the psychological impact of TFA were identified in the literature review (chapter 1, section 1.2). Both were published in 2011 (Steinberg, 2011; Wool, 2011) indicating a high level of interest in the topic. Although insightful, these reviews are limited by their focus on quantitative measures of mental health outcomes and, therefore, fail to provide insights on women's holistic experience of TFA. These limitations warrant a systematic review and synthesis of qualitative studies about the experience of TFA.

2.1.1 The development of systematic reviews and syntheses of qualitative evidence

Qualitative methods are particularly suited to explore new areas of research, or areas of research which require understanding individuals' emotions and perceptions of the world (Strauss & Corbin, 2008). In the past 15 years, the development of systematic reviews of qualitative evidence has gathered pace (Campbell et al., 2003; Sandelowski, Docherty, &

Emden, 1997; Shaw, 2012; Tong, Flemming, McInnes, Oliver, & Craig, 2012). This development partly results from the large number of qualitative studies in social sciences conducted in the past two decades, and from a general appetite to apply the rigorous methods for systematically appraising and synthesising quantitative data to qualitative evidence (Atkins et al., 2008; Campbell et al., 2003). Consequently, a trend in building more holistic pictures of human experience by moving away from the quantitative evidence-based model has been observed in the past ten years (Dixon-Woods et al., 2006). The progressive inclusion of qualitative studies into Cochrane reviews (Campbell et al., 2003), and the creation, in 2004, of the Cochrane Qualitative Research Methods group (www.cqim.cochrane.org), whose remit is to conduct systematic reviews of qualitative data, illustrate this shift. This trend also derives from a desire to ground policies in the best available evidence (e.g. NICE and the use of evidence-based models) and to build more complete and holistic representation of phenomena (Campbell et al., 2003; Dixon-Woods et al., 2006; Shaw, 2012; Tong et al., 2012).

The emphasis on qualitative methods is also part of a wider movement in translational research calling for a more prominent role of qualitative inquiries in building knowledge (Campbell et al., 2011; Tripp-Reimer & Doebbeling, 2004). This shift is illustrated, for example, by the evidence-based model developed by the Joanna Briggs Institute (Pearson, Jordan, & Munn, 2012), which posits that an information gap exists at the very beginning of the translational process. This model suggests that failure to successfully translate evidence into practice partly results from a failure to identify the initial needs for knowledge, which leads to ill-defined research questions. Getting the research question right is, therefore, a pre-requisite of successful evidence to practice translation. This requires stakeholders' involvement (patients and clinicians) in identifying information needs and formulating relevant research questions, both of which are usually generated from qualitative investigations (Pearson et al., 2012). Chesla (2008) further suggested that qualitative evidence can be used in the translational process itself, through refining interventions and adapting them to particular contexts, populations and settings. Leeman and Sandelowski

(2012) also proposed using qualitative inquiries to gather health professionals' experiences, for example of delivering interventions, which would complement the information required for a successful translational process. Collectively, these developments illustrate the increasingly important role ascribed to qualitative studies and qualitative reviews in building knowledge and translating this knowledge into practice.

2.1.2 Aims of the review

The literature review presented in chapter 1 (section 1.2) identified a knowledge gap regarding women's holistic experience of TFA. The aim of this review is, therefore, to understand the experiences of women undergoing TFA. The review findings will complement existing knowledge about the experience of TFA derived from quantitative evidence and may provide insights into the way women cope with TFA.

2.2 Methods

2.2.1 Design

2.2.1.1 Meta-ethnography

The data for this review were synthesised using meta-ethnography (Noblit & Hare, 1988). Methodologies for synthesising qualitative evidence can be split into two broad categories: aggregation and interpretation. As an interpretative method of data analysis, meta-ethnography belongs to the latter tradition. It "involves induction and interpretation, and in this respect resembles the qualitative methods of the studies it aims to synthesise" (Britten et al., 2002, p.210). Meta-ethnography is a reliable methodology (Atkins et al., 2008; Britten et al., 2002) originating from the work of Noblit & Hare (1988). Initially used in the field of education research, it has been used extensively in the healthcare context (Campbell et al., 2003; Garside, Britten, & Stein, 2008; Malpass et al., 2009; Munro et al., 2007), and reproductive health (Benza & Liamputtong, 2014; Elmir, Schmied, Wilkes, & Jackson, 2010).

2.2.1.1.1 Advantages and disadvantages of using meta-ethnography

Meta-ethnography's main advantage lies in its interpretative nature. This means that it is possible to achieve new understandings of a phenomenon, which would not have been apparent by simply examining individual studies (Campbell et al., 2003). Given its interpretative focus, meta-ethnography is appropriate to synthesise studies which, themselves, use interpretative methods of data analysis. Consequently, studies based on identifiable and interpretative qualitative method of data collection and analysis (e.g. grounded theory or phenomenology) are more likely to be included in a meta-ethnography than descriptive ones. This, in itself, is an indication of the quality standards used in selecting the studies in meta-ethnographic reviews. Using meta-ethnography, however, has several limitations. Firstly, although meta-ethnography has attracted much interest in the past decade, it is still a relatively unknown methodology among researchers and publishers. Secondly, due to its interpretative nature, it can be considered subjective, particularly with regards to the inclusion criteria. Indeed, Noblit and Hare (1988) posited that a key inclusion criterion is a study's propensity to generate relevant themes and offer a valuable contribution to the synthesis.

The subjectivity of this inclusion criteria and the underlying issue of quality appraisal is not exclusive to meta-ethnography. Debates about whether and how qualitative studies should be evaluated are on-going (Atkins et al., 2008; Dixon-Woods et al., 2007; Garside et al., 2008). One of the main issues is the potential conflict between quality and relevance, whereby screening studies on quality grounds may exclude studies of lesser quality, but which could still contribute to the understanding of the phenomenon (Sandelowski et al., 1997). Furthermore, the assessment tools used to appraise the quality of qualitative studies have been criticised for being too generic, particularly because each qualitative approach has its own sets of principles and requirements (Dixon-Woods et al., 2006). Sandelowski and colleagues (1997) also argued that, it is generally the article rather than the study that is being evaluated, as most journals have word-count limits preventing researchers from elaborating on their method and selection process. Still, some researchers consider these

assessment tools useful in enhancing studies' validity and credibility (Campbell et al., 2011). In recent years, several meta-ethnographies (Atkins et al., 2008; Benza & Liamputtong, 2014; Campbell et al., 2003; Elmir et al., 2010; Malpass et al., 2009) have incorporated quality appraisal to their review process, using tools such as the Critical Appraisal Skills Programme (CASP, 2014). Therefore, it is possible to appraise the studies' quality when conducting a meta-ethnography.

A third contentious area regarding meta-ethnography is the fact that sampling of the studies was initially purposive to the area of investigation (Campbell et al., 2003). Consequently, coverage was not always comprehensive. More recently, some meta-ethnographies have used more systematic and comprehensive search strategies, which has led to larger numbers of studies being included in the reviews (Munro et al., 2007; Savin-Baden, McFarland, & Savin-Baden, 2007). This demonstrates that meta-ethnography can be used in conjunction with a systematic and comprehensive approach to searching and selecting studies.

Based on the above considerations, meta-ethnography was deemed appropriate to systematically search, appraise and synthesise qualitative studies on women's experience of TFA. In the meta-ethnography presented in this chapter, a thorough process to appraise the studies' relevance and quality, based on recognised tools such as CHIP (Context, How, Issues, Population, [Shaw, 2010]) and CASP, was used to enhance the review's validity.

2.2.2 Search strategy and data sources

Eight electronic databases were searched independently to identify qualitative studies of women's experiences of TFA. These included Academic Search Elite, CINAHL, Embase, ISI Web of Knowledge, Maternity and Infant Care, MEDLINE, PubMed, and PsychARTICLES. The databases were searched from inception to October 2011-week 3, which corresponds to the start of the research programme.

A manual search was also conducted on footnotes, references of key articles and prominent researchers in the area of TFA (e.g. Helen Statham). Reference sections of all

selected articles were also reviewed. Boolean search based on key words, thesaurus, MeSH, and free text were carried out. Search terms were broad to maximise identification of relevant records. These included: pregnancy termination, induced abortion, therapeutic abortion, fetal abnormality, fetal anomaly, adaptation, adjustment, experiences, qualitative research, qualitative studies, and interview. The initial search was conducted by the researcher, with the researcher's second supervisor independently reviewing the titles and abstracts of the retrieved articles. Full texts of potential articles were reviewed by both the researcher and researcher's second supervisor independently.

2.2.3 Study selection

2.2.3.1 Inclusion criteria and quality assessment

To be included in the review, the studies had to be relevant to the research question (Campbell et al., 2003). This was assessed using the CHIP framework (Shaw, 2010). 'Context' referred to the setting (clinical/community), 'How' to qualitative studies, 'Issues' to experiences of TFA, and 'Population' to adult women. In addition, studies had to fulfil seven inclusion criteria. They had to report findings from primary or secondary data and comprise predominantly women's experiences. This meant that studies containing men's or health professionals' accounts were only included providing that women formed a substantial part of the sample and that the analysis of women's accounts was clearly identifiable.

To be included in the review, studies also had to be based on identifiable qualitative methods of data collection (e.g. interviews, observations), and use interpretative methods of data analysis (e.g. grounded theory, phenomenology) to ensure that only interpretative studies were included. Studies had to be peer-reviewed to enhance quality, and be written in English to avoid translation bias. Finally they had to offer a valuable contribution to the synthesis. As discussed in section 2.2.1.1.1, this criterion differs from others as it involves a subjective appraisal of study quality. This criterion is, however, in line with meta-ethnographic guidelines (Noblit & Hare, 1988). Still, to enhance the review's validity, study quality was assessed using the CASP checklist for qualitative studies (see Appendix I),

which has been successfully used in other meta-ethnographies (Benza & Liamputtong, 2014; Campbell et al., 2003; Munro et al., 2007). The checklist consists of assessing study quality using ten questions covering methodological and ethical considerations, clarity and transparency of the analysis, as well as the study's own contribution to knowledge. Although this checklist is designed to elicit critical evaluation of qualitative research evidence, it does not indicate the minimum number of criteria studies should fulfil to be categorised as 'good quality.' For the purpose of this review, positive answers to each of the questions were aggregated to evaluate the quality of the studies selected. All studies achieved a score of six out of ten and above and therefore, were deemed of sufficient quality to be included in the review. This assessment was carried out by the researcher and cross-validated by the researcher's second supervisor. Both researchers were in agreement that the selected studies were of sufficient quality to be included in the review.

2.2.3.2 Exclusion criteria

A number of studies were excluded from the review despite fulfilling the initial inclusion criteria. Several research articles based upon a single, common dataset, but offering different perspectives to the experience of TFA were initially considered for inclusion (McCoyd, 2007; McCoyd, 2008; McCoyd, 2009a; McCoyd, 2009b; McCoyd, 2010a; McCoyd, 2010b). However, to avoid over-representation and because there were overlaps between articles, only the original article was included in the review (McCoyd, 2007). The final list of studies to be included in the review was agreed through a series of meetings between the researcher and the researcher's second supervisor. The level of agreement between researchers was high.

2.2.4 Reflexivity

Reflexivity is an important element in qualitative research. Alvesson and Sköldbberg (2009) posit that there are two characteristics of reflexivity: careful interpretation of the data and reflection. Careful interpretation presupposes that interaction with the data leads to and

results from interpretation in an iterative cycle. The researcher does not simply “mirror the relationship between the ‘reality’ or ‘empirical facts’ and the research results, but interprets the data” (Alvesson & Sköldbberg, 2009, p.9). The second component, reflection, focuses on the researcher and his/her sociocultural environment. Reflection involves self-evaluation of the researcher’s own preconceptions, perspectives on a topic and interpretations of the data during the research process (Malterud, 2001). Malterud (2001) further argues that qualitative research should not aim to suppress these idiosyncrasies, but rather integrate them to the research process, while remaining cognisant of these potential personal biases. In this research programme, an on-going self-assessment of the researcher’s own position regarding the issue of pregnancy termination for fetal abnormality was performed. In this context, it is important to acknowledge the position of the researcher as a supporter of women’s choice in the area of reproductive health as this would impact upon the way the research was conducted and the data interpreted, as well as the proposed implications of the research in terms of policy and practice.

2.2.5 Data extraction and synthesis

Noblit and Hare (1988) proposed seven steps to conducting a meta-ethnography and described the analytic process as iterative. This process is illustrated in Table 2.1. The synthesis involves “translating the studies into one another,” whereby studies are analysed in relation to one another to determine whether the themes relate to (reciprocal synthesis) or refute each other (refutational synthesis). The synthesis is based on the analysis of first order constructs (participants’ quotations) and second order constructs (themes identified by the study’s authors) to generate third order constructs (themes created by the researcher [Atkins et al., 2008]). The generated themes (third order constructs) are then compared across studies, and a line of argument is developed. A line of argument represents inferences the researcher makes to create a coherent and meaningful entity. It is an interpretative framework within which the topic of interest is conceptualised (Malpass et al., 2009).

Table 2.1. Conducting meta-ethnography (adapted from Atkins et al., 2008)

Step	Task	Description of task
1	Getting started	Selecting the area of interest and research question
2	Deciding what is relevant to the initial interest	Study selection: defining the focus of the synthesis, locating relevant studies, inclusion decision and quality assessment
3	Reading the studies	Repeated reading of the studies and noting the interpretative themes (third order constructs): data extraction
4	Determining how the studies are related	Comparisons of themes (third order constructs) and assessment of how these relate to each other: related (reciprocal synthesis), unrelated/opposed (refutational synthesis), inference (line of argument synthesis)
5	Translating the studies into another	Comparisons of themes across studies, whilst keeping an open mind for new themes
6	Synthesising translations	Creating a new framework that goes beyond the sum of the parts
7	Expressing the synthesis	Writing the synthesis

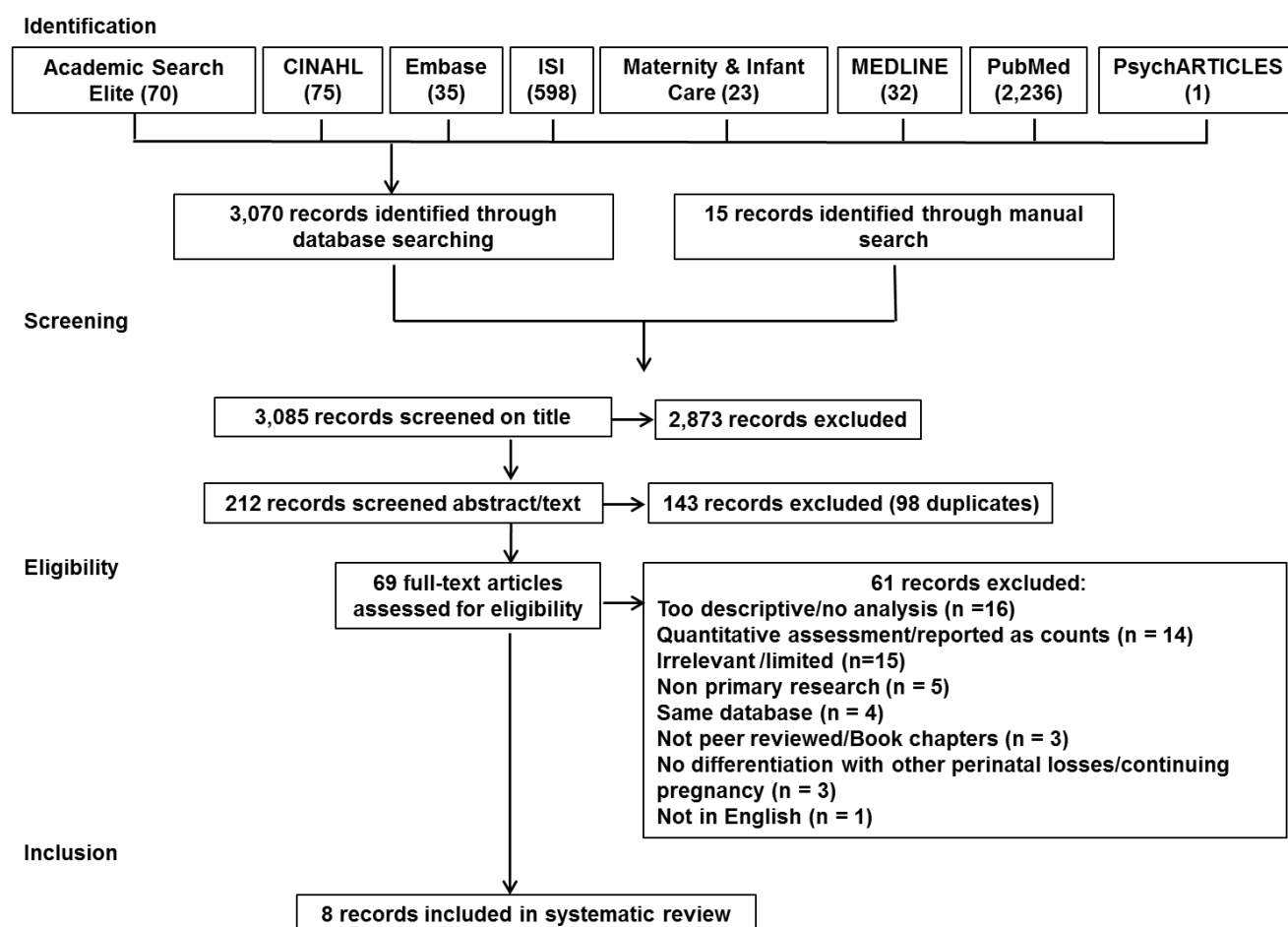
The selected studies were read several times. A table for each study was created, which included: details of the method (e.g. type of data collection and analysis, sample size), location of the study, context of the study (e.g. abortion legislation), key first order constructs (participants' quotations), second order constructs (themes identified by the study's authors), summary of the main findings, proposed third order constructs (themes generated by the researcher) and observations (e.g. sample bias). Tables were put in chronological order of publication (Atkins et al., 2008). Themes generated by the researcher based upon the first study were then compared to those of the second study to establish their relation to each other. This analysis was repeated for all studies. As the themes closely related to each other, a reciprocal translation was conducted. An interpretative framework (or line of argument) was also subsequently produced.

The preliminary analysis was conducted by the researcher. In the context of reflexivity, it is important to recognise that as an interpretative method of analysis, a meta-ethnography is likely to bear the mark of the researcher who produces it (Noblit & Hare, 1988). Therefore to enhance the validity of the findings, the preliminary analysis was cross-validated by the researcher's second supervisor. This consisted of checking that nothing significant had been missed from the studies' first and second order constructs, and that the analysis and interpretative framework were sufficiently rooted in the data, clear and meaningful. This cross-validation resulted in no changes being made to the meta-ethnographic analytical framework.

2.3 Findings

Altogether, 3,085 records were identified. A large number of citations (3,016) were excluded because they were irrelevant to the research questions (e.g. clinical article about termination method), non-primary research articles (book chapters, opinion articles), in a language other than English or duplicates. Full texts of the remaining 69 articles were obtained and read independently by the researcher and the researcher's second supervisor. Details of the search and selection strategies are displayed in Figure 2.1.

Figure 2.1. Search strategy and identification of records included in the meta-ethnography



2.3.1 Description of the studies

Eight studies were selected for this review (Bryar, 1997; Ferreira da Costa, Hardy, Duarte Osis, & Faúndes, 2005; Gammeltoft et al., 2008; Graham et al., 2009; Hunt, France, Ziebland, Field, & Wyke, 2009; Leichtentritt, 2011; McCoyd, 2007; Rillstone & Hutchinson, 2001). The articles were published between 1997 and 2011. Seven studies were cross-sectional and retrospective, and one was prospective (Rillstone & Hutchinson, 2001). Three studies were conducted in the USA (Bryar, 1997; McCoyd, 2007; Rillstone & Hutchinson, 2001), two in the UK (Graham et al., 2009; Hunt et al., 2009), and one each in Brazil (Ferreira da Costa et al., 2005), Vietnam (Gammeltoft et al., 2008) and Israel (Leichtentritt,

2011). Thus, this review covers women's experiences of TFA from varied political, cultural, and clinical contexts.

Five studies were conducted among women only (Bryar, 1997; Ferreira da Costa et al., 2005; Gammeltoft et al., 2008; Leichtentritt, 2011; McCoyd, 2007). Three studies included men as well as women (Graham et al., 2009; Hunt et al., 2009; Rillstone & Hutchinson, 2001), with two also incorporating health professionals' accounts (Graham et al., 2009; Rillstone & Hutchinson, 2001). Two studies focused more specifically on feticide (Graham et al., 2009; Leichtentritt, 2011). Altogether, this review is based on 129 women's experiences. All studies used identifiable qualitative methods of data collection and analysis (phenomenology, grounded theory, framework analysis, ethnography, thematic analysis, discursive and narrative analysis). The study characteristics are shown in Table 2.2.

The review findings are split in two sections. The first section (2.3.2) presents the themes identified in the review. The second section (2.3.3) outlines the interpretative framework (or line of argument) within which women's experience of TFA can be conceptualised. Throughout the findings section, references to the reviewed studies are made using letters A to H as displayed in Tables 2.2 and 2.3.

Table 2.2. Study characteristics

Studies	Country	Participants	Data collection	Methodology	Explored
Bryar, 1997 (A)	USA	3 women	Interviews	Phenomenology	Decision making, adjustment to loss, meaning of loss
Rillstone, 2001 (B)	USA	13 women, 9 men 2 health professionals 3 continued pregnancy	Interviews	Grounded theory	Coping with a new pregnancy, experiences of TFA, management of anguish in new pregnancy
Ferreira da Costa, 2005 (C)	Brazil	10 women	Interviews	Thematic analysis	Experiences of TFA from diagnosis to termination, planning subsequent pregnancy, legal aspects
McCoyd, 2007 (D)	USA	30 women	Interviews	Grounded theory, framework analysis	Psychosocial responses, expectations, dilemmas, social factors and consequences of the loss
Gammeltoft, 2008 (E)	Vietnam	17 women	Observations, interviews	Ethnography, thematic analysis	Experiences of the procedure and its aftermath
Graham, 2009 (F)	UK	9 women, 3 men, 21 health professionals	Interviews	Thematic approach, discursive analysis	Attitudes to/experiences of feticide
Hunt, 2009 (G)	UK	38 women, 10 men	Secondary analysis of interviews	Framework analysis	Experiences of decision making immediately after TFA
Leichtentritt, 2011 (H)	Israel	9 women	Interviews	Narrative analysis	Experiences of feticide and of TFA more generally

2.3.2 Themes identified in the review

Four themes were identified in the review: ‘shattered world,’ ‘losing and regaining control,’ ‘stigma and secrecy’ and ‘the power of cultures.’ Each theme encompassed several subthemes derived from participants’ accounts (first order constructs), the themes identified by the study’s authors, and in some cases, themes present in the discussion section (second order constructs). Table 2.3 shows the occurrence of themes across the reviewed studies.

Table 2.3. Themes identified across studies

Themes	Shattered world	Losing & regaining control	Stigma & secrecy	Power of cultures
Studies				
Bryar, 1997 (A)	X	X	X	X
Rillstone, 2001 (B)	X	X	X	X
Ferreira da Costa, 2005 (C)	X	X	X	X
McCoyd, 2007 (D)	X	X	X	X
Gammeltoft, 2008 (E)	X	X	X	X
Graham, 2009 (F)	X			
Hunt, 2009 (G)	X	X		X
Leichtentritt, 2011 (H)	X	X	X	X

2.3.2.1 Theme 1: Shattered world

This theme comprises four subthemes: an emotional earthquake, a story of loss, an assault on the self and ambivalence. These subthemes, alongside illustrative quotations, are presented in Table 2.4.

Table 2.4. Subthemes and illustrative quotations for the theme 'Shattered word'

Subthemes	Themes in studies	Illustrative quotes
Emotional earthquake	The hardest thing we ever did (A); Saying hello and goodbye (A); Mental anguish (B); The shock of diagnosis (C); Going through the termination (C); Sorrow and pain (5); Mythic expectations (D); Shock and brutality of transition (G); Difficult decision making (H); The unbearable experience of feticide (H)	"It's indescribable the depth of pain in your soul... (...) I don't want to keep living every day in this much pain." (B) "Because you start to look at the ultrasound ... then you start to say: I'm killing it, I'm helping to kill the baby inside my belly. I don't want to do this; it's a very difficult thing to do." (C)
Story of loss	Loss of innocence (B); The diagnosis (C); Profound loss (E); Also latent in all studies	"There was no pretending it just didn't happen. (...) And as much pain as it was going to cause, I think we needed not to be in denial that there had actually been a baby in our life and now there wasn't." (B) "Ah! It's a horrible feeling, really bad, because it's about losing a child." (C)
Assault on the self	Re-examining beliefs (A); Mental anguish (B); Dilemma of identity (D); Mythic expectations (D); Going through the termination (C, E); Physical and emotional pain (E); Self-blame and self-doubts (E); Uncertainty (E); The unbearable experience of feticide (G)	"My normal has changed (...) Your perspective has changed. Your everything has changed." (A) "My husband and I thought we would keep the baby if it was 'just Down's' (...) but there is nothing like hearing those words to your face. (...) Reality of the fetal anomaly news hits so much harder than conceptual thinking takes into account." (D)
Ambivalence	Fighting love (A); Making the decision, fulfilling obligations, doing the right thing (A); Decision's rationale and fear of hoping (B); Ambivalence towards new pregnancy (B); Mythic expectations (D); Dilemma of conception and bonding (D); Guilt and fear (E); Whether to see the baby (G); Difficult procedure and outcome (H)	"Trying not to put an identity on the baby (...) leading to the naming part, because then it felt like we should give her a name. But it feels sort of dual; first, once I name her, then I know she is really gone [crying openly] and the other thing is, it makes her more of a personality or a person who's gone." (D) "You try and capture every moment, every kick you feel ... at the same time you don't want to feel her, as you know what is about to happen." (H, before feticide)

Subtheme 1: An emotional earthquake

The analogy between TFA and an earthquake is prominent in all studies. For some women, pregnancy termination for fetal abnormality is akin to an emotional earthquake that shakes their core beliefs and requires reconstruction: *“Like someone was taking a two by four and just smashing you up the side of the head.”* (B) Women describe intense physical and emotional pain, with some mentioning *“want[ing] to die.”* (D) The psychological pain is usually the most difficult to overcome (A), particularly when feticide is involved and women feel or witness their baby’s last movements on screen (C; H) or when women labour and/or recover in wards with women who have positive pregnancy outcomes (E). The brutal transition between the state of pregnancy and non-pregnancy as well as the resulting difficulty to adapt to it physically, emotionally and cognitively, also contribute to feelings of devastation (A; G): *“I couldn’t even think about it. (...) my brain couldn’t move from planning a birth to planning a funeral.”* (G)

For women giving birth to their baby, the transition between *“saying hello and goodbye”* (A) within the same encounter is particularly difficult. Many women are stunned and unprepared for making decisions surrounding the baby’s birth. These decisions include whether to see or hold the baby, the funeral type, and whether to take the baby’s photo or hand/foot prints (G). The magnitude of the discrepancy between pregnancy expectations and outcome only furthers women’s distress, as these pregnancies often result from meticulous planning and lifestyle changes (E). In many cases, women feel already ‘a little bit pregnant’ prior to pregnancy: *“For me, I started planning for that baby long before I was even pregnant. I stopped drinking, cut down coffee, made life-style changes in anticipation.”* (D)

Subtheme 2: A story of loss

Following the termination, women are left to contemplate their loss, often yearning for their child long after the termination (E). The nature of the mourning process is on-going and women accept that this is a *“lifelong affair”* (B) with the pain subsiding but never disappearing entirely. Through the loss of their child, women also lose the immediate future

they had planned and imagined (D; E). A loss of reproductive self-esteem is also observed, particularly in the Vietnamese study. Women feel they have failed to bear a healthy child, failed themselves and those around them, and failed to gain social approval that accompanies the production of a healthy child: *“I felt ashamed not to have a normal child like other women.”* (E) The diagnosis of fetal abnormality also results in a loss of innocence, particularly during subsequent pregnancies:

“At a certain point, the numbers cease to be comforting. They say ‘OK you’re back in the general population, with a risk of ½ of 1%.’ That, to me, is terrifying. I’ve been in that ½ of 1% and I know how easily you can get into that category without knowing it.” (A)

Subtheme 3: An assault on the self

TFA also represents an “assault” on the self (B). It undermines women’s sense of security and shakes their values and spiritual beliefs (A; D). Women start their pregnancy in a (false) sense of security. The diagnosis therefore comes as a shock:

“I think Matt and I had the feeling that most parents do – no history of birth defects in our family, we are young and healthy, I took prenatals and got good care, ate right, etc., so that meant that our baby would be fine.” (D)

Many believe that they *“wouldn’t terminate the pregnancy anyway.”* (D) Following the diagnosis, women are left with a heightened sense of vulnerability (B). Some struggle with their values and spiritual beliefs over the decision to terminate (A; C; D; E). Once shaken, core beliefs have to be re-built and new ones created as women’s sense of normality is greatly disrupted. Terminating the pregnancy also has profound consequences on women’s self-identity as mothers. The decision to terminate implies choosing between becoming the *“mother of a disabled child or a bereaved mother.”* (D) Women also question their value as mothers (are they to blame for the abnormality?), whilst others question their moral courage over their decision not to bring to the world a child with impairment (E): *“I have guilt for not*

being the kind of person who could parent this particular type of special need.” (D) Childless women experience the additional difficulty of feeling like mothers but being denied the social status of motherhood (D).

Women also question their body, which some hold responsible for creating an imperfect child (E) and healing too quickly compared to the mind (A; D). The return of menstruation signals to women their readiness to be physiologically pregnant, something often in stark contrast with how they feel emotionally:

“It’s a real smack in the face, I mean, that threw me for a good couple of days, it was just like, I’m really, really not pregnant. It’s sort of like, okay, my body’s healthy again, when is my mind going to catch up?” (A)

Incongruence between women’s body and emotional state is also experienced if lactation occurs, which women find particularly difficult (E). Following the termination, women engage in the often laborious task of rebuilding their internal world and *“redefining normality.”* (A)

Subtheme 4: Ambivalence

Ambivalence is manifest in the decision to terminate the pregnancy as it involves conflicting feelings (F). It is a subtle balancing act between the baby’s prospects and potential quality of life, and the woman, her partner’s and children’s needs (A; B; C; E): *“I felt terrible but I kept thinking about my other child because I couldn’t just think of myself. I had to think about him too, didn’t I?”* (C) The decision often carries high levels of uncertainty as many prognoses are based on probabilities (H). For many women, the decision to end their pregnancy is one they wish they never had to make. However, the distress at having to make that decision can coexist with the relief at being given the opportunity to make it. This relief may relate to having spared their child a life of suffering and spared other children the daunting prospect of caring for an impaired sibling. It is also linked to their own perceived limitations regarding their capacity to raise a child with an impairment (A; C; E). In some cases, the relief relates to their spiritual beliefs. In Vietnam, for example, a baby’s abnormality can be considered the

result of family members' immoral behaviour. Thus, some women welcome the opportunity to prevent the birth of an impaired child (E).

Ambivalence is also apparent in women's relationship to their baby, swaying between the need to protect and distance themselves from him/her. Women describe "*fighting love for their baby*" (A), and express concurrent feelings of "*guilt and fear*" (E) towards the baby; guilt at robbing their child of a life (E; F) and fear that the baby's soul may come back to haunt them, potentially hindering their reproductive future (E). Women are also conflicted between their need for time to gather and process information and the difficult experience of continuing "*giving life while thinking about taking it.*" (H) Women are also torn by the decisions they have to make. These include pre termination decisions such as whether to have a feticide or not and what this choice implies for the baby's birth and his/her potential suffering (F). They are also torn by the post termination decisions they have to make, such as those relating to the post mortem, the baby's remains and what to disclose to others (D; G; H).

2.3.2.2 Theme 2: Losing and regaining control

The second theme identified in the review is 'losing and regaining control.' It comprises four subthemes: the paradox of choice, loss of control, regaining control and surviving the ordeal and beyond. These subthemes, alongside illustrative quotations, are presented in Table 2.5.

Table 2.5. Subthemes and illustrative quotations for the theme 'Losing and regaining control'

Subthemes	Themes from studies	Illustrative quotes
The paradox of choice	Making the decision, fulfilling obligations (A); Painful decision (B); Decision reflection (the right decision B); Decision to terminate (C); Requesting legal authorisation (C); Dilemma of choice (D); Perceived impact of feticide upon parents (F); Requesting authorisation (H)	"I decided to do it because there was nothing else to do. There was no point in keeping a child that wasn't going to survive." (C) "I think I made the right decision but it's never going to be anything I'm so completely at ease with, you know. It's a bridge that you hope never to have to cross." (F)
Loss of control, (body and emotions)	Loss of control over emotions (A) and over body (lactation, E); Uncertainty and lack of understanding (E); Feeling unprepared (G); Little control over decision and requesting authorisation (C, H)	"Days that I'm fine in the morning, and by noon, I'm in the pits and then by 3, I'm okay again." (A) "I want the doctors to explain in more detail. I do not understand when they use medical words. They told me my fetus is soaked in water. I do not understand the reason why. I still don't understand." (E)
Regaining control	Developing emotional armour, limiting disclosure, delaying attachment (B); Increasing attachment to health professionals and selected others (B); Dilemma of the whole story (D); Feticide as a necessary intervention (F); Deciding whether to see and handle the baby, whether to have a funeral or cremation, have photographs and hand/foot prints (G)	"I didn't think about her as a baby, definitely didn't project it to ... anything further down the road like having her. Lots of little special things that I have done when I was pregnant the other times, picking a special song that I sang to them or a story that I read to them in utero. I didn't do that with this baby." (B) "I do think that bearing the secret was an additional stress on me, no question about it, but telling them the truth would have, or so I imagined, be additional stress as well." (D)
Surviving the ordeal and beyond	Finding meaning (growing together, renewed empathy, A); Redefining normal, reconnecting (A); Subsequent pregnancy, re-emergence of mental anguish (B); Developing emotional armour (B); Planning another pregnancy, strengthening ties (C); Evaluating the experience (becoming stronger) (C); Sense of relief (C, E)	"The initial finding out and dealing with it was such a growing-together experience. You just look at each other and say 'If we can live through this, arguing about taking out the garbage ceases to be important'." (A) "What was good was the self-esteem I gained because I never thought that one day I would go through all of this and still be able to walk with my head held high." (C)

Subtheme 1: The paradox of choice

Most women in the review depict their decision making as a choice between “*terrible and horrible*” (B) or two “*alternatives, both of which are unpleasant.*” (D) Some report taking the decision to terminate their pregnancy because they perceive the situation as hopeless (C). Thus, many women do not see termination as a real choice or a situation over which they have much control. Women’s sense of agency in the decision-making process is limited and some feel disempowered. This is the case, for example, when women have to request legal authorisation to end their pregnancy, as was the case in Brazil at the time the study was conducted (C). Women also report feeling humiliated and resent having to explain their circumstances to bureaucrats who have the ultimate decisional power (C). In Israel, women also have to obtain the medical centre’s approval for termination beyond 24 weeks’ gestation: “*I was required to decide, but I didn’t really have the power to make the decision.*” (H)

Yet, despite feelings of helplessness, the decision to terminate the pregnancy is seen as the right one. For some women, it is the first parental decision they get to make for their baby (A; B; E). This decision may be one of the only ways women can exert control over their situation, which may explain the sense of achievement reported in some studies: “*I felt victorious because it was the only thing I could do for him at that time. I couldn’t do anything else, and I had to have the strength to do that.*” (C) In some case, women continue to evaluate the decision long after the termination (A; H).

Subtheme 2: Loss of control

The perceived lack of agency over the decision is coupled with a lack of control over emotions and grief reactions. Women are unprepared for the magnitude and duration of the pain (A; B; C; D; E). This sometimes leads them to question the rightness of their decision assuming that “*the right decision couldn’t possibly hurt this much*” (D). They also feel unprepared for the decisions they have to make following the termination (G), which adds to their sense of helplessness. Women also express a lack of control over the healing process.

They often do not anticipate the “roller-coaster” (A) of emotions and the time involved in regaining a sense of normality. The lack of understanding about their situation also contributes to feelings of helplessness. Lack of information about the baby’s condition, the possible causes for it, the procedure and what to expect as a result, is described as a source of distress (E). It also maintains women in a state of passivity, uncertainty and despair.

Subtheme 3: Regaining control

Attempts to regain control over the situation take different forms. They include controlling one’s social environment by limiting contacts with others: “*I’ve become a bit of a hermit for a while. It’s like I’m safe here (...) I want to be in an environment I can control*” (A) and limiting self-disclosure (A; B; D). These strategies serve the purpose of self-protection, and are also clear attempts at staying in control of emotions. Seeking information is another way of regaining control, for some women assume that understanding their situation may prevent the anomaly re-occurring (E): “*I had a real need to understand exactly what had happened to our first child ... If I could understand it, then I could control it, and if I could control it, then I could prevent it.*” (B) In the absence of clear explanations women create answers for themselves and some blame themselves for the loss of their child: “*Is it because of the food I ate? There was bird flu and we did eat a lot of chicken.*” (E) Others reclaim control through the decisions made post termination, e.g. organising a funeral for their baby (G). Attempts to keep emotional control are also observed during subsequent pregnancies through the development of “*emotional armour*” whereby attachment to the baby is delayed for as long as possible (B).

Subtheme 4: Surviving the ordeal and beyond

The aftermath of TFA is akin to ‘the day after’ (the earthquake). Women are in shock, but also feel very much alive. Some consider the experience as an ultimate test of strength of character (C) and of the relationship with their partner (B). Women are acutely aware that the decision to terminate is theirs alone, even when taken in consultation with their partner

(C; E). Casting themselves as survivors, women describe going through “*the hardest thing they ever did*” (A) with bravery and resilience (B; C). Some report growing stronger as a result of the termination (C). Deriving meaning is also important to some women: “*Our mantra has become, what are we going to get out of this?*” (A), and growing in strength is one way to impart meaning to their experience. Others find solace in their “*renewed empathy*” (A) towards others and the consolidation of family ties (A; C). Women learn to live with the loss, the nature of pain evolving from an acute to a chronic ‘condition.’ Managing the pain involves several strategies such as “*lowering expectations*” (A) and seeking answers (B; E).

Surviving the ordeal also implies turning to the future, which for some women involves planning a new pregnancy. Another pregnancy is generally soothing but can also be bitter-sweet, another illustration of ambivalence: “*We were both quite apprehensive, and you know you sort of feel happy but at the same time . . . you have these incredible fears inside you.*” (B) In a context of a heightened sense of vulnerability, a new pregnancy is seen as a leap of faith requiring courage and determination, but which is eventually rewarding: “*no guts, no glory.*” (B)

Whilst many women attempt to regain control over their situation, their efforts are often hindered by the stigma and secrecy that surround TFA, which lead to women feeling alienated.

2.3.2.3 Theme 3: Stigma and secrecy

The third theme identified in the review is ‘stigma and secrecy.’ It encompasses the subthemes of isolation and becoming a social outcast, and disenfranchised grief. These subthemes, alongside illustrative quotations, are displayed in Table 2.6.

Table 2.6. Subthemes and illustrative quotations for the theme ‘Stigma and secrecy’

Subthemes	Themes from reviewed studies	Illustrative quotes
Isolation & becoming a social outcast	Living a lie (A); Consequences of mental anguish (fear of stigma, B); Mythic expectations (I was very afraid of running into someone who would pass judgment, D); Dilemma of choice and of the whole story (D); Relationship strains (D); Feticide as an unspoken experience (H)	"I felt kind of like I was, you know, living in fear that I would suddenly receive a scarlet letter." (B) "About 3-4 weeks after Maddy's burial, I really felt him [partner] not only pulling away from me emotionally, but also felt as though he was pushing me to 'be okay'. I resented it. And I was terribly hurt and felt completely alone." (D)
Disenfranchised grief	Living a lie (A); Dilemma (of choice and the whole story, D); Feticide as an unspoken experience (H); Inadequacy of language (H)	"The people I worked with (...) I simply told them 'I lost the baby.' Then some people who I told we simply lost the baby due to a genetic condition commented on how brave we were to continue the pregnancy. This just added to the guilt." (D) "I don't dare to say what we went through, it's something you don't talk about. I know my work colleagues were told it was a stillborn... I was never asked and never talked about what happened. We all keep the silence." (H)

Subtheme 1: Isolation and becoming a social outcast

The stigma attached to abortion generates an atmosphere of secrecy and shame that leads women to censor themselves. This was particularly apparent in the three studies conducted in the USA (A; B; D). The experience of TFA grants access to a ‘selective’ club no one wishes to enter (B). In countries where attitudes towards abortion are possibly less openly polarised, women still feel unable to fully share their story. For example, the Israeli study refers to TFA as a “*taboo*” and describes women facing a “*wall of silence*” (H). In the reviewed studies, some women report a fear of “*being judged*” (D). Many choose to label their experience a miscarriage or only disclose the full story to a selected few, an inaccuracy they struggle to live with. However, the prospect of social rejection can be too hard to

contemplate: *"I only told the people I knew would support me. To have anyone condemn me would have hurt too badly. I felt fragile as glass."* (D) This leads to women feeling incongruent with themselves and others, feeling like they are *"living a lie"* (A) and ultimately, feeling alienated (A; B). Discord may also appear within the safe haven of close relationships due to a perceived lack of empathy (D), which in turn, increases women's sense of vulnerability.

Silencing part of the story can reveal itself to be a 'double-edged sword,' protecting women from potentially hurtful reactions, but also hindering their healing process through their inability to access valuable support. By only sharing part of their story, women may be unable to fully process their loss. This may further undermine their identity as a bereaved mother and represent a renewed incursion to their self-concept. Despite reservations, women who have risked full disclosure report positive experiences (B; D).

Subtheme 2: Disenfranchised grief

Whether women choose to disclose their full story or not, most feel that their grief is disenfranchised as their loss is not sanctioned by society. Because theirs is a "chosen loss," (E) and "nobody knew the baby" (G) women feel that their child's existence and their grief are not acknowledged: *"I remember some of the cruellest comments were regarding his name. 'Why don't you save the name Jared in case you have a living child.' Jared was the name we gave him and it was his and nobody else's."* (D) This disenfranchisement also reflects women's cultural background. For example, in Vietnam, women are encouraged to forget their baby: *"My elders tell me not to think about the fetus"* and the location of the grave is often kept secret from them (E). Similarly, in Israel, there are no formal rituals for babies who die before 40 days (H).

The language used to define termination for fetal abnormality also contributes to women's grief being disenfranchised. Although women agree that technically the procedure is an abortion, they want their experience to be differentiated from abortions for non-medical reasons (D). Some label it a *"therapeutic premature delivery"* (C) or compare it to switching a

life support machine off (A), a process closer to euthanasia than abortion. The inadequacy of language to describe their experience further alienates women as they are unable to effectively communicate what has happened to them. This inadequacy is also noticeable in the absence of terminology as is the case in Israel where there is no word for feticide (H).

Terminology to refer to the baby is another example of disenfranchisement. Whilst most women use the term 'baby,' some health professionals prefer using medical terminology such as 'fetus' (E). This is, however, contrasted by women who would rather not "*think of it as a baby*" (G) or by women who felt that they "*lost a pregnancy more than a baby.*" (F)

The secrecy and stigma surrounding TFA strongly influence women's experience. In turn, the way women and those around them respond to TFA contributes to shaping societal attitudes towards TFA. It is, therefore, impossible to dissociate the experience of TFA from its cultural environment as TFA is a social as well as an individual experience.

2.3.2.4 Theme 4: The power of cultures

The final theme identified in the review is the 'power of cultures.' This theme is mostly latent across studies. It comprises three subthemes: the politico-socio-legal environment, the clinical environment and the legacy of the past. These subthemes, alongside illustrative quotations, are displayed in Table 2.7.

Table 2.7. Subthemes and illustrative quotations for the theme 'The power of cultures'

Subthemes	Themes from studies	Illustrative quotes
Politico-social-legal environment	Requesting authorisation (C, H); Lack of financial support (D); Dilemma of choice (pro-choice vs. pro-life, D); Women encouraged to forget (E); Inadequacy of language, absence of norms or rituals (H)	<p>"It's difficult to speak about this, because it was a very difficult moment. You are going there in pain [to the Office of the Attorney General]. Are they thinking about what I am going through? About what I am feeling? I have to go there, my husband and I have to go there alone... and sign papers." (C)</p> <p>"The pro-choicers aren't much better. It's hard to use people like us as political propaganda when we freely admit that we have aborted our BABIES. When so much of the debate is based on when does life begin and when we proclaim that our babies were alive and are our children. That makes it messy." (D)</p>
Clinical environment	Labouring/recovering among women with positive pregnancy outcome (E); Reverence towards health professionals (E); Feticide not performed (E)	<p>Study author's comments: "Three days after we return to room 28 (...) [She] shares the room with six other women, some of them with their newborn infants next to them in the bed." (E)</p> <p>"Not even the doctor dared look at it. She looked away while cutting the cord. She felt uncomfortable. She said, 'It is such happiness to assist at the delivery of a perfect child, but this one...' I felt sorry for her for having to go through that." (E)</p>
The legacy of the past	The legacy of the Vietnam war (E)	Study author's comments: "Vietnam's population strategy for the years 2001-2010 emphasises enhancement of the quality of the country's population." (E)

Subtheme 1: Politico-socio-legal environment

Social context plays an important role in shaping women's experience as societal attitudes, values and beliefs translate into political, legal and clinical applications. The political climate is a major influence on women's experiences: polarised debates about abortion may result in women being stigmatised and alienated (A; B; D). Abortion laws are also influential as they

dictate the timing and medical conditions for which pregnancies can be terminated. For example, in Brazil, at the time the study was conducted, abortions were illegal but tolerated in cases of lethal fetal abnormalities (C). In Israel, terminations beyond 24 weeks' gestation require approval from the medical centres' multidisciplinary committees (H). Thus, gestational age and the baby's prognosis impact upon women's decisions, which, in turn, may influence their grief reactions. In the USA, abortion is legal but operates differently across states. In Vietnam, feticide is not performed prior to inducing labour. This possibly influences women's experiences given that some babies are born alive: "*When the little one came out, it gave some gasping sounds and two cries. Then they took it to another room.*" (E) Conversely, feticide is also described by some as the most traumatic part of the termination (C; H) "*This is the worst part, when they [pause], when they inject [pause], they gave me valium by injection at that point because I was in a terrible shape.*" (H)

Yet, within those differing contexts, some women feel pressurised to terminate their pregnancy because of society's strong support for prenatal diagnosis (H). Furthermore, this covert pressure takes place within political environments generally advocating the inclusion of people with disabilities, which some women find confusing (D).

Subtheme 2: Clinical environment

Clinical considerations, such as the doctor-patient relationship, also influence women's experience. In the Vietnamese study, for example, women defer to clinicians in a way not observed in other studies. Clinicians are seen as holding expert knowledge and despite their frustration at the lack of information, women do not dare contravene the rules and ask for clarifications. In some instances, they feel ashamed of involving physicians in an "*unpleasant experience.*" (E) This implicit power imbalance influences the level of control women feel they can exert, which may hinder their healing process. By contrast, in other medical cultures, women have the opportunity to see and hold their baby, which some find helpful: "*I think it would have been much harder for me to come to terms with the loss of [baby] had I not had a chance to say goodbye properly*" (G), although others prefer not to (G).

The environment women are cared for when undergoing TFA is another influential element. Most TFAs are carried out in hospitals, but in the USA, they tend to be conducted in abortion clinics (McCoyd, 2010a). This may impact upon women's experience, given the controversies that may centre on these clinics. In the same way, the Vietnamese study reports women recovering post termination in the same room as women who have had positive pregnancy outcomes. This is also likely to increase women's distress. Finally, whether the cost of TFA is covered by public healthcare also impacts upon women's experience. In the UK, TFA is mostly carried out under NHS contract (RCOG, 2010). By contrast, in the USA, states are not required by law to cover 'elective' abortion. This results in many women relying upon private insurance providers to cover the cost of the termination (McCoyd, 2010a). This may prevent equal access to abortion services, which is likely, again, to impact upon women's experience.

Subtheme 3: The legacy of the past

Finally, the legacy of the past also contributes to shaping women's experiences. The rise in birth defects observed in Vietnam in the past decades has been associated with the release of the toxic Agent Orange by occupying troops during the Vietnam war (E). Thus, the Vietnamese policy "*of enhancement of the quality of the country's population*" (E, p.47) may be a direct attempt to obliterate the past. Within that context, the social pressure to produce a healthy child may account for the sense of shame some women may experience when diagnosed with a fetal abnormality and the custom of quickly pushing women through their grieving process. Similarly, the experience of TFA in Israel is rooted in the country's pro-natalist approach, which is partly driven by religious beliefs, the legacy of the Holocaust, and the subsequent drive for survival (Sperling, 2010).

2.3.3 Interpretative framework: TFA as an existential crisis

Following meta-ethnographic guidelines, an interpretative framework (or line of argument) within which to conceptualise the experience of TFA was generated from the themes identified in the review. These themes suggest that TFA is experienced as a trauma, with women feeling overwhelmed, disempowered, and isolated in their bereavement.

Nevertheless, for some, TFA also represents an opportunity for growth. Thus, in many ways, the experience of TFA can be seen as an “existential crisis.” The link between TFA and an ‘existential crisis’ has been noted in the Vietnamese study (Gammeltoft et al., 2008) and the literature about decision making following a diagnosis of fetal abnormality (Sandelowski & Barroso, 2005). The ‘existential crisis’ seems an appropriate interpretative framework within which to understand the experience of TFA because the characteristics of the experience of TFA closely relate to existential considerations.

Existentialism has its foundations in the 19th century philosophy of Kierkegaard (1813-1855) and Nietzsche (1844-1900) who both emphasised the concepts of freedom of choice and personal responsibility in the states of ‘being’ (present) and ‘becoming’ (future). The movement reached widespread popularity in the 20th century with the work of Heidegger (1889-1976), Sartre (1905-1980) and Camus (1913-1960) among others. Existentialism gave rise to the existentialist psychology movement with May (1909-1994) as one of its founders, and to the existential psychotherapy movement with Frankl (1905-1997) and Yalom as prominent figures. Existential Psychotherapy is based on the concept that psychological wellbeing derives from an internal equilibrium between four existential considerations: death, freedom and the responsibility it implies, isolation and meaning (Yalom, 1998). An ‘existential crisis’ arises when the balance between these four considerations (death, freedom, isolation and meaning) is disrupted and/or when individuals’ internal defences are seriously undermined (Yalom, 1998).

The four existential considerations are particularly relevant to the experience of TFA. The first one, death, implies the confrontation to life’s finitude (Yalom, 1998). As a type of abortion, TFA is, indeed, a life and death matter. Women have to decide between giving and

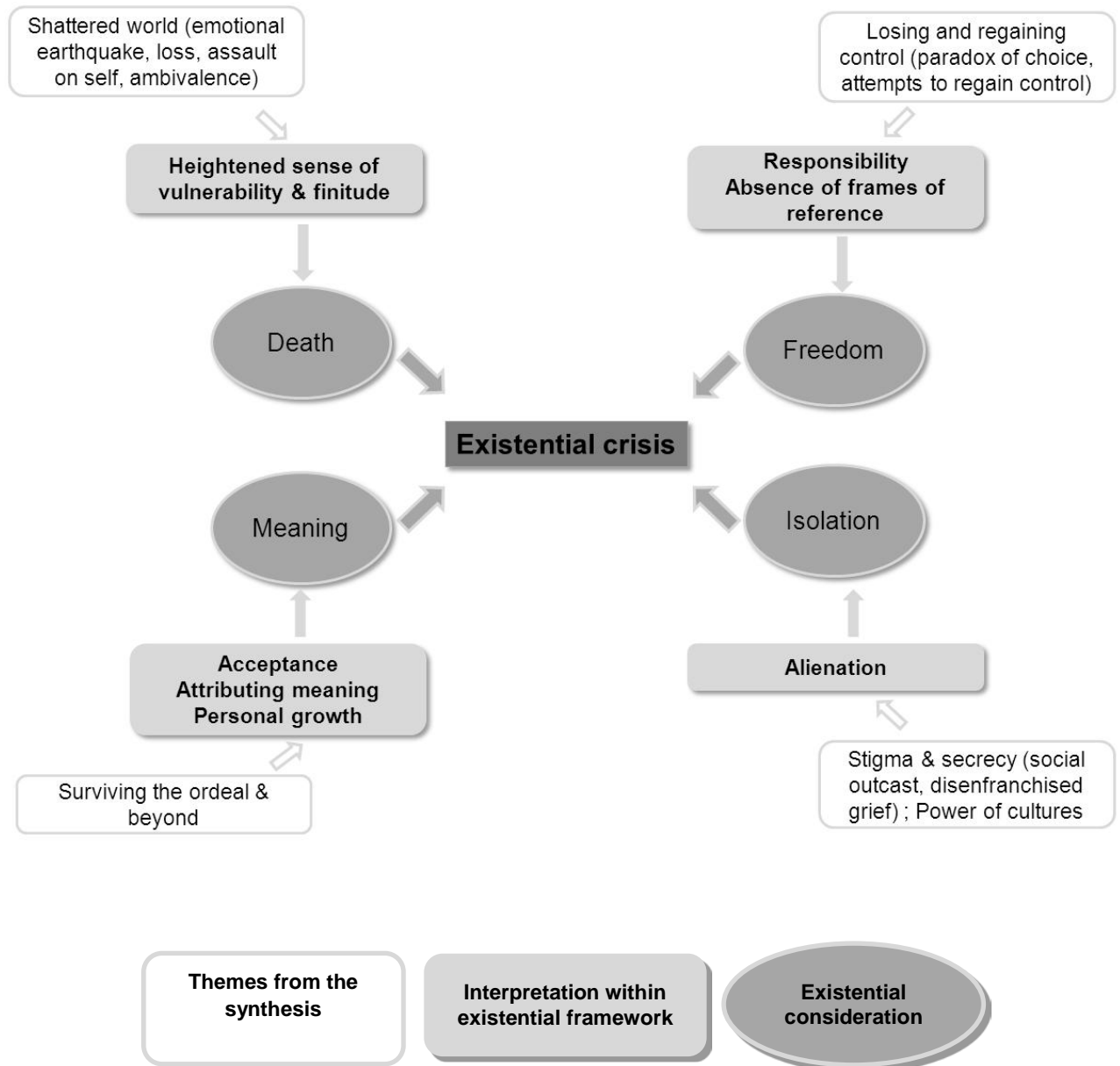
denying life. Questions such as whose right it is to make the decision, whether the decision is morally justifiable, and what lives are worth living are part of women's decision-making process and closely relate to the first existential consideration. The second existential consideration is freedom. In existentialist terms, freedom refers to freedom of choice (free-will) and the responsibility for shaping the future (Yalom, 1998). In the context of TFA, when deciding to terminate their pregnancy, women exert their free-will. In doing so, they actively shape their future but also bear the responsibility for their act. Freedom also implies the absence of 'safety nets' to contain one's choices (Yalom 1998). This, also, can be linked to the experience of TFA. The secrecy and stigma surrounding TFA result in many women feeling unable to disclose their story, which in turn, prevent them from accessing support. Furthermore, because TFA is a relatively new phenomenon (chapter 1, sections 1.1.1.1 and 1.1.1.2), women are unable to draw upon previous generations' experiential knowledge of how to deal with this event.

The third existential consideration is isolation. In existentialist terms, isolation means that individuals are fundamentally alone and yet, they long for social closeness and a sense of belonging (Yalom, 1998). Similarly, many women undergoing TFA feel alienated in their choice, and many choose to silence themselves in a bid to prevent social rejection. The last existential consideration is meaning. Meaning is an essential element of existentialism, which encompasses deriving meaning, growing from the experience and achieving a sense of purpose (Frankl, 1959; Yalom, 1998). Some women in the reviewed studies report positive outcomes from their experience including feeling stronger, enjoying closer ties with loved ones and having more empathy towards others. This may be a way to impart meaning to their experience.

If the experience of TFA clearly incorporates existential considerations, the themes identified in the review ('shattered world,' 'losing and regaining control,' 'stigma and secrecy') also underline TFA's potential to both disrupt women's psychological balance and weaken their psychological defences. Therefore, the experience of TFA has the potential to trigger

an existential crisis. The experience of TFA as seen from an existentialist perspective is illustrated in Figure 2.2.

Figure 2.2. Pregnancy termination for fetal abnormality: The existential crisis framework (based on Yalom, 1998)



2.4 Discussion

This meta-ethnography was undertaken to address the first knowledge gap identified in the literature review (chapter 1, sections 1.2.1.2 and 1.4.2.1) and sought to examine women's holistic experience of TFA. The results indicate that TFA is experienced as a traumatic event, akin to an existential crisis. It is one of shattered world, losing and regaining control, stigma and secrecy, but it also presents an opportunity for growth. The review also suggests that women perceive TFA as a unique form of bereavement, which is often misunderstood and stigma-bearing. The results also indicate that women's experiences of TFA both shape and reflect the political, cultural and clinical environment in which they occur. Thus, TFA is an individual as well as a social experience. These results are discussed in the next sections, alongside an evaluation of the review's limitations. The implications of the review in terms of theory, practice and future research are discussed in chapter 8.

2.4.1 TFA as a traumatic event

Across the reviewed studies, the experience of TFA was predominantly portrayed as a trauma, one of shock and devastation. These findings support some of the quantitative evidence, which underlines women's psychological difficulties to adjust to TFA (Kersting et al., 2005, 2009; Korenromp et al., 2009; Statham et al., 2001). In this review, women reported feeling unprepared for the magnitude and duration of the pain which followed TFA. Many described their lack of control, and sometimes understanding, over the situation, and most felt isolated in their loss. The experience of TFA also impacted upon women's identity as mothers and generated ambivalent feelings which women found difficult to process.

Some of these experiences have also been observed in the context of other perinatal losses. For instance, Keefe-Cooperman (2005) suggested that women who miscarry also experience a loss of biological self-esteem for creating 'an imperfect child.' They also experience self-blame, although, in their case, self-blame relates to a perceived lack of self-care, not to the decision to end the pregnancy. Similarly, women who choose to continue their pregnancy after a diagnosis of fetal abnormality also exhibit ambivalent feelings

towards the pregnancy and the baby (Jones et al., 2005; Lalor et al., 2009). They, too, find that their identity as mothers is being challenged. Some also feel isolated because, once the abnormality is detected/confirmed, the focus entirely shifts to the unborn child for the remainder of the pregnancy (Jones et al., 2005). These emotional reactions have also been observed in women who give birth to pre-term infants, although to a lesser extent than in those who undergo TFA (Kersting et al., 2009), and in women whose babies are diagnosed with congenital heart disease in-utero (Rychik et al., 2013).

Research also suggests that women who choose to terminate their pregnancy for non-medical reasons also experience feelings of isolation, which may relate to the stigma and secrecy surrounding abortion (Norris et al., 2011). They too may choose to censor themselves (Norris et al., 2011; Trybulski, 2005), and may face existential questioning relating to life, death, meaning, morality, and feelings of attachment to the fetus (Stålhandske, Makenzius, Tydén, & Larsson, 2012). Similarly, the concept of disenfranchised grief, which was prominent in the reviewed studies, is a recurrent feature in the perinatal loss literature, whether the loss is a miscarriage, stillbirth, neonatal death (Flenady et al., 2014; Lang et al., 2011; Moore et al., 2011; Wilson, 2014), or termination for fetal abnormality (Thachuk, 2007). It has also been observed in some studies on abortion for non-medical reasons (Hess, 2004).

However, the experience of TFA is distinct from other perinatal losses in that it is self-perpetrated, and from elective abortion in that the pregnancy is, in most cases, wanted. It encompasses emotional reactions and challenges that are specific to both perinatal losses and abortion for non-medical reasons. This makes the experience of TFA particularly complex and difficult.

2.4.2 The potential for growth

This meta-ethnography also emphasises women's potential for growth following TFA. Through the experience of TFA, women demonstrate their resilience, finding ways to adapt to their new situation whilst reflecting on its significance. Some women discovered strengths

they did not know they possessed and some experienced closer bonds with significant others as a result. These findings are in line with the limited research on personal growth following a diagnosis or fetal abnormality and perinatal loss, which shows that women experience positive changes, in particular in the domain of relating to others (Black & Sandelowski, 2010; Thomadaki, 2012). They are also in line with the wider literature on posttraumatic growth which suggests that growth only occurs when an event has severely disrupted individuals' worldviews and belief systems and that it is the cognitive work associated with dealing with this disruption and creating new belief systems which generates growth (Joseph, 2011; Tedeschi & Calhoun, 1996, 2004). TFA has the potential to trigger such crisis and generate growth as a result.

The concept of disenfranchised grief is also relevant to personal growth because it refers to the difficulty in expressing (and thus legitimising) the loss, and the difficulty in expressing the drive to restore equilibrium and grow from the experience (Attig, 2004). Therefore, framing the experience in a pre-defined (negative) way may result in neither women's grief nor their healing process being socially sanctioned in a way that is helpful to them.

2.4.3 Bereavement or abortion paradigm

The review also suggests that women perceive TFA as a unique form of bereavement, which is often misunderstood and stigma-bearing. This 'unique bereavement model' is at odds with the clinical and societal paradigm of abortion within which TFA is usually conceptualised and operationalised. For instance, some women in the reviewed studies were keen to distance themselves from the pro-life versus pro-choice abortion debate (McCoyd, 2007), a position observed in other TFA studies (Asplin, Wessel, Marions, & Georgsson Öhman, 2012; Fisher & Lafarge, 2015; McCoyd, 2010a). The abortion paradigm fails to respond to the TFA experience in a holistic way, and both reflects and perpetuates inappropriate policies and care, fuelling misunderstanding and stigma.

The incongruence between women's aspirations regarding the way TFA should be regarded and societal responses to it, reflects a lack of understanding of what TFA represents and involves for women. This lack of understanding may be due to an absence of frames of reference for dealing with TFA. As TFA is a relatively new phenomenon, experiential knowledge of how to deal with it (from the women's and health professionals' perspective) is sparse. Furthermore, the continuous technological developments in prenatal screening and diagnosis mean that women are faced with new reproductive options, for which there are no "scripts" to follow (McCoyd, 2009b).

The lack of understanding about TFA is reflected in women's being unprepared for the procedure and its aftermath. It is also reflected in the paucity of long-term support mechanisms available to women. Although this review did not identify specific deficiencies in aftercare, the isolation reported by women points to a deficit in this area. This deficit has been reported in the literature (Asplin et al., 2014; Fisher & Lafarge, 2015; Green & Statham, 2007; White-Van Mourik, Connor, & Ferguson-Smith, 1990). It is possible that were TFA considered a form of bereavement rather than a clinical procedure, long-term support might be more readily available.

2.4.4 The importance of context

The review also demonstrates the importance of context, as women's experiences are strongly rooted in their sociocultural environment. It suggests a need for policies that create a context in which women are unconstrained by legal restrictions and social norms in their decision making, and for these policies to translate into clinical care. The Brazilian study provides a clear plea to legalise termination in cases of lethal fetal abnormality. Although, it is now legal to end a pregnancy for anencephaly in Brazil (fetal skull not developing properly), terminating a pregnancy for other lethal fetal anomalies remains a criminal offence (Mirlesse & Ville, 2013). Similarly, the Israeli study provides evidence of the legal and clinical obstacles faced by women who wish to terminate their pregnancy. Finally, the polarisation of the debate surrounding TFA (and more generally abortion) in the USA does little to support

women as it may lead to stigmatisation. Although these observations are specific to the countries from which the reviewed studies originated, the implications are relevant globally.

2.4.5 Limitations of the review

The review has several limitations. It focuses on articles written in English, excluding potentially insightful research. It also excludes descriptive qualitative studies, among them case studies, which could also contribute to furthering the understanding of TFA. High-income countries were over-represented, with only two studies originating from developing countries. However, this bias reflects the geographic origin of studies on TFA. A bias in the sample demographics was also observed, particularly in studies conducted in high-income countries, in which participants were predominantly white, middle class, and well educated. This bias has been noted in other TFA studies (Korenromp et al., 2009; Statham et al., 2001). Furthermore, in the USA, this profile may accurately reflect the population who undergo TFA given that, by law, states are not required to cover elective termination (McCoyd, 2010a). Still, one may argue that evidence used for policy making in high-income countries is biased towards a particular segment of the population. None of the studies was longitudinal, therefore, it is not possible to ascertain how women's experience varied over time. Finally, as for any qualitative analysis, the authors' subjectivity has to be acknowledged. Meta-ethnography is a highly interpretative process. As such, it may bear the mark of the main investigator. For example, in this review, it is likely that the theme 'the importance of context' which identifies the legal, political and social constraints within which women make decisions about undergoing TFA may reflect the researcher's personal stance in support of women's reproductive choices. However, the cross-validation of the study selection and the analysis process mitigates against the risk of bias. Importantly, meta-ethnography does not claim to be anything other than an interpretive method to create a whole from a diversity of parts (Noblit & Hare, 1988).

2.5 Conclusions and implications for the thesis

The meta-ethnography has strengthened the rationale for the empirical work to be conducted. It has confirmed the paucity of evidence about women's coping strategies when dealing with TFA, which was initially observed in the quantitative literature. In doing so, it lends further credence to the rationale for conducting a study into women's coping strategies (Studies 2a and 2b, chapters 4 and 5). This meta-ethnography has also clearly demonstrated the potential for growth following TFA. This provides further support for exploring the concept of posttraumatic growth in relation to TFA (Study 4, chapter 7). Interestingly, since the initial search for evidence was conducted in October 2011, several studies on women's experiences of TFA have been published. This has led to the inclusion of six further studies (Asplin et al., 2014; France et al., 2013; Gawron et al., 2013; Kerns et al., 2012; Koponen et al., 2013; Lafarge, Mitchell, & Fox, 2013b) in the review published in *Reproductive Health Matters*. This is a testimony of the current relevance of TFA and the level of interest it generates.

Chapter 3 - Methods

This chapter presents the methods used to undertake the research programme's empirical work. It is divided into three sections. The first section discusses the research's theoretical framework, namely the pragmatic paradigm, and the rationale for adopting a mixed methods approach. It also outlines the methodological approaches used to address the research objectives. The second section focuses on the methods used to undertake the research's quantitative work. It discusses and describes the sampling, data collection, ethical considerations and statistical analyses conducted on the quantitative data. The third section addresses the methods utilised to undertake the research's qualitative work.

3.1 Theoretical framework

The theoretical framework of this research is grounded in the pragmatic paradigm (Creswell & Plano Clark, 2007) and is based on a mixed methods approach to research. The next sections (3.1.1 to 3.1.4) discuss the rationale for adopting this theoretical framework and research approach.

3.1.1 Paradigms in social research

Paradigms represent ways of seeing the world and can be considered as frameworks within which research is conducted. Creswell and Plano Clark (2007) suggested that researchers bring their own worldview to the research process, and that this shapes the way their research is conducted. They also proposed that worldviews are defined by five elements: ontology, epistemology, axiology, methodology and rhetoric. Ontology is concerned with the nature of reality. It covers questions such as whether there exists one or multiple realities in the world and what form this reality may take. Epistemology deals with the nature and acquisition of knowledge. It is an expression of how one sees and interprets the world, and examines the relationship between the researcher and the research topic. Axiology relates to

the nature of values, including those of the researcher and participants, and addresses the question of bias. Methodology covers the process of conducting research and covers questions such as whether to use a deductive (top-down) or inductive (bottom-up) approach. Finally, rhetoric refers to the language used in the research, including to communicate its findings (Creswell & Plano Clark, 2007).

There are four main paradigms in social research. These include postpositivism, constructivism, advocacy and participatory, as well as pragmatism, which has gained increasing attention in the past decade (Creswell & Plano Clark, 2007; Johnson & Christensen, 2012). The rationale for adopting a pragmatic paradigm and a mixed method approach lies in the theoretical grounding of pragmatism and its contribution to the research process. These are discussed in the next section.

3.1.2 Theoretical grounding of pragmatism

Pragmatism is inherently linked to the traditional postpositivist and constructionist paradigms. Postpositivism is based on the assumption that there exists a relationship between the world and its representation, and that there is an objective truth (Creswell, 2011; Creswell, Klassen, Plano Clark, & Clegg Smith, 2011; Willig, 2013). It is based on a deductive reasoning (a top-down process). It aims to verify or reject hypotheses about the world, and generalise theories to other contexts. Thus, it is closely related to quantitative research methods. By contrast, constructivism presupposes that there exist multiple subjective realities, which are shaped by individuals' experience and environment (Creswell et al., 2011; Willig, 2013). This paradigm promotes the study of the complexities and idiosyncrasies of human experience, and thus, is associated with qualitative research (Creswell et al., 2011; Willig, 2013). Constructivism relies on an inductive reasoning (a bottom-up process), whereby theories are generated from the data. It also places the participants' and researcher's values at the centre of the research process.

Traditionally, these two paradigms have been presented as antithetic, un-bridgeable approaches (Creswell & Plano Clark, 2007; Creswell, 2011; Feilzer, 2010; Smith &

Heshusius, 1986). Howe (1988) referred to this position as the incompatibility thesis.

Pragmatism was born from this theoretical incompatibility and is referred to as the “third way” (Johnson & Onwuegbuzie, 2004) or “third paradigm” (Johnson, Onwuegbuzie, & Turner, 2007). Pragmatism aims to bridge the gap between the postpositivist and constructivist paradigms. By bringing together two opposite paradigms, pragmatism also enables researchers to combine the methods associated with each paradigm (quantitative and qualitative).

3.1.3 Pragmatism and the mixed methods approach

Pragmatism has been increasingly used in social research in the past two decades (Bryman, 2006; Creswell, 2011; Creswell et al., 2011; Johnson & Onwuegbuzie, 2004; Johnson & Christensen, 2012; Morgan, 2007; Teddlie & Tashakkori, 2010). Johnson and Onwuegbuzie (2004), some of the first advocates of pragmatism, argued that the debate should move from looking at the differences between the two approaches to looking at the commonalities, which they defined as: a common aim to understand humans and the world they live in, the use of empirical data, and of a set of rules to maximise validity and minimise bias. They also argued that epistemological considerations should be differentiated from research approaches, and that researchers should be free to use a particular method, even if it does not match their epistemological stance (e.g. qualitative researchers using quantitative scales). This “third way” is now considered a valid alternative to the quantitative versus qualitative divide (Bryman, 2006; Creswell et al., 2011; Creswell & Plano Clark, 2007; Johnson et al., 2007; Johnson & Christensen, 2012; Morgan, 2007; Tashakkori & Teddlie, 2003; Teddlie & Tashakkori, 2010).

Pragmatism is based on the concept that one should use “what works, using diverse approaches and valuing both objective and subjective knowledge” (Creswell & Plano Clark, 2007, p.26). Pragmatists advocate an outcome-oriented approach to research in which the research question takes precedence over the conception of the world (Creswell & Plano Clark, 2007; Teddlie & Tashakkori, 2010). They favour a mixed methods approach to

research, in which the most appropriate method is used to answer the research question (Johnson & Onwuegbuzie, 2004; Teddlie & Tashakkori, 2010).

3.1.4 Rationale for adopting a mixed methods approach

There are advantages to using a mixed methods approach. First, it enables researchers to both explore and verify hypotheses (Tashakkori & Teddlie, 2003). In doing so, the researchers can gain information from multiple perspectives and obtain a comprehensive understanding of the phenomenon of interest. It also facilitates the comparison, validation and triangulation of results (Creswell et al. 2011). Furthermore, when used together, quantitative and qualitative methods can complement each other and compensate for each other's limitations (Bryman, 2006; Creswell & Plano Clark, 2007). The mixed methods approach, however, has also been criticised for its philosophical grounding and the lack of epistemological consensus surrounding it. This is illustrated by debates about whether it is underpinned by a single or multiple paradigms (Creswell, 2011; Creswell & Plano Clark, 2007; Denzin & Lincoln, 2011).

Despite these limitations, a mixed method approach is appropriate to this research because of the diversity of the research objectives, which are: 1) to synthesise the qualitative evidence of women's holistic experience of TFA; 2) to examine women's coping strategies when dealing with TFA, as well as measure and assess the relationship between coping strategies and perinatal grief; 3) to explore health professionals' perceptions of how women cope with TFA and ascertain to what extent these perceptions are congruent with women's accounts; 4) to measure posttraumatic growth in the context of TFA and assess its relationship with coping strategies and perinatal grief.

These research objectives are of a very different nature. One objective aims to review the literature (Objective 1). Two of the objectives seek to explore a phenomenon (Objective 2 [part 1] and Objective 3), whilst the others aim to measure and examine relationships between variables (Objective 2 [part 2] and Objective 4). To address these diverse research objectives, a mixed method approach is required. Objectives 2 (part 1) and

3 are best addressed through qualitative methods as they are particularly suited to explore new areas, or areas which require understanding individuals' emotions and perceptions of the world (Strauss & Corbin, 2008). By contrast, Objectives 2 (part 2) and 4 are more suited to quantitative methods (Bryman, 2012). The following section outlines the methodological approaches used in the studies reported in this thesis to address these diverse research objectives.

3.1.5 Methodological approaches

Objective 1 was addressed through a meta-ethnography and the study is fully reported in chapter 2. Therefore, the remainder of this section focuses on the methodological approaches used in the empirical studies conducted to answer Objectives 2 (parts 2 and 3), 3 and 4 of the research project.

3.1.5.1 Design

The aim of the research is to gain an understanding of women's coping with TFA. Although the manner in which coping processes may vary over time is an interesting issue, it is not a primary aim of this project. Therefore, a cross-sectional retrospective design is considered suitable for the three empirical studies. Despite some limitations, including the inability to establish causation between variables and the potential for *post hoc* rationalisation, this type of design is appropriate to investigate phenomena in the population at a single point in time (Bowling, 2009; Bryman, 2012). This is the purpose of this research. Nevertheless, the question relating to the way women's coping strategies evolve over time is relevant and a preliminary longitudinal analysis is presented in chapter 7 (section 7.3.4). This issue is also discussed in chapter 8 (section 8.6).

3.1.5.1.1 Methodological approaches to answer the research objectives

Objective 2

The research's second objective consists of exploring women's coping strategies when dealing with TFA, as well as measuring and assessing the relationship between coping strategies and perinatal grief. This objective is twofold; the first part requires a qualitative approach, whilst the second necessitates a quantitative one. Therefore, to answer this objective a mixed methods study was conducted. Coping strategies were explored using online qualitative interviews with women who had undergone TFA (Study 2a, chapter 4). In addition, quantitative scales were used to measure women's use of coping strategies and their levels of perinatal grief. Statistical analyses were conducted to assess the relationship between the two sets of variables (Study 2b, chapter 5).

Objective 3

The third research objective is to explore health professionals' perceptions of women's coping with TFA and ascertain to what extent these perceptions are congruent with women's accounts. This objective warrants a qualitative approach because such an approach would enable both the in-depth exploration of health professionals' perceptions, and the comparison with the women's qualitative accounts. Thus, a qualitative study was carried out to answer this objective. It consisted of face-to-face interviews with health professionals (Study 3, chapter 6).

Objective 4

The fourth research objective focuses on measuring posttraumatic growth in the context of TFA as well as assessing its relationship with coping strategies and perinatal grief. This objective is best addressed through a quantitative approach. Thus, a quantitative study was conducted, in which quantitative instruments were used to measure the variables and assess their relationship (Study 4, chapter 7).

The subsequent sections of this chapter deal with the methods used in the research's empirical work. The next section (3.2) focuses on the methods used in the empirical quantitative studies, including: sampling, data collection, ethical considerations, and statistical analyses. It discusses the rationale for using particular approaches and describes the methodological procedures.

3.2 Quantitative empirical work

Two of the research objectives (Objectives 2 [part 2] and 4) are addressed through quantitative methodologies. These objectives share several characteristics. Both aim to measure relationships between variables and both focus, in part, on the coping strategies used by women when dealing with TFA. Consequently, the methodological rationale and procedures are similar for these two quantitative studies (Studies 2b and 4). These are presented in sections 3.2.1 to 3.2.4.

3.2.1 Sampling

Most of the empirical work in this research involves collecting data from women who have undergone TFA in the UK (except for the third research objective, which necessitates gathering data among health professionals). Given the low incidence of TFA in the general population (3,099 terminations in England and Wales in 2014; DH, 2015), a targeted sampling approach was necessary. Recruiting participants from online support groups appeared the most appropriate strategy, whilst remaining cognisant of this approach's possible limitations.

3.2.1.1 Antenatal Results and Choices

There exists a number of support groups for parents who experience perinatal loss (e.g. Stillbirth and Neonatal Death Charity, Sands) and online forums dealing with perinatal loss

(e.g. Babyloss.com). In the UK, one organisation specifically provides support to parents in the context of TFA. Antenatal Results and Choices (ARC) was established as a charity in 1988 under the name SATFA (Support after Termination for Fetal Abnormality). ARC aims to provide practical and emotional support to parents when an abnormality is detected in their baby (ARC, n.d.). The charity has approximately 1,700 parent members and is contacted by up to 6,000 clients annually. Of those, 700 contact ARC because they are facing the prospect of, or are undergoing TFA. Approximately 500 of those join ARC as members (J. Fisher, personal communication, November 18, 2014).

ARC runs a national helpline and provides access to a network of volunteers who support parents on an ad hoc basis. ARC also assists healthcare professionals in delivering high quality care, by running training programmes on topics such as 'breaking bad news' and 'supporting parents' choices' (ARC, n.d.). ARC holds local meetings, which give members an opportunity to meet parents in a similar situation. However, these meetings are infrequent. Therefore, most ARC members communicate through the email network and, since May 2011, through a password-protected online forum. The email network and online forum register approximately 1,000 and 1,400 members respectively (J. Fisher, personal communication, November 18, 2014).

Given the size of the email database and online forum membership, recruiting participants through ARC can be considered as a viable method to provide access to women who have undergone TFA. The fact that ARC membership has already been utilised as a sampling pool in academic research on TFA (Fisher et al., 2015; Fisher & Lafarge, 2015; Hill, Fisher, Chitty, & Morris, 2012), adds credence to it being used as a sample group in this research. Nevertheless, it is important to examine the implications of using this group as a sample pool in this research project.

3.2.1.2 Recruiting participants from online support groups

The recruitment of research participants through online support groups has gained momentum since the introduction of the internet and the subsequent increase in the number

of online support groups (Coulson & Malik, 2012; Hughes, 2012). Online support groups have been used extensively, both as a sampling pool and research topic in their own right, in health research (Coulson & Shaw, 2013; Crabtree, Haslam, Postmes, & Haslam, 2010; Han et al., 2008; Mo & Coulson, 2013).

3.2.1.2.1 Advantages of recruiting participants from online support group

There are several advantages of recruiting participants from online support groups. Hewson and Laurent (2008) proposed that one of the advantages of using online support groups is the ability to reach a large and geographically spread audience, which may result in bigger sample sizes and higher statistical power. Another advantage is that it provides access to specific and potentially hard to reach groups of individuals. The latter is particularly relevant when conducting research among individuals who may feel uneasy about disclosing their health status and/or may feel, in some way, stigmatised (Coulson & Shaw, 2013; Hewson & Laurent, 2008). Research suggests that people who feel stigmatised may turn to online communities to reduce feelings of loneliness and foster a sense of belonging (Barak, Boniel-Nissim, & Suler, 2008). As highlighted in chapter 1 (section 1.1), TFA is a sensitive topic, which generates polarised views and may lead to stigmatisation (see also Study 1, chapter 2). Thus, an important consideration in devising the sampling strategy for this research focused on women's potential reluctance to share their experience outside the perceived 'safety' of a support group.

3.2.1.2.2 Disadvantages of recruiting participants from online support group

Recruiting participants from online support groups also has limitations. These mainly relate to the representativeness of such samples (Gosling, Vazire, Srivastava, & John, 2004; Hewson & Laurent, 2008). Two main sources of bias are identified. First, individuals who are not members of online support groups, either through inability or choice, are not represented. With internet penetration nearing full capacity (84% of households in the UK, ONS, 2014c), the issue of internet coverage and access, and potential biases in the internet

population is less problematic. However, individuals who chose not to join online support groups remain excluded from research projects using this type of sample. Furthermore, within members of online support groups, research participation also depends on individuals' level of engagement within the group. Evidence indicates that lurkers (i.e. individuals who read rather than post messages on online communities) spend less time connected to online communities and are less motivated by social exchange than those who post messages (Malik & Coulson, 2011; Nonnecke, Andrews, & Preece, 2006; Ridings, Gefen, & Arinze, 2006). Therefore, individuals less active within the online group may also be less likely to participate in research.

The second source of bias lies in the profile of individuals who engage in online support groups activities. Research has shown that participating in online support groups activities may be, in itself, therapeutic (Barak et al., 2008) and empower individuals (Bartlett & Coulson, 2011; van Uden-Kraan et al., 2008). Thus, individuals who engage in support group activities may display better psychological adjustment than those who do not. On the other hand, research also suggests that using online support groups may not necessarily result in better psychological adaptation and may even lead to rumination (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Malik & Coulson, 2008). Therefore, there is currently no consensus on how well adjusted psychologically members of online support groups may be in comparison to non-members.

In addition to potential limitations relating to the representativeness of samples from online support organisations, it is also possible that membership of such organisations may influence the findings of studies conducted in the area of coping. Evidence suggests that individuals seeking membership of these organisations are in need of information and emotional support (Malik & Coulson, 2008). Therefore, when investigating coping strategies among members of support organisations, it is important to remain cognisant of the fact that membership of such organisations may constitute a coping strategy in itself. Furthermore, it is also likely that usage of coping strategies such as seeking emotional or instrumental support may be over-represented within those groups.

3.2.1.3 Rationale for recruiting participants through ARC's email network and online forum

Although it is important to be aware of the limitations of using online support groups as sample pools, the issues of representativeness described above are unlikely to have an unduly negative impact upon the research findings. As internet penetration approaches full capacity (84% in the UK [ONS, 2014c]), issues about potential biases in internet population due to coverage are less problematic. Furthermore, in this research, the target sample comprised women of childbearing age. In 2013, almost all women aged up to 44 years old (98%) had used internet (ONS, 2014d). Consequently, it was assumed that most women would have internet access and be computer literate, and thus would be able to answer the online surveys/interviews.

More importantly, although ARC members may not be representative of the totality of women undergoing TFA, they represent a significant proportion of that group. ARC estimates that around 500 new members join the charity each year, with a further 200 contacting the helpline, and that these are parents (almost exclusively women) who are undergoing or have undergone TFA. Based on a prevalence of 3,099 terminations a year (DH, 2015), ARC members represent approximately 20-25% of the population of women known to undergo TFA in England and Wales. ARC does not hold a database of its members, therefore, there is little information on their demographic profile. Although this is a limitation of using this group as a sample pool, given that there is no demographic information available on the population of women who undergo TFA as a whole, it is not possible to assess whether these two groups (ARC members and non-members) differ significantly from each other.

In an effort to enhance the validity of the research, the option of recruiting women through the NHS was examined. This option was, however, disregarded because of the difficulties in obtaining NHS ethical approval documented in the TFA literature in England (Breeze, Statham, Hackett, Jessop, & Lees, 2011; Graham et al., 2009). This position was

confirmed by comments from senior researchers working in the area of TFA and by the researcher's personal experience on related projects. Furthermore, recruiting participants through the NHS would have reduced the research's scope to coping with a recent termination. It would have restricted the exploration of a wider range of coping experiences and of the occurrence of posttraumatic growth following TFA.

Based on these considerations, recruiting participants from ARC's email network and online forum is considered the most appropriate sampling strategy for the quantitative empirical work. It provides access to a 'hard to reach' group, which is geographically spread. The fact that ARC membership represents 20-25% of women known to undergo TFA in England and Wales, and that many women make use of the email network and online forum, greatly contribute to alleviating concerns about the sample's representativeness. This, in conjunction with the difficulty in obtaining NHS ethical approval for studies in the area of TFA, underpins the selection of this sampling strategy. However, the possible impact of using ARC as a sampling pool upon the research findings on coping may constitute a genuine limitation of the research. This issue was taken into account whilst analysing the data pertaining to women's use of coping strategies, and is discussed further in chapters 4, 5 and 8.

3.2.1.4 Recruitment of participants

All participants were women members of ARC. They were initially recruited through ARC's email network. ARC's administrator sent an email to the group providing basic information about the study. Those interested in participating were advised to email the researcher to register their interest. They were then emailed an information sheet and a consent form. On return of the signed consent form, participants were emailed the link to the online survey. The method of data collection is discussed in section 3.2.2. Women who had originally registered their interest but had not returned their consent form were emailed once to remind them of the study. No further contact was made after that point. A similar procedure was used to recruit women from ARC's online forum. The ARC administrator posted a message

about the study. Members interested in participating clicked on a link directing them to the online survey. The survey's first two pages displayed information about the study, which replicated the information sheet sent to women via email. Before starting the survey, participants had to respond positively to four questions designed to elicit their consent to participate in the study.

To be eligible, women had to be at least 18 years old. Initially, they also had to have undergone TFA at least 6 months prior to participating in the survey. The intention in using this criterion was to avoid causing distress among women whose termination was recent. However, following comments from women unable to participate in the study because of the less-than-six-month exclusion criterion, the decision was made to include any women who had undergone TFA, irrespective of when the termination had occurred.

Participants were recruited in several stages over a period of three years (April 2011-2014). Participants for Study 2b (chapter 5) were recruited between April 2011 and July 2012. Some of the participants also completed the qualitative study (Study 2a, chapter 4) at the same time. The recruitment for Study 4 (chapter 7) took place between February and May 2014. Participants who had participated in Study 2b and agreed to take part in further research were re-contacted via email to ask if they would be willing to participate in another study (Study 4). Two weeks after the initial contact, a reminder email was sent to those who had not completed the survey. No further contact was made after that point. The breakdown of participants recruited via each recruitment method (email/online forum vs. re-contact) is provided in chapter 7 (section 7.3.1).

3.2.1.5 Sample size calculations

Prior to collecting data, it is important to calculate the sample sizes required to carry out the intended statistical tests (Field, 2009). Power calculations are used to estimate the optimum sample size to detect statistical significance (Hair, Black, Babin, & Anderson, 2013). These are based on four components. The first one is the level of significance attributed to the data findings. It is generally set at 0.05, which means that there is a 5% chance that the result is

due to chance. The second component is the level of power. The greater the power, the less likely the researcher is to commit a type II error (false negative or rejection of a potentially significant result). This level is generally set at 0.8 (or 80%), which means that there is a 20% risk of committing a Type II error (false negatives). The third component is the effect size. An effect size is a way of quantifying the difference between two groups. It is often reported using the Cohen's *d* measure and can be categorised as small (up to 0.2), medium (0.2-0.5) and large (0.5-0.8; Cohen, 1988). The final component is the number of variables used in the statistical tests. Generally, the higher the number of variables, the larger the sample needs to be. The G*Power (version 3.1) program (Faul, Erdfelder, Lang, & Buchner, 2007) is a useful tool to determine the optimum sample sizes.

For the quantitative empirical work, the intention is to use multiple regression analyses to examine the relationship between coping strategies and perinatal grief, and between coping strategies, perinatal grief and posttraumatic growth. Coping strategies in addition to several demographic, obstetric and termination-related variables are to be used as predictor variables, whilst the perinatal grief and posttraumatic growth variables are to be used as outcome variables. A sample estimation was run using G*Power based on 20 predictors i.e. 13 coping strategies subscales from the Brief COPE (Carver, 1997) and seven obstetric, termination-related and demographics variables known to be associated with psychological adjustment following TFA. Using an alpha value of 0.05, a power value of 0.80 and an effect size of 0.15, the sample size required was 157 participants ($F(20, 136) = 1.63$, $p < 0.05$). Obtained sample sizes are discussed in chapter 5, section 5.3.1 and chapter 7, section 7.3.1.

3.2.2 Data collection

The choice of sampling strategy has important implications for the method of data collection. Given that participants were to be recruited from ARC's email network and online forum and that these members are geographically spread, an online method of data collection

presented itself as a sensible option. The next section outlines the rationale for adopting this method and describes how it was implemented.

3.2.2.1 Rationale for collecting quantitative data online

One common method of online data collection involves online surveys (Bryman, 2012; Hewson & Laurent, 2012). These have been used in many areas of health research: living with HIV (Rosser et al., 2009), cancer (Watson, Sugden, & Rose, 2010), infectious disease (Brooks-Pollock, Tilston, Edmunds, & Eames, 2011) and infertility (Domar et al., 2012). Participants are usually recruited via email or through a web page (Duffy, 2002; Hewson & Laurent, 2008) and access the survey by clicking on a web link, which takes them to the questionnaire.

This method of data collection has several benefits (Gosling et al., 2004; Hewson, 2008; Hooley, Wellens, & Marriott, 2012). Some relate to the online recruitment of participants and were discussed in section 3.2.1.2 (i.e. access to larger and/or 'hard to reach' samples [Hewson & Laurent, 2008]). Hooley and colleagues (2012) further suggested that online data collection is convenient to participants, which may encourage participation, and that it enhances data accuracy. For example, online survey software (e.g. SurveyMonkey) offer functionalities that maximise data completion and accuracy. These include ensuring that all items on a scale are rated before participants move to the next question, or routing people through the survey, so that only those who need to answer a question are asked that particular question (Hooley et al., 2012).

Conversely, researchers may exert less control over the data collection process, particularly over participants' environment at the time of completion (Hewson & Laurent, 2008; Hooley et al., 2012). Participants may be rushed or distracted when filling the survey, which may affect their answers. Another disadvantage of online data collection lies in the response rates, which have been shown to be lower than for other methodologies. Consequently, the researcher may have to over recruit to compensate for participant attrition. Nonetheless, Hooley and colleagues (2012) suggested ways to mitigate the risk of

non-completion and enhance data quality. These include: consistency of layout and question types (e.g. multiple answers questions, rating scales), as well as brevity, which has been shown to yield lower attrition rates.

By incorporating these suggestions, it is, therefore, possible to offset the limitations of this method of data collection and enhance the accuracy of the data gathered. Based on these considerations, online data collection can be considered optimal because it offers a simple and efficient way to collect accurate data among a geographically spread, and hard to reach group.

3.2.2.2 Procedure for data collection

The data for the quantitative empirical work were collected through online surveys, hosted on a secure and dedicated website (www.surveymonkey.com). Participants were given as much control as possible over their environment, in that they had the freedom to respond to the survey in their own time and at their own pace, and they could leave and re-enter the survey at their leisure. No cut-off date was specified and the surveys remained open until no new data were collected. It was thought that this flexibility would enable participants to dedicate quality time to complete the survey. To enhance data accuracy, great care was taken to use clear and simple language in wording the questions. Participants were also routed to the relevant questions. When completing the online survey for Study 4, women who had already participated in Study 2b were not asked to provide information about their terminated pregnancy again. The researcher added this information at the analysis stage. Finally, regarding the surveys' response rates, it was considered that the steps described above would contribute to promoting survey completion. Throughout the research process, no difficulty was encountered in obtaining the required sample sizes.

3.2.2.3 Questionnaires

The questionnaires used in Studies 2b and 4 were identical except for the addition in Study 4 of the posttraumatic growth, method of termination offered and religious status questions.

Minor changes were made to the wording of several questions (e.g. termination method), but these did not alter the way the questions were asked or coded in any significant way.

Questionnaires are displayed in Appendices II and III.

The questionnaires contained questions about coping strategies, levels of perinatal grief and posttraumatic growth. The scales used to measure these constructs are described in the next section (3.2.2.4). The questionnaires also comprised questions about the terminated pregnancy and women's obstetric history, including: time of TFA, number of pregnancies, number of living children at the time of TFA, gestational age at TFA, method of abnormality detection, abnormality prognosis, method of termination, women's reproductive history post-TFA, and how women felt about their decision to terminate. The questionnaires used a combination of open and closed questions. Some variables required both open and closed responses. For example, for 'time elapsed since termination,' women were first asked to enter the month and year of termination, and then asked to select one of four timeframe categories: up to six months prior to study participation, 7-12 months, 13-24 months, over 24 months.

In this research, various categories are used to describe the sample. 'Time elapsed since termination' is based on four categories of answer as described above. 'Method of abnormality detection' is defined as 'routine check' or 'directed search.' 'Method of termination' is classified as 'surgical,' 'medical (pill)' and 'induction of labour' (with or without feticide). The 'abnormality prognosis' is defined as 'lethal/incompatible with life,' 'not lethal/compatible with life' or 'unsure.' Women's 'reproductive history post termination' contains five categories: 'had a baby,' 'pregnant,' 'suffered another pregnancy loss,' 'not pregnant but hoping to be' and 'not wanting another pregnancy.' Women could select more than one answer to this question. Finally, the variable 'feeling about the decision to end the pregnancy' is categorised as 'comfortable with decision' (i.e. would make the same decision again), 'uncomfortable with decision' (i.e. would not make the decision again) and 'unsure.'

The questionnaire also included demographic questions: age, level of education, marital status, socioeconomic status of the chief income earner, ethnicity and religious

stratus. At the end of the questionnaire, women had the opportunity to comment on the study and leave their contact details if they wished to receive a summary of the findings. The questionnaire was tested on three participants, which resulted in no changes being made.

3.2.2.4 Scales

Several scales were used in the quantitative studies, including: the Brief COPE (Carver, 1997), the Short Perinatal Grief Scale (Potvin, Lasker, & Toedter, 1989), and the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996). The subsequent sections (3.2.2.4.1 to 3.2.2.4.3) outline the rationale for using these scales and provide a description of each one.

3.2.2.4.1 The Brief COPE

The Brief COPE is a measure frequently used in coping research (Krägeloh, 2011). It has been used extensively in health research (Bautista, Rundle-Gonzalez, Awad, & Erwin, 2013; Cartwright et al., 2009; Schnider et al., 2007); reproductive health (Gourounti, Anagnostopoulos, & Lykeridou, 2013; Lord & Robertson, 2005); trauma (Glass et al., 2009), and posttraumatic growth (Schmidt, Blank, Bellizzi, & Park, 2012; Schroevers & Teo, 2008). The Brief COPE's validity and reliability are well established with Cronbach's alpha values ranging from 0.50 to 0.90 (Carver, 1997). Given the scale's psychometric properties and its wide use in psychological research, the Brief COPE can be considered a suitable scale to measure the coping strategies used by women dealing with TFA.

The Brief COPE (Carver, 1997) is a short version of the COPE Inventory (Carver et al., 1989). It comprises 28 items grouped in 14 two-item subscales, each one depicting a particular coping strategy. Items are rated on a four-point Likert scale (*I haven't been doing this at all, I have been doing this a little bit, I have been doing this a medium amount, I have been doing this a lot*). The fourteen subscales include: 'self-distraction,' 'active coping,' 'denial,' 'substance use,' 'use of emotional support,' 'use of instrumental support,' 'humour,'

'behavioural disengagement,' 'venting,' 'positive reframing,' 'planning,' 'acceptance,' 'turning to religion' and 'self-blame.'

'Self-distraction' includes coping strategies such as turning to work and other activities, and doing something to think less about the situation. 'Active coping' involves doing something about the situation and trying to improve it. 'Denial,' on the other hand, represents a refusal to believe what has happened. 'Substance use' relates to the use of alcohol or other drugs to alleviate distress. The 'use of emotional support' refers to receiving comfort and support from others. The 'use of instrumental support' involves trying to get help and advice from others. 'Humour' refers to attempts at making fun of the situation. 'Behavioural disengagement' depicts giving up attempts to deal with the situation. 'Venting' involves expressing negative and unpleasant feelings. 'Positive reframing' refers to trying to see the situation in a positive light and finding benefits from it. 'Planning' depicts devising a strategy to deal with the situation and actively thinking about steps to improve it. 'Acceptance' relates to acknowledging the reality of the situation and learning to live with it. 'Religion' involves turning to religion or spirituality to find comfort. Finally, 'self-blame' is about criticising oneself for what has happened.

Carver (1997) suggested that the scale can be tailored to the study and that it is possible to use all or only some of the subscales. Following these guidelines, the subscale 'humour' was removed because it was deemed insensitive in the context of TFA. The wording of the instructions and some of the statements were also adapted to fit the study's topic by making explicit reference to the termination.

3.2.2.4.2 The Short Perinatal Grief Scale

Numerous scales have been used to measure psychological distress. In relation to TFA, studies have used measures of depression, posttraumatic stress or complicated grief to assess women's levels of psychological distress (Iles & Garth, 1993; Kersting et al., 2005, 2007, 2009; Korenromp et al., 2007a; Mirlesse et al. 2011; Salvesen, et al., 1997; Statham et al., 2001). The same evidence, however, also shows that despite being experienced as a

traumatic event, TFA does not necessarily lead to women experiencing pathological levels of distress. Therefore, these measures may not be relevant to all women. The Short Perinatal Grief Scale ([Short PGS], Potvin et al., 1989) is considered a suitable tool to use in this research because it was specifically designed to measure grief following perinatal loss and had been used in the context of TFA (Gaudet, Séjourné, Camborieux, Rogers, & Chabrol, 2010; Hunfeld, Wladimiroff, & Passchier, 1994; Nazaré et al., 2013, 2014; Toedter, Lasker, & Janssen, 2001; Zeanah et al., 1993). The scale demonstrates high levels of validity and reliability (Hunfeld et al., 1993; Toedter et al., 2001; Zeanah et al., 1993) with Cronbach's alpha values between 0.70 and 0.96 (Toedter et al., 2001). Thus, the decision was made to use the Short PGS to measure psychological distress following TFA.

The Short PGS derives from the Perinatal Grief Scale (Toedter, Lasker, & Alhadeff, 1988). It comprises 33 items scored on a five-point Likert scale (*strongly agree, agree, neither agree nor disagree, disagree, strongly disagree*). Although the scale was originally designed to reflect the theoretical domains of grief (i.e. disbelief, anger, loneliness, and guilt), a factor analysis identified a three-factor structure (Toedter et al., 2001). The Short PGS items are, therefore, grouped into three 11-item subscales: 'active grief,' 'difficulty coping' and 'despair.' These subscales illustrate progressive pathological levels of grief.

'Active grief' represents 'uncomplicated grief' and includes items such as 'I feel the need to talk about the baby' and 'I get upset when I think about the baby.' The two other subscales, 'difficulty coping' and 'despair,' indicate increasing pathological levels of grief (or complicated grief). 'Difficulty coping' comprises items such as 'I can't keep up with my normal activities' and 'I feel as though I'm just existing and not really living since he/she died.' 'Despair' is considered a more severe outcome than 'difficulty coping.' It includes items such as 'I feel guilty when I think about the baby' and 'the best part of me died with the baby.' The three subscales are also combined into the 'total PGS' (total grief) measure. Although the Short PGS contains a subscale labelled 'difficulty coping,' it aims to measure grief as an outcome and does not reflect coping processes. As such, it is distinct from the

Brief COPE. The wording of the instructions and some of the statements were also adapted to make explicit reference to the termination.

3.2.2.4.3 *The Posttraumatic Growth Inventory*

The PTGI Inventory ([PTGI], Tedeschi & Calhoun, 1996) is one of the most frequently used instruments to measure posttraumatic growth. It has been widely utilised in health research (Schmidt et al., 2012; Schroevers & Teo, 2008; Taku et al., 2008), including reproductive health (Paul et al., 2010), and in the context of bereavement (Calhoun et al., 2010; Engelkemeyer & Marwit, 2008). The PTGI has well-established validity and reliability with Cronbach's alpha values varying from 0.67 for 'appreciation of life' to 0.90 for the 'PTGI overall' scale (Tedeschi & Calhoun, 1996). Given the relatively recent focus on positive outcomes following trauma, the PTGI has not yet been used in the context of TFA. Nonetheless, given that TFA is regarded as a traumatic event (see chapters 1 and 2), it is appropriate to use this scale in this context.

The PTGI comprises 21 items scored on a six-point Likert scale (*I did not experience this change as a result of my crisis, I experienced this change to a very small degree, I experienced this change to a small degree, I experienced this change to a moderate degree, I experienced this change to a great degree, I experienced this change to a very great degree*). All items are positively worded. Items are grouped into 5 subscales: 'relating to others,' 'new possibilities,' 'personal strength,' 'spiritual change' and 'appreciation of life.' 'Relating to others' comprises seven items. It depicts renewed compassion and emotional connection to others and includes statements such as 'I am more willing to express my emotions' or 'I better accept needing others.' 'New possibilities' includes five items. It relates to the personal exploration of new directions and a sense of renewed mastery. It covers statements such as 'I established a new path for my life' or 'I developed new interests.' 'Personal strength' represents acceptance and belief in one's ability to overcome the crisis. It contains four items such as 'I discovered that I'm stronger than I thought I was' or 'I have a greater feeling of self-reliance.' 'Spiritual change' is a two-item subscale. It depicts greater

understanding of spiritual matters and includes the following statements: 'I have a stronger religious faith' and 'I have a better understanding of spiritual matters.' Finally, 'appreciation of life' relates to increased appreciation for life and one's own values, and new priorities. It is made up of three items and includes statements such as 'I can better appreciate each day' or 'I changed my priorities about what is important in life.' The subscales are also aggregated into the 'PTGI overall' measure. Similarly to the other scales, the wording of the instructions and some of the statements were adapted, making explicit reference to the termination.

3.2.3 Ethics

Ethical considerations relating to the research, and the way they were addressed are outlined in the next section.

3.2.3.1 Ethical considerations of online research

Online research has to fulfil a number of ethical criteria, some of which are standard, whilst others relate specifically to this method of data collection. The British Psychological Society's guidelines into ethical practice in online research ([BPS], 2007, 2013) and the Association of Internet Researchers ([AoIR], 2012) highlighted specific areas researchers need to consider prior to conducting online research.

The first area concerns participants' anonymity. Both the BPS and AoIR emphasise the importance of protecting the data collected. It is generally considered good practice to download the data into a secure computer and remove the data from the web-based data collection and storage tools because, despite security precaution, internet content can be relatively easily accessed by a third party (AoIR, 2012; BPS, 2013; Hooley et al., 2012). In this research, the surveys were hosted on a dedicated and secure website (www.surveymonkey.com), using the enhanced security option to maximise participants' anonymity. This functionality consists of creating a secure connection between an individual and a web server through the encryption of the information exchanged (Knussen &

McFadyen, 2010). Data were downloaded from the web-based site in nine different batches between April 2011 and April 2014. On each occasion, the IP addresses were removed from the databases.

Online surveys also have to fulfil several standard ethical requirements (AoIR, 2012; BPS] 2007, 2013). These include: providing participants with an information sheet, obtaining informed consent, debriefing or offering participants a summary of the results and reminding them of their right to withdraw (BPS, 2007, 2013). Some of these requirements are more difficult to fulfil in an online rather than a face-to-face environment. For example, assessing how truly informed participants are and how truly they consent to participate in a study is challenging (Hewson & Laurent, 2008; Hooley et al., 2012). This is particularly important given that evidence suggests that individuals tend to skip information sections on the internet (e.g. terms and conditions) and accept or consent without fully reading them (BPS, 2007).

Internet guidelines, therefore, stipulate that researchers have to provide participants with detailed but easy to understand information, which may be accessible from multiple locations (BPS, 2007, 2013). In this research, participants were provided with information designed to be exhaustive yet simple to understand. All materials were reviewed by the ARC team to ensure they were appropriate to the target audience. Participants were given information about the survey's objectives, procedures, analysis, and plan for dissemination as well as their rights as participants. This information was displayed on the information sheet and/or the first two pages of the online survey. In addition, basic information about the survey was included in the ARC administrator's post. The information sheets for Studies 2b and 4 and the consent form are displayed in Appendices IV, V and VI. All participants were offered a summary of the results on completion of the survey, which most chose to receive.

3.2.3.2 *Acknowledging the potential for distress*

An important ethical consideration in this research relates to the sensitivity of the topic. Thus, the potential for distress to be experienced by participants as a result of participating in the study had to be acknowledged. Accordingly, participants were advised to contact ARC's

helpline or network of volunteers should they feel the need to speak to someone as a result of completing the survey. The issue of self-disclosure and its potential impact upon individuals has been widely discussed in the literature (Frattaroli, 2006; Pennebaker, 1989). Evidence suggests that participation in group discussions is beneficial to women who have experienced TFA (Statham et al., 2001) and that self-disclosure of thoughts and feelings can enhance psychological adjustment (Pennebaker, 2004). In this research, several participants commented that participating in the studies constituted a welcome opportunity to share their story and help other women in the future. Furthermore, none of the respondents reported experiencing distress as a result of participating in the studies, and no one contacted the ARC's helpline.

3.2.3.3 *Ethical considerations relating to the researcher*

A further ethical consideration relates to the researcher's own membership in ARC's network of volunteers, which had some implications in terms of confidentiality and duality of roles. Although it was considered that the researcher being a member of ARC's network of volunteers could benefit the research, through bringing insights into women's experiences, steps were taken to avoid conflict between the two roles. Participants' names were changed to safeguard participants' anonymity. The researcher's contact details were also removed from the list of volunteers that was to be sent by the ARC team to women contacting the helpline as a result of participating in the study.

Ethical approval for all aspects of the project was obtained from the School of Psychology, Social Work and Human Sciences' Ethics committee at the University of West London prior to the fieldwork starting. The research protocol had also been positively reviewed by a senior research midwife prior to submitting the project to the university's ethics committee.

3.2.4 Quantitative analyses and statistical tests

Analyses of the quantitative data involved descriptive and inferential statistics. Statistical tests were used to examine group differences in the use of coping strategies, levels of perinatal grief and posttraumatic growth. As both studies aimed to examine the relationship between variables, correlations and multiple regression analyses were also carried out. The rationale for conducting these analyses is presented in the next sections. Given that most of the data collected were based on interval measurement, it was assumed that parametric tests would be used in the analyses (Field, 2009). The assumptions underpinning the use of parametric tests are discussed in detail in chapter 5, section 5.2.2.5. Results of the quantitative analyses are presented in chapter 5, section 5.3 and chapter 7, section 7.3.

3.2.4.1 Analyses of group difference: *t* test and ANOVA

The literature review (chapter 1, section 1.2) indicated that several factors may be associated with women's psychological adaptation to TFA, including factors linked to the terminated pregnancy (e.g. gestational age; [Davies et al., 2005; Kersting et al., 2005]) and women's obstetric history (e.g. children since the termination [Statham et al., 2001]). Inferential statistical tests were used to assess group differences in the use of coping strategies, levels of perinatal grief and posttraumatic growth. These included independent *t* tests and Analysis of Variance (ANOVA). Both independent *t* test and ANOVA aim to detect mean differences between groups (Field, 2009). The *t* test is based on a dichotomous group membership (e.g. first pregnancy/not first pregnancy), whereas ANOVA tests mean differences between three (or more) groups (Field, 2009). In this research, the dependent variables were coping strategies, perinatal grief and posttraumatic growth. Independent variables included demographic, obstetric and termination-related variables, some of which were dichotomous (e.g. first pregnancy vs. not first pregnancy), whilst others were not (e.g. time since TFA: up to six months, 7-12 months, 13-24 months and over 24 months prior to study participation).

3.2.4.2 Multiple regression analyses

Multiple regression analyses were used to examine the relationship between coping strategies and perinatal grief (Study 2b) and between coping strategies, perinatal grief and posttraumatic growth (Study 4). Regression analyses are used to assess the extent to which variables from a set of independent variables, or predictors, predict the dependent variable, or outcome (Cohen, Cohen, West, & Aiken, 2003; Hair et al., 2013). They are generally run on variables exhibiting significant correlations with one another (Tabachnick & Fidell, 2007). However, regression goes further than correlation analysis in that it can predict rather than observe relationships between variables. Nevertheless, regression does not address causation between variables (Tabachnick & Fidell, 2007). Constantine (2012) suggested that establishing causation would require using experimental designs (e.g. randomised controlled trials), or path analyses such as Structural Equation Modelling, as well as identifying and examining alternative explanations for the relationships between variables. Despite this limitation, regression analysis can provide useful insights into the way variables relate to each other (Constantine 2012; Tabachnick & Fidell, 2007).

In this research, hierarchical regression analyses were used to examine the data. Hierarchical regression consists of adding a subset of predictor variables sequentially to measure each variable's individual contribution to the model. In doing so, it controls for the potential impact of other variables or covariates by suppressing their statistical effect (Field, 2009). Hierarchical regression is appropriate to answer the research objectives as it enables the assessment of the relative contribution of coping strategies, demographic, obstetric and termination-related variables in predicting the outcome variables (i.e. perinatal grief and posttraumatic growth). It also enables the researcher to establish whether the predictors statistically significant in step one remain significant once the second set of predictors have been introduced (Cohen et al., 2003; Field, 2009). In these studies, coping strategies were entered first (step one) and demographic, obstetric and termination-related variables second (step two). The rationale for entering the variables in this order was based on the principle of research relevance (Cohen et al., 2003), whereby, in hierarchical regression, the main

variables of interest are entered first. In this research, the main focus of analysis was to examine the predictive value of coping strategies on perinatal grief and posttraumatic growth. The purpose of adding demographic, obstetric and termination-related variables in step 2 was to ascertain whether these variables had any predictive value above and beyond coping strategies.

In running regression analyses, the aim is to identify the fewest number of predictors with the best predictive value (Tabachnick & Fidell, 2007). The choice of predictors is usually guided by past research (Cohen et al., 2003; Field, 2009). Previous literature and preliminary data analysis were used to inform the choice of predictors (predicting variables). Standard diagnostic tests were also conducted on the regression models. These included testing for highly correlated predictor variables, residual outliers and values that may have excessive effect on the model (Field, 2009; Tabachnick & Fidell, 2007). These diagnostics tests are described in chapter 5, section 5.3.4.2.3 and chapter 7, section 7.3.6.2.2.

In this section, the methods used in the quantitative empirical work have been discussed and a range of procedures have been described. The next section (3.3) focuses on the methods used in the qualitative empirical work of the research. This includes: sampling, data collection, ethical considerations and analysis techniques.

3.3 Qualitative empirical work

Two of the objectives in this research programme are addressed through qualitative methodologies. Objective 2 (part 1) aims to explore women's coping strategies when dealing with TFA. Objective 3 aims to assess health professionals' perceptions of women's coping, and ascertain to what extent health professionals' perceptions are congruent with women's accounts. These objectives differ significantly in terms of the population of interest and the purpose of analysis. Objective 2 (part 1) focuses on women and requires a

methodology which enables the in-depth exploration of coping strategies to answer it, whereas Objective 3 centres on health professionals and necessitates a methodology which allows comparison with another dataset. Thus, different approaches to the sampling, data collection and analysis were required. These two approaches are presented in the next sections.

3.3.1 Qualitative exploration of women's coping strategies when dealing with TFA

Similarly to the quantitative empirical work, this research involves collecting data from women who have undergone TFA. Consequently, most of the methodological considerations and the procedures discussed in the previous section (3.2) are relevant to the qualitative study on women's coping strategies.

3.3.1.1 Sampling

As outlined in section 3.2.1, ARC members who are active on the email network and online forum form an appropriate sampling pool to conduct the research pertaining to women. There is no reason to suggest that a different sampling method would be more suitable for the qualitative empirical work. Thus, the participants of this qualitative study were members of ARC and were recruited following the procedure described in section 3.2.1.4. The profile of the participants is described in chapter 4, section 4.2.2.

3.3.1.2 Data collection

Similarly to the quantitative empirical work, the type of sample has important implications for the method of data collection. The rationale for using an online method of data collection for the quantitative studies has been discussed in section 3.2.2.1. However, it remained to be ascertained whether this method would also be appropriate to collect qualitative data.

3.3.1.2.1 Collecting qualitative data online

There are several methods for collecting qualitative data online: online interviews, online diaries, online focus groups, online blogs or chat rooms (Hewson, 2007). Researchers use either a synchronous or asynchronous approach, whereby the data collection occurs in real time or is delayed (Hewson, 2007; Hewson & Laurent, 2008). The choice between synchronous and asynchronous methods depends on the type of data required. Hewson and Laurent (2012) suggested that asynchronous methods may involve higher levels of reflexion from participants and thus, may generate richer, more detailed data than synchronous methods. However, they also indicated that asynchronous methods may also be more susceptible to conversation 'drying up.'

Collecting qualitative data online has several benefits. Firstly, it may encourage self-disclosure, as privacy levels are perceived to be higher in an online rather than a face-to-face environment (Hewson & Laurent, 2012). Participants may feel less inhibited and thus, may be more likely to disclose personal information (Hewson, 2007; Hooley et al., 2012). This method has also been shown to encourage "depth and reflexivity" (Hewson, 2007, p.411), particularly when using asynchronous data collection (Hewson & Laurent, 2012). As participants have time to provide written feedback, they are more likely to reflect on their experience, which, in turn, may enhance the richness of the data. Furthermore, given the absence of non-verbal communication and social cues between researcher and participants, qualitative data gathered online are considered to be less subject to social desirability bias than when gathered face-to-face (Hewson, 2007). Collecting qualitative data online can also be seen as a more 'democratic' process as it minimises the power dynamics between interviewer and interviewee (Hewson, 2007; Hooley et al., 2012), 'freeing' participants of potential social pressures.

On the other hand, collecting qualitative data online, in particular asynchronously, limits the researcher's capacity to build a personal rapport with participants (Hewson & Laurent, 2012), which, in some case, may undermine participants' self-disclosure. The lack of non-verbal cues may also result in misunderstandings and in some subtleties in

participants' accounts being lost (Hewson & Laurent, 2012). Furthermore, in an online, asynchronous environment, the researcher is unable to probe participants' responses (Hooley et al., 2012). However, this is only problematic if the data collected do not answer the question or are not rich enough.

3.3.1.2.2 Rationale for collecting qualitative data online

Before deciding on the use of an online method to gather qualitative data for this research, the strengths and weaknesses of other methods also needed to be examined. The first one, face-to-face interviewing, presents several advantages when compared to online data collection. These include rapport building with participants and the opportunity to probe and pick up non-verbal cues (Breakwell, 2012; Opendakker, 2006). However, this method also presents logistical challenges in terms of the time and resources required to conduct the fieldwork (including travel) and transcribe the data. Telephone interviewing eliminates some of the logistical challenges inherent to face-to-face interviewing, such as the need to travel (Opendakker, 2006), and when compared to online collection, provides the researcher with the ability to build a rapport with participants and probe answers if necessary. Nevertheless, similarly to online collection, non-verbal cues are lost to the interviewer (Howitt, 2013; Novick, 2008; Opendakker, 2006). Furthermore, telephone interviewing may be perceived as "casual" by participants and thus, may not be suitable to research potentially distressing topics (Howitt, 2013, p.68).

Focus groups present some logistical benefits compared to face-to-face interviewing in that the researcher is able to speak to several participants at once (Millward, 2012). However, they also require time and resources to conduct the fieldwork and transcribe the output. Importantly, focus groups are reliant on group dynamics and, as such, are usually considered less appropriate when collecting personal, narrative accounts (Howitt, 2013). In addition, whether focus groups are appropriate to research sensitive topics remains to be ascertained (Jordan et al., 2007).

Based on these considerations, collecting qualitative data online can be considered an appropriate method to use in the research for four main reasons. Firstly, given that TFA is a highly sensitive subject, considerations about whether women would welcome the opportunity to share their experience, and in which environment (face-to-face, telephone, focus group or online) they would feel most comfortable to do so, had to be taken into account. It is thought that an online environment would encourage self-disclosure and reflexivity. Secondly, as ARC members are geographically spread, using an online method would remove the logistical challenges inherent to a face-to-face methodology. Thirdly, the practicality of using the same method to collect quantitative and qualitative data also has to be acknowledged. Finally, this method of data collection does not require transcribing the data, which is an added benefit.

Before making the final decision to use an online method of data collection, an asynchronous online method was tested on three participants, who answered a series of open ended questions. Preliminary analyses indicated that the data collected were rich and insightful. They provided detailed descriptions of women's experiences and displayed high level of reflexivity. Thus, an online, asynchronous method of data collection was implemented for the qualitative study pertaining to women's coping strategies.

3.3.1.2.3 Procedure of data collection

Data were collected through an online survey hosted on a secure and dedicated website (www.surveymonkey.com). All participants who completed the qualitative study, except one, also answered the quantitative questionnaire (Study 2b). Thus, the procedure for collecting the quantitative data was also used to gather qualitative data (e.g. people could leave and re-enter the survey, no cut-off points were specified, see section 3.2.2). In addition, steps were taken to address the limitations inherent to the online method of data collection in the context of qualitative research, i.e. the lack of rapport between researcher and participants and the inability to probe (see section 3.3.1.2.2). Although direct contact between researcher and participants could not take place, brief information about the researcher and her contact

details were made available to participants. The researcher's membership in ARC's network of volunteers was also disclosed. Several participants chose to contact the researcher after completing the study to provide additional information or ask further questions. This suggests that participants did not consider the researcher too remote from the research process. With regards to the inability to probe, a series of prompts were used to help participants answer the questions. They were, however, kept to a minimum and carefully worded to ensure that the feedback collected was, as much as possible, participant-led (Biggerstaff & Thompson, 2008).

3.3.1.2.4 Topic guide

The qualitative topic guide comprised open-ended questions about the process of coping with the termination, with specific attention paid to coping strategies. Topics included: the process of coping with the termination, coping strategies used at the time of the termination and post termination, which were considered helpful or unhelpful and why. The concept of moving on, the support received, and considerations about the future were also explored. Questions included: "Regardless of whether they were successful or not, what things did you do to get through the termination procedure itself?", "Regardless of whether they were successful or not, what things did you do to come to terms with the aftermath of terminating the pregnancy?" Demographic, obstetric and termination-related information were also gathered. These are described in section 3.2.2.3. The topic guide is displayed in Appendix VII.

3.3.1.3 Ethics

The ethical considerations for the qualitative empirical work pertaining to women are the same as for the quantitative work. These include: ethical considerations related to online research collection (e.g. anonymity, informed consent, standard ethical requirements such as use of an information sheet), the potential for distress, and ethical considerations related to the researcher's membership in ARC's network of volunteer. These have been described

in section 3.2.3. The information sheet and informed consent for this study are displayed in Appendices IV and VI.

3.3.1.4 Data analysis

There are several methods of analysis appropriate for qualitative data. Some of the most commonly used include interpretative phenomenological analysis (IPA), thematic analysis (TA) and grounded theory (GT). These methods are evaluated in the next section in relation to the study's research objective.

3.3.1.4.1 Overview of the main methods of qualitative data analysis

IPA and GT are generally considered methodologies rather than methods, in that they shape the way the whole research is conducted (Braun & Clarke, 2006; Smith, Flowers, & Larkin, 2009). However, for simplicity purposes, and because discussion on this topic would be beyond the scope of this thesis, IPA, GT and TA are referred to as methods of data analysis in this thesis. These methods have common characteristics. They use an inductive method of data analysis and similar analytical steps. Transcripts are read several times, reduced to meaningful units/codes, which are then aggregated into wider categories/themes (Braun & Clarke, 2006; Glaser & Strauss, 1967; Smith et al., 2009). They also involve various degrees of data interpretation (Braun & Clarke, 2006).

These methods also differ from each other. IPA is known for providing rich insights into personal accounts, and focusing on individual experience and the meaning attributed to it (Smith et al., 2009). Its idiographic focus and high level of interpretation differentiate it from other qualitative approaches. In comparison, GT aims to build a theory of a phenomenon and mainly focuses on social processes (Braun & Clarke, 2006; Glaser & Strauss, 1967; Howitt, 2013; Pringle, Drummond, McLafferty, & Hendry, 2011; Strauss & Corbin, 2008). It is a highly iterative method, which relies on participants' feedback to shape the data collection and analysis (Howitt, 2013; Strauss & Corbin, 2008). As for TA, its flexibility is often emphasised as it can be used with several data types and with relatively large sample sizes

(Braun & Clarke, 2006). Its analytical process differs from IPA in that it focuses on identifying patterns across a data set rather than within each account (Braun & Clarke, 2006; Smith et al., 2009). Another significant difference is that TA can be used deductively as well as inductively (Joffe & Yardley, 2004; University of Auckland, n.d.). Based on these descriptions, IPA was considered to be a suitable method to explore women's coping strategies and is examined further in the next section.

3.3.1.4.2 Interpretative Phenomenological Analysis

IPA is a relatively new methodology and has its roots in health psychology (Smith, 1996). In the past decade, it has been widely used in health research (Biggerstaff & Thompson, 2008; Brocki & Wearden, 2006; Cartwright, 2007; Fox & Diab, 2013), including reproductive health (Goodwin & Ogden, 2007; Shaw, 2011) and perinatal loss (Ryninks, Roberts-Collins, McKenzie-McHarg, & Horsch, 2014). IPA is based on the concept that individuals interpret and make sense of events, objects and people in their life (Smith & Eatough, 2012) and that experience has a particular significance to individuals (Smith et al., 2009). Smith and colleagues (2009) posited that IPA has three theoretical underpinnings.

The first theoretical underpinning is phenomenology, which is concerned with the study of experience and perceptions of phenomena. Phenomenology originates in the philosophy of Heidegger (1889-1976). It is often presented in direct opposition to positivism given its strong emphasis on experience. In phenomenology, the focus lies on the role of context in shaping individual perceptions and interpretations. IPA's second theoretical underpinning is hermeneutics, which is the theory of interpretation. In IPA, there is a double hermeneutics, whereby the researcher interprets the participant's own interpretations of a phenomenon. Thus, IPA is based on the principle that the researcher is fully part of the research process and brings his/her own values and experiences. IPA's third theoretical underpinning is idiography. Idiography is concerned with the individual and the particular. It is in direct opposition with the nomothetic principles associated with quantitative research, which aim to establish general patterns. In IPA, idiography is expressed through the

emphasis on individual experiences and a commitment to detail in the analysis and reporting. The aim of IPA is to portray participants' personal experiences of an event and the meaning they may attribute to it (Smith et al., 2009). It aims to identify similarities and differences about the experience of a phenomenon, and goes beyond individual experiences to create an interpretation of what the phenomenon may represent (Larkin, Watts, & Clifton, 2006).

3.3.1.4.3 Rationale for using interpretative phenomenological analysis

IPA is known for providing rich insights into personal accounts (Smith et al., 2009). IPA's perspective is unique in that it provides an in-depth understanding of the meaning of an experience (Larkin et al., 2006) that other qualitative approaches cannot deliver. IPA has also been praised for its flexibility (Larkin et al., 2006; Smith et al., 2009). Although IPA is most commonly used to analyse data collected through semi-structured interviews, other types of data have also been successfully used in conjunction with IPA. These include diaries, personal accounts, letters and internet forum posts (Mulveen & Hepworth, 2006; Palmer, Larkin, de Visser, & Fadden, 2010; Smith et al., 2009). A key requirement of IPA is that the data should be "rich and participants should have been granted an opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length" (Smith et al., 2009, p.56).

There are also some limitations to using IPA. IPA has been criticised for its reliance on written text (analysis of transcripts; [Willig, 2001, 2013]). Willig (2013) argued that language "constructs rather than describes reality" (p.94), therefore participants' accounts may reflect how they talk about their experience rather than the experience itself. Furthermore, IPA is dependent on participants' ability to articulate their thoughts and feelings (Willig, 2013), which may introduce a bias towards well-educated participants. This bias has been documented in the literature about TFA in Western countries (Korenromp et al., 2009; McCoyd, 2007; Statham et al., 2001), and may reflect the profile of women who are willing to share their experience of TFA.

In the context of a complex experience such as TFA and given its focus on experience (phenomenology), interpretation (double hermeneutic) and the individual (idiography [Larkin et al., 2006; Smith et al., 2009]), IPA can be considered the most appropriate method to analyse the data pertaining to women's coping strategies. The reliance on written text was not considered to be problematic as it is conducive to generating rich and reflexive data. Consequently, IPA was used to analyse the data collected in Study 2a (chapter 4). Similarly to meta-ethnography, given that IPA is a highly interpretative methodology, a high level of reflexivity is required when using this methodology. The issue of reflexivity is also considered in chapter 2, section 2.2.4.

The next section covers the methodology of the study conducted to address Objective 3 (Study 3, chapter 6), which examines health professionals' perceptions of women's coping.

3.3.2 Health professionals' perceptions of women's coping with TFA

This research objective is distinct from the others as it requires conducting research with health professionals rather than with women.

3.3.2.1 Background

The investigation into health professionals' perceptions of women's coping was conducted as part of an international research project on the practice of prenatal diagnosis. The aim of the project was to gain insights into the communication between health professionals and patients about fetal abnormality and the ensuing management of the pregnancy. Specifically, it aimed to compare practices between countries and identify discrepancies between the patients' needs and what is provided to them. The project involved observations of fetal medicine consultations and face-to-face interviews with health professionals about their own

practice of prenatal diagnosis. It is in the context of these interviews that health professionals' perceptions of women's coping with TFA were explored.

The sampling and data collection in this study were designed to address the objectives of the international research project. Nonetheless, they were considered appropriate to the exploration of health professionals' perceptions of women's coping. The international research project provided the researcher with a unique opportunity to access a range of fetal medicine professionals, in different roles, at various levels of seniority and in different clinical settings. The fact that the data were to be collected face-to-face was considered to be a benefit, giving the researcher some control over the interview. This was deemed important because the interview covered two distinct topics (the practice of prenatal diagnosis and health professionals' perceptions of women's coping), and it was assumed that this would involve some cross-over (one topic being mentioned within the time allocated for the other) and require a degree of explanation to participants. It was, however, left to the researcher to determine which methods would be most suitable to analyse the data. The sampling and data collection for this study, are described in the next sections (3.3.2.2 to 3.3.2.4). The method of data analysis is examined in section 3.3.2.5.

3.3.2.2 *Sampling*

The aim of the international research project was to interview a range of professionals including consultants, midwives, and sonographers with differing levels of seniority about their practice of prenatal diagnosis. Accordingly, a purposive sampling strategy was used in this study. Participants were recruited from three hospitals in England. Site 1 is a large fetal medicine unit (FMU), referral centre and teaching hospital. It provides over 15,000 clinical treatments a year and has over 40 members of staff. Site 2 is a local obstetrics and gynaecology unit, which provides 'standard' fetal medicine services (e.g. ultrasound, amniocentesis and chorionic villus sampling). At the time of interview, it employed two consultants in obstetrics and fetal medicine, several midwives and sonographers (exact

numbers not known). None of the staff was exclusively dedicated to fetal medicine. Site 3 is also a large fetal medicine unit and referral centre, with a similar profile to Site 1.

Any health professionals involved in the pregnancy management of women referred to their unit were eligible to take part. Attention was paid to secure the participation of a range of health professionals. The fact that the sites varied in terms of size and fetal medicine services provided also ensured that a diversity of professional experience was represented.

3.3.2.2.1 Recruitment of participants

Given that the sites differ significantly (in size and organisation), a specific recruitment procedure was used for each one. In Site 1 (large FMU), the lead consultant introduced the researcher to the unit's members of staff during a team meeting. This gave the researcher the opportunity to present the study and answer questions. Following this introduction, and over the course of a few weeks, the researcher approached members of staff individually. Participants were provided with an information sheet about the study. If they agreed to take part, an appointment was made for the interview.

The recruitment procedure for Site 2 (smaller unit) was different. The lead consultant provided the contact details of members of staff the researcher could approach. As this unit is smaller than Site 1, the selected contacts already represented different roles and seniority levels. All were involved in providing fetal medicine services. The researcher sent them some information about the study via email. If professionals agreed to take part, an appointment was made. Finally, the recruitment in Site 3 consisted of contacting a professional already known to the researcher via email. This site was not part of the international research project. The participants' profile is described in chapter 6, section 6.2.2.

Participants were recruited over a three-week period. The required number of interviews for the international research project was 15. It was anticipated that data saturation would be reached by this point. As the fieldwork progressed, interim analyses

were conducted to check whether any new themes could be identified in the data. Data saturation was apparent at 15 interviews; therefore, no further interviews were required.

3.3.2.3 Data collection

3.3.2.3.1 Method and procedure

Interviews were conducted with health professionals at the clinical sites. One of the requirements was that the interview took place outside working hours. In most instances, interviews took place during lunch-time hours or at the end of the working day. In some cases, health professionals came to the hospital on their day off specifically to do the interview. All interviews were conducted face-to-face and took place in a private room. Interviews were recorded digitally and transcribed verbatim. The fieldwork was conducted between May and July 2013.

3.3.2.3.2 Topic guide

The topic guide focused on health professionals' perceptions of women's coping with a diagnosis of fetal abnormality. Questions included: "Could you describe the way you perceive women cope with a diagnosis of fetal abnormality?", "Some women decide to terminate their pregnancy following a diagnosis of fetal abnormality, how do you think they cope with the termination? And afterwards?" Participants were also asked to provide a brief summary of their career path to fetal medicine, and whether they had personal experience of fetal abnormality. Age and gender were also recorded. The topic guide is displayed in Appendix VIII.

3.3.2.4 Ethics

This study was approved by the University of West London Ethics Committee in July 2012 and by a NHS Research Ethic Committee in February 2013. Participants were provided with an information sheet. They were made aware of their rights as participants (including confidentiality, right to withdraw, etc.). Consent was obtained from all participants. The

information sheet and consent form for this study are available from the researcher on request. Participants were also offered a summary of the results.

3.3.2.5 Data analysis

In contrast to the sampling and data collection, the researcher was free to select the most appropriate method to analyse the data. The next section described the method used to analyse the data, namely thematic analysis (TA), and the rationale underpinning this selection.

3.3.2.5.1 Thematic analysis

The study aims to explore health professionals' perceptions of women's coping and ascertain to what extent health professionals' perceptions are congruent with women's accounts. Thus, the analysis requires both an inductive and deductive approach. A review of the main methods of data analysis provided in section 3.3.1.4.1 indicates that the duality of approach (inductive and deductive) is compatible with TA (Braun & Clarke, 2006; Joffe & Yardley, 2004).

TA has been widely used in health research (Bogosian, Moss-Morris, Bishop, & Hadwin, 2011; Newby, Wallace, & French, 2012) including reproductive health (Hadjigeorgiou & Coxon, 2013; Malik & Coulson, 2008). As with other qualitative approaches, TA is suited to explore topics on which there is limited evidence (Joffe & Yardley, 2004). It is also particularly useful where there is no specific theoretical underpinning to the data collection and analysis (Braun & Clarke, 2006). TA is less concerned with the detail and the individual (idiography) than IPA, and more focused on patterns across the data (Braun & Clarke, 2006). In that respect it has been compared to content analysis (Joffe & Yardley, 2004).

3.3.2.5.2 *Rationale for using thematic analysis*

One of the main strengths of TA is its adaptability to different contexts, epistemologies and research questions (Braun & Clarke, 2006). It can be used with different types of qualitative data such as interviews, focus groups, or an open-ended question at the end of a questionnaire (Braun & Clarke, 2006; Joffe & Yardley, 2004). As previously mentioned, it can also be used inductively and deductively (Coulson, 2005; Fereday, & Muir-Cochrane, 2006; Joffe & Yardley, 2004; University of Auckland, n.d.). TA also has limitations. It has been described as descriptive rather than interpretative (Pope, Mays, & Popay, 2007). Claims that TA does not go far enough in the analysis and interpretation of data have, however, been disputed (Braun & Clarke, 2006; University of Auckland, n.d.). Buetow (2010) also questioned the concept of 'most occurring theme' which underpins TA, and argued that occurrence does not necessarily reflect importance.

Despite some limitations, TA can be considered a suitable method of analysis for the health professionals' data because of its ability to use both an inductive and deductive approach. In this study (Study 3, chapter 6), in the first instance, an inductive approach was used to explore the data. A deductive approach was then employed, which consisted of applying the code frames generated from the women's accounts to the health professionals' data. The data analysis for this study is described in chapter 6, section 6.2.3. Similarly to the other qualitative approaches utilised in this research (meta-ethnography and IPA), TA relies on interpretation and thus, must be conducted within a reflexive context. This was particularly relevant for this study given that most of the health professionals interviewed had already been observed in their clinical practice by the researcher as part of the international research project. It is possible that the observations may have influenced any preconceptions the researcher may have had on how these professionals would answer the questions relating to women's coping strategies.

3.4 Conclusions and implications for the thesis

This chapter has outlined the theoretical and methodological rationale underpinning the empirical work undertaken as part of this research, and described the methodological approaches and procedures used. The paucity of research in the area of coping with TFA, coupled with the diversity of the research objectives, largely determined the pragmatic, theoretical orientation and mixed methods nature of the research. Considerations of various sampling strategies led to the conclusion that despite some caveats, ARC's email network and online forum was an appropriate sampling pool for the research pertaining to women undergoing TFA. Similarly, an evaluation of several methods of data collection concluded that an online methodology was suitable to gather both quantitative and qualitative data relating to women participants. The quantitative scales were discussed and shown to have good reliability and validity. The statistical tests were also outlined.

Issues relating to the methods of data analysis for the qualitative elements of the research were also considered. In keeping with the pragmatic paradigm, the rationale for selecting the methods of analysis was based on the research objectives and analytical purposes. This resulted in the choice of IPA to analyse the data on women's coping strategies when dealing with TFA, and TA to analyse the health professionals' data on their perceptions of women's coping.

The subsequent chapters (chapters 4 to 7) outline the empirical work conducted in this research, each chapter covering an individual study. The starting point of this empirical work focuses on the exploration of women's coping strategies (see chapter 4).

Chapter 4 - Women's coping with pregnancy termination for fetal abnormality: An Interpretative Phenomenological Analysis of women's experiences

This chapter describes the research's first empirical study (Study 2a), which examines women's coping strategies when dealing with TFA, at the time of the procedure and afterwards. The chapter provides an overview of the methodology used in the study (discussed in more detail in chapter 3) and contains a detailed profile of the participants. It also presents the themes identified in the data, which are organised into two parts: the coping strategies used at the time of the termination procedure and those used afterwards. A discussion of the findings and an evaluation of the study's limitations are provided at the end of the chapter. The analysis reported in this chapter generated a research article (Lafarge, Mitchell, & Fox. [2013b] Women's experiences of coping with pregnancy termination for fetal abnormality), which has been published in the peer-reviewed journal Qualitative Health Research.

4.1 Introduction

The literature review and the meta-ethnography presented in chapters 1 (section 1.2.) and 2 have highlighted a dearth of research on the coping strategies used by women when undergoing TFA. This is despite evidence of a relationship between coping strategies and psychological adjustment (Carver & Connor-Smith, 2010; Lazarus & Folkman, 1984). Coping in health-related research has shown that 'avoidant' coping strategies (e.g. avoidance and behavioural disengagement) are generally associated with higher levels of distress (Cartwright et al., 2009; Duangdao & Roesch, 2008; Littleton et al., 2007; Moskowitz et al., 2009). By contrast, active coping and positive reframing have been linked to more positive psychological outcomes (Moskowitz et al., 2009). Research into bereavement has indicated similar patterns, with avoidant coping and low levels of cognitive restructuring linked to higher levels of distress and grief (Harper et al., 2014a; Schnider et al., 2007). Given the

paucity of research into coping in the context of TFA, it was deemed necessary to first explore this topic from a qualitative perspective. Therefore, the objective of this study was to investigate women's coping strategies when undergoing TFA. The study explored the coping strategies used by women at two different points in the TFA process, during the procedure and afterwards. These time points are different in nature. The procedure is a short-term medical intervention, which takes place in a clinical environment where women are cared for by a number of health professionals. By contrast, the aftermath of the procedure marks the beginning of a longer-term grieving process for women. Women generally have limited contact with health professionals during that period (see chapter 2, section 2.4.3). Thus, a secondary aim of this study was to ascertain whether women used different coping strategies at different time points.

4.2 Methods

4.2.1 Summary of the methodology

The methodological elements of this study have been described in chapter 3, section 3.3.1. Participants were women members of ARC. All were over 18 years old and had undergone TFA. Data were collected online using SurveyMonkey between April 2011 and July 2012. The qualitative interview schedule consisted of open ended questions about the process of coping with the termination, with specific attention paid to coping strategies during and after the termination. Demographic, obstetric and termination-related information were also collected. For more detail see chapter 3, sections 3.2.2.3 and 3.3.1.2.4. Ethical approval was obtained from the University of West London Ethics Committee. The scope of the study was clearly outlined to participants through the provision of an information sheet and informed consent was obtained for all. Issues relating to the sensitivity of the topic and the researcher's duality of roles have been discussed in chapter 3, section 3.2.3.

4.2.2 Participants' profile

In total, 27 women participated in the qualitative study. Of those, 19 had been recruited through the email network and eight through the online forum. Twenty six women also answered the quantitative element of the research (Study 2b, chapter 5). The woman who did not answer the quantitative element cited technical issues as a reason for not completing it.

Women were aged between 24 and 44 years old ($M = 34.1$ years old) and all were married or living with their partners. Of those who answered the ethnicity question (introduced after the fieldwork had started), all ($n = 8$) were White British. Seventeen had completed higher education. Pregnancies were terminated between 12 and 30 weeks of gestation ($M = 19$ weeks). For 13 participants, this was their first pregnancy. Two women had undergone three TFAs. For the majority of women ($n = 19$), the termination had occurred more than 6 months prior to study participation. In most cases ($n = 24$), the abnormality had been detected through a routine check. In 14 cases, the abnormality prognosis was considered to be incompatible with life. These included genetic conditions such as Edwards' syndrome (a form of trisomy) or a structural anomaly such as bilateral renal agenesis (the absence of kidneys). Twelve women considered the abnormality prognosis to be compatible with life, for example Down's syndrome or brain abnormalities. The majority of women ($n = 21$) underwent medical termination. The method of termination related to gestational age with all surgical terminations conducted before 18 weeks of gestation. Most women ($n = 18$) indicated that they would make the same decision again, seven were unsure and two stated that they would not make the same decision. Since the termination and at the time of interview, seven women had had a child, five were pregnant, 14 were hoping to be pregnant and one stated that she no longer wished to try for a baby. A profile of participants is displayed in Table 4.1. Names of participants were changed to protect their identity.

Table 4.1. Participants' profile

Name	Age	Time since TFA (months)	Gestational age (weeks)	Abnormality Prognosis	Method of termination	Number of termination	Number of pregnancy	Comfortable with decision	Reproductive history post-TFA
Anna	34	13-24	21	Compatible	Medical	1 st	1 st	Not sure	Had a child
Bonnie	36	7-12	22	Unsure	Medical	1 st	2 nd	Yes	Pregnant
Christine	41	7-12	13	Compatible	Medical	1 st	2 nd	Not sure	Want a child
Donna	31	13-24	20	Compatible	Medical	1 st	2 nd	Yes	Had a child
Ellie	25	13-24	24	Compatible	Medical	1 st	1 st	No	Had a child
Frances	31	7-12	23	Incompatible	Medical	1 st	1 st	Yes	Pregnant
Gemma	44	24+	17	Compatible	Medical	1 st	1 st	Not sure	Don't want a child
Holly	36	13-24	17	Incompatible	Surgical	1 st	1 st	Yes	Want a child
Isobel	35	7-12	12	Incompatible	Surgical	3 rd	4 th	Yes	Want a child
Justine	34	24+	14	Incompatible	Medical	1 st	4 th	Not sure	Had a child
Kerry	32	24+	14	Incompatible	Surgical	1 st	1 st	Yes	Pregnant
Lorna	40	7-12	15	Compatible	Medical	1 st	2 nd	Yes	Want a child
Megan	31	13-24	18	Incompatible	Medical	1 st	4 th	Yes	Had a child
Natalie	33	7-12	13	Incompatible	Surgical	3 rd	3 rd	Yes	Want a child

Table 4.1. Participants' profile (continued)

Name	Age	Time since TFA (months)	Gestational age (weeks)	Abnormality prognosis	Method of termination	Number of termination	Number of pregnancy	Comfortable with decision	Reproductive history post-TFA
Olivia	31	13-24	21	Compatible	Medical	1 st	2 nd	Not sure	Had a child
Penny	31	7-12	21	Incompatible	Medical	1 st	1 st	Yes	Want a child
Rose	38	13-24	23	Incompatible	Medical	1 st	1 st	Yes	Want a child
Sally	37	24+	24	Incompatible	Medical	1 st	1 st	Not sure	Had a child
Theresa		7-12	18	Compatible	Medical	1 st	4 th	Yes	Want a child
Ulrika	36	< 6	16	Compatible	Surgical	1 st	4 th	Yes	Want a child
Valentine	38	< 6	30	Compatible	Medical	1 st	1 st	Yes	Pregnant
Wendy	38	< 6	23	Incompatible	Medical	1 st	1 st	Yes	Want a child
Xara	34	< 6	20	Incompatible	Medical	1 st	1 st	Yes	Want a child
Yvonne	35	< 6	21	Compatible	Medical	1 st	2 nd	Yes	Want a child
Zoe	33	< 6	26	Compatible	Medical	1 st	3 rd	No	Want a child
Alison	24	< 6	14	Incompatible	Surgical	1 st	2 nd	Not sure	Want a child
Beatrice	28	< 6	13	Incompatible	Medical	1 st	1 st	Yes	Pregnant

4.2.3 Data analysis

4.2.3.1 Conducting IPA

Data were analysed using IPA. As outlined in chapter 3 sections 3.3.1.4.2 and 3.3.1.4.3, IPA is particularly suited to this type of exploratory research because it uncovers people's individual experience and the meanings they attribute to it (Smith et al., 2009). Thus, it is deeply rooted in individual narratives. In analysing the data using IPA, the researcher also seeks to provide an interpretation of these narratives (Larkin & Thompson, 2012). The data collected fulfilled a key IPA requirement in that the data were rich and insightful (see Smith et al., 2009 p.56).

Conducting IPA consists of identifying commonalities and differences about a given experience. The IPA process of analysis is iterative (Smith et al., 2009). The analysis is conducted on a case-by-case basis. As the analysis progresses, the researcher goes back to earlier texts to integrate them and develop the analysis further. Smith and colleagues (2009) suggested six steps in conducting IPA: 1) data familiarisation, 2) initial coding, 3) identifying themes, structuring the themes and establishing potential connections between them, 4) producing a summary table, 5) analysis of subsequent cases, and 6) identifying patterns across cases. In this analysis, data were formatted and line-numbered. The researcher read and reread the texts, and made notes about the concepts emerging, the text itself, its emotional content as well as the language used. From these notes, a number of themes were identified, which were then classified into categories or superordinate themes. Themes and superordinate themes were then compared across individual accounts. A framework was then created, which most accurately epitomised women's experiences of coping with TFA. One coding framework was devised for the coping processes used at the time of the procedure and one for the coping processes used afterwards. In accordance with IPA requirements, the aim of the analysis was to create a "whole" that would go beyond the sum of its parts to provide an interpretation of the experience (Smith et al., 2009). To enhance rigour and validity, randomly selected sections of text were independently co-coded by the researcher's second supervisor. The level of agreements between the researcher and

the second supervisor was high and resulted in no change being made to the coding frameworks.

4.2.3.2 Sample size in IPA studies

Twenty seven women participated in this study. This represents a large sample in IPA standards (Brocki & Wearden, 2006; Smith et al., 2009). IPA is generally used with small samples, although there is a degree of flexibility (Smith et al., 2009). Samples have been found to vary from a single case study to over 30 participants, with studies based on larger samples usually conducted through online technology (Brocki & Wearden, 2006). Smith (2011) indicated that 'large' samples are acceptable in IPA on the condition that the researcher provides quotations from more than one participant for each theme alongside an indication of how recurrent the themes are. Dickson, Knussen and Flowers (2007) have defined a theme to be recurrent in IPA if it is mentioned by at least half of the participants. These recommendations guided the analyses reported in this chapter.

A relatively large sample (27 participants) was deemed appropriate in this study for several reasons. Firstly, as data were collected online, the researcher did not have control over the number of participants who chose to respond to the study. Secondly, the researcher did not wish to limit the number of participants before getting a sense of the quality and richness of the data. Thirdly, interim results based on 19 participants suggested that there was still scope for some themes to be explored further. Finally, given that women had willingly given their time to answer questions on a particularly sensitive topic, the researcher felt that it was unethical to discard any accounts.

After 25 personal accounts, the data showed signs of saturation and thus, no further data were sought after the last of the 27 personal accounts was received. The concept of data saturation, whereby no new themes are identified in the data, is somewhat at odds with IPA (Brocki & Wearden, 2006). IPA's idiographic focus means that IPA does not aim to be exhaustive (Smith et al., 2009). In addition, given that the process of analysis is iterative, the potential for generating new themes is almost never-ending. Brocki and Wearden (2006)

suggested that an IPA analysis may be considered complete when it represents the idiosyncrasy of individual experiences in a coherent and meaningful way. Based on this definition, there was little value in collecting further data after 25 accounts as the analysis already provided a meaningful interpretation of what coping with TFA may involve for women.

4.3 Findings

The objective of the study was to investigate women's coping strategies when dealing with TFA. These were examined at two different time points in the TFA process, during the procedure and afterwards. The findings section is therefore organised in two parts: coping with the procedure and post termination coping.

4.3.1 Coping with the procedure

Five superordinate themes were identified in the data, which depicted the main coping strategies used by women when dealing with the termination procedure. These included: 'receiving/providing support,' 'acknowledging the baby,' 'problem solving,' 'dissociating oneself from the procedure,' and 'attributing meaning to the birth experience.' These superordinate themes also encompassed several themes. The coding framework for women's coping with the procedure is displayed in Table 4.2. The numbers next to the participants' pseudonyms refer to the line number in the data file.

Table 4.2. Coding table for women's coping strategies at the time of the procedure

Superordinate themes	Themes	Codes	Quotations
Receiving/ providing support	Receiving support	Support from partner	Anna: 28; Bonnie: 145; Donna: 382; Ellie: 466; Frances: 591; Gemma: 699, 701-3; Holly: 845-6; Isobel: 937; Keira: 1179-80; Laura: 1435; Megan: 1614; Natalie: 1727; Olivia: 1856; Penny: 2007; Rose: 2180; Sally: 2341; Theresa: 2507; Ulrika: 2637; Valentine: 2767-8; Wendy: 2878-9; Xara: 3025; Yvonne: 3136-7; Beatrice: 3478
		Support from family members	Christine: 250-1; Donna: 383-4; Ellie: 466; Rose: 2192-5; Wendy: 2878-9; Beatrice: 3475-9
		Support from health professionals	Bonnie: 145-8; Ellie: 468-9; Frances: 591-2; Justine: 1057-60; 1064-70; Megan: 1614-5; Rose: 2180-1; Wendy: 2884-5; Beatrice: 3488-90
		Religious support	Anna: 30-1; Gemma: 716-8; Laura: 1452-4; Wendy: 2888-90
	Providing support	Supporting partner Being strong for the baby	Gemma: 703-4; Natalie: 1730-1 Rose: 2181-4
Acknowledging the baby	Spending time with the baby	The baby is real	Theresa: 2528-30; Justine: 1071-3; Penny: 2033-4; Wendy: 2887-8
		Bonding with the baby	Donna: 362-3; Bonnie: 150-1; Gemma: 711-5; Theresa: 2507-10; Zoe: 3231-3
		Baby belongs to the family	Laura: 1443-4
		Seeing the baby's anomalies	Laura: 1444-6; Wendy: 2885
	Conferring an identity on the baby	Naming the baby	Laura: 1450-2; Donna: 362-3; Gemma: 718; Penny: 2032-40
		Photos	Anna: 31-2; Bonnie: 151; Gemma: 709-11; Laura: 1469; Ellie: 476-7; Holly: 863; Megan: 1622; Rose: 2202; Sally: 2353; Theresa: 2530; Penny: 2054
		Clothes/teddy	Anna: 32-3; Christine: 260; Ellie: 475; Laura: 1475
Saying goodbye	Funerals	Bonnie: 158-60; Laura: 1460-1; Ellie: 505-6; Olivia: 1869-72; Theresa: 2522-4; Penny: 2032-40	
	Having the baby blessed	Anna: 30-1	
	Teddy/photos with the baby	Anna: 33-5; Donna: 392; Penny: 2008-10	

Table 4.2. Coding table for women's coping strategies at the time of the procedure (continued)

Superordinate themes	Themes	Codes	Quotations
Problem solving	Preparation	Seeking factual information	Zoe: 3222-4; Laura: 1352-4; Yvonne: 3137-8; Wendy: 2881-3;
		Experiential knowledge	Yvonne: 3139, 3177-9; Gemma: 699-701; Laura: 1354, 1357-60, 1365-7; Rose: 2166; Isobel: 928-30; Rose: 2188-91
	Focusing on the task	Time to prepare	Beatrice: 3472-4
		Focusing on delivery Taking one step at a time	Valentine: 2768; Beatrice: 3474-5; Sally: 2346-7 Yvonne: 3135-6
Dissociating oneself from the procedure	Self-distraction	Watching TV	Christine: 250-2
		Reading newspapers/magazines	Isobel: 937-8; Rose: 2195
	Blocking the pain	Out of body experience	Natalie: 1734-5
		Going on autopilot/focusing on task Relying upon pain relief	Isobel: 941-3; Olivia: 1857-9; Anna: 29-30; Donna: 384-5; Keira: 1180-2; Megan: 1615-6; Yvonne: 3135
Attributing meaning to the birth experience	Attributing meaning to the birth experience	Pain as punishment	Anna: 28-9
		Cathartic pain	Beatrice: 3482-3
		Pain as a bonding process	Theresa: 2507-15
		Expectation of a dignified birth	Bonnie: 150; Justine: 1067-8
		Final act as a mother	Valentine: 2769

4.3.1.1 Superordinate theme 1: Receiving/giving support

'Support,' whether receiving or providing it, was one of the most commonly reported coping strategies used during the procedure.

Theme 1: Receiving support

Women unanimously identified their partner as their main source of support: "*I had my husband with me. I couldn't have gone through this whole experience without him there.*"

(Xara) Support was also derived from the presence, actual or virtual, of other family members. One participant mentioned her mother waiting in the corridor; another had her mother and mother-in-law in the delivery room. Another woman carried a picture of her 3-year-old son in the delivery room, which provided focus and strength.

Support from health professionals was also considered essential to women's experience. This involved health professionals listening to and addressing women's fears about the procedure, and providing physical and emotional comfort. One woman described: "*The consultant also held my hand tight . . . this warmth from the staff I will always remember.*" (Ellie) Professionals' support was generally available to women, which they were grateful for: "*The midwives were very kind overall and treated the baby with respect, which was helpful.*" (Wendy) However, in some cases, support was not provided, which generated distress. One woman was left on her own for most of the procedure, including the baby's delivery:

It was so undignified and to see that little body on my own with no support was terrible. I called for the midwife who laughed and made a joke about how quick I had been then she left the room, allowing me then to deliver the after birth myself, again alone. (Justine)

Another woman referred to the perceived lack of warmth from the hospital staff: "*I don't feel I had enough support from medical staff it was all very matter of fact.*" (Megan)

Religious support was important to some participants. Given the perceived moral dimension of TFA, some women expressed a fear of being judged: *“We went to the Hospital Chapel and met with a Chaplain. She was absolutely lovely. I was initially worried that she may judge us, but she didn’t. She was sympathetic and very understanding, which helped.”* (Laura)

Theme 2: Providing support

For some women, supporting their partner through the procedure and focusing on their partner’s fear and pain helped alleviate their own: *“It was all a shock, I think more so for my husband. I think part of me coped because I worried about him and was trying to make him feel better about me.”* (Natalie) One woman also reported supporting her baby through the procedure. Recalling the moment the feticide was performed, she described attempting to shield her baby from the stress of the procedure:

I tried to just breathe through it using deep calm breaths so as not to move too much. I didn’t want to cause the baby any distress and I wanted him to die peacefully. It was very important that I obeyed the doctor’s instruction to make it as quick and straightforward for them. (Rose)

4.3.1.2 Superordinate theme 2: Acknowledging the baby

‘Acknowledging the baby’ was another important coping strategy. It was regarded by most participants as a way to accept, and thus cope with the loss. It involved spending time with the baby, conferring an identity onto her/him and saying goodbye.

Theme 1: Spending time with the baby

Many of the women who had a medical termination chose to spend time with their baby after delivery, which they generally found comforting. It provided women with the opportunity to acknowledge and bond with their baby. Women were also able to check for any

resemblance to family members, thus recognising the baby as their own. They could also check their child's physical anomaly for themselves, which helped them come to terms with their decision: "*He did not have any legs and this made it easier to know that he definitely did have abnormalities that were apparent and that we had made the right decision.*" (Laura) For some women, spending time with their baby was the first step in accepting what had happened. For others, however, seeing the baby proved upsetting, because it confronted them with the reality of the baby's death. Other women felt disturbed at how their baby looked: "*She did look strange and that frightened me a bit, I was scared to look at her.*" (Wendy) A few participants opted against seeing their baby, mostly because they believed that the experience would cause additional long-term distress.

Theme 2: Conferring an identity on the baby

Acknowledging the baby also involved conferring an identity on him/her. This included taking photos and naming the baby: "*Naming my baby was important to me as I had carried her for 20 weeks and she had been a person who I had connected with.*" (Donna) The importance of a clear identity for the baby is illustrated by one woman's story. This woman was distraught to learn that the gender of her baby stipulated at the autopsy differed from the birth report. It left her confused about the identity of the baby she had lost:

We were devastated to realise that we'd had the funeral in the wrong name, the wrong name was on the coffin and we'd told our friends and family the wrong name which left us having to deal with some very difficult questions. This left us absolutely furious, even to the extent that it felt like the initial grieving process had been taken away from us or even at times that we'd lost two babies. (Penny)

Underlying this anger was the feeling of having betrayed and denied the baby a proper goodbye, another important factor in coping with the loss.

Theme 3: Saying goodbye

Women described leaving the delivery suite/hospital without their baby as heart-breaking: “*to go through labour and birth like a normal delivery, then having to leave the delivery suite without your baby is heart-breaking.*” (Olivia) Parting with the baby typically involved three actions: arranging the funeral (which most participants hoped would bring some sense of closure), having the baby blessed, and/or placing soft toys or photos of themselves in the coffin with the baby. A participant recalled: “*I held the toy throughout the labour and then left it with him. It was cremated with him. This helped and still brings me comfort to know he had a ‘friend’ to look after him on his journey.*” (Anna)

4.3.1.3 Superordinate theme 3: Problem solving

In some instances, women adopted a ‘problem solving’ approach to the termination. This involved preparing for the procedure and focusing on the task ahead.

Theme 1: Preparation

Preparation for the procedure consisted of seeking factual information about the baby’s condition and the termination procedure. This information was often sourced from the internet and, in some cases, from support group leaflets. Women also relied on experiential knowledge. One woman had already undergone two TFAs, and thus felt prepared for the third procedure: “*We knew the drill as it were.*” (Isobel) Others had contact with a group volunteer before the termination, and thus, were aware of what to expect during the procedure: “*I also called an ARC volunteer twice when we were considering ending the pregnancy and this was extremely helpful to talk to someone who had been through it some years before.*” (Yvonne) Some of the women who had not been through labour before sought information about the birth process from friends and relatives.

Information seeking could engender a sense of empowerment: “*I am the type of person who likes to have prior knowledge about things as it helps me deal with them when they happen; it prepares me.*” (Laura)

Theme 2: Focusing on the task

Concentrating on the task of delivering the baby was another way of focusing the mind, and thus coping with the procedure. One woman said that *“taking one thing at a time, or think[ing] of it in four hour blocks”* (Yvonne) helped her through the termination. Another reported: *“During labour I just focussed on what I needed to do.”* (Valentine)

4.3.1.4 Superordinate theme 4: Dissociating oneself from the procedure

‘Dissociating from the procedure’ involved self-distraction and blocking the pain.

Theme 1: Self-distraction

Most women described TFA and, in particular, the procedure to end the pregnancy, as the most difficult experience they ever had to go through. Therefore, some tried to distance themselves from what they considered an ordeal. This involved self-distraction, such as watching television, reading magazines and newspapers, or going for walks: *“I also took plenty of newspapers and magazines and books to try and keep my mind occupied with fluff.”* (Isobel);

Try and shut my brain to not think of what was going on. Took some photos in of my little boy to remind me of my lovely boy I had at home. Watch TV to give me something else to concentrate on. (Christine)

Theme 2: Blocking the pain

Attempts to block the pain were also reported, with some participants mentioning having an *“out of body experience”* (Natalie) or going on *“autopilot.”* (Isobel) The use of analgesia during labour was also widespread because it was seen as a way to disconnect with the procedure and avoid unnecessary suffering. One woman used analgesia despite being physically comfortable: *“Directly afterwards I was offered some pethidine for the pain, and although I wasn’t in pain I accepted it. It numbed my brain and helped me sleep when I got*

home.” (Keira) Underpinning the use of analgesia lay expectations and meaning attributed to the birth experience itself.

4.3.1.5 Superordinate theme 5: *Attributing meaning to the birth experience*

Among women who gave birth to their baby, the birth experience could be an influential factor in the way they coped with the termination, as the birth conveyed specific expectations and meanings. In some cases, attributing meaning to the birth constituted a resource women could draw upon to help them cope with their baby's delivery. Whereas some women tried to shield themselves from the physical pain of labour as much as possible, others considered the pain to be constitutive of the birth process and to convey a particular meaning. One woman described the pain as “*cathartic*.” (Beatrice) Another regarded the use of analgesia as a failure on her part and wanted to experience the pain to punish herself for the decision she had made: “*Initially I wanted to feel all the pain of my labour to make myself suffer, but then I couldn't cope so the midwife gave me diamorphine.*” (Anna) For one participant, giving birth without analgesia was her way to normalise the birth and bond with her child. She had used very little pain relief for the birth of her previous children and wanted to do the same for this baby:

I also wanted to approach my daughter's labour as similarly as possible to the labours of my previous children. I felt like I owed it to her. That at least I could bond with her to that extent, give her the same labour as I'd given my other two children . . . For me it was very important. There maybe wasn't a baby to “protect” as such, but there was still a baby to bond and connect with for as long as possible. I needed to be with her throughout, and feel her. (Theresa)

Finally, some women mentioned their wish to give birth with dignity, which implied the provision of compassionate care. Although this was in most cases provided, there were instances where compassionate care was not provided: “*I had amazing pain and called for the midwife. She told me to get used to it as I'd be having them all day!*” (Justine)

4.3.2 Post termination coping

Four superordinate themes were identified in the data, which depicted the coping strategies women most relied upon to deal with the aftermath of the termination. These included: 'remembering the baby,' 'receiving/providing emotional support,' 'avoidance' and 'looking to the future.' The superordinate themes comprised several themes. The coding framework for post termination coping is displayed in Table 4.3.

4.3.2.1 Superordinate theme 1: Remembering the baby

'Remembering the baby' was a key element in post termination coping and was commonly reported by women. It involved acknowledging the baby and the use of rituals and token acts.

Theme 1: Acknowledging the baby

This strategy involved talking about the baby to partners, friends, and family, as well as sharing stories with other support group members, which most found soothing. Having a remembrance service also enabled women to acknowledge the baby and provided some closure: "*The funeral provided closure for us all, also knowing he was buried really helped.*" (Ellie) A few women chose to read poems at the service, whilst others played meaningful pieces of music. For some, however, the service was a painful experience, emphasizing the unnatural order in which a parent loses a child:

People often say that a funeral is a good way to gain closure - I however felt on the day of her funeral that I was losing her all over again, it's just not natural for a mum to attend the funeral of one of her children. (Olivia)

Table 4.3. Coding table for women's coping strategies after the procedure

Superordinate themes	Themes	Codes	Quotations		
Remembering the baby	Acknowledging the baby	Talking about the baby	Ellie: 479-80; Gemma: 736-8; Keira: 1192-3; Wendy: 2908-9; Yvonne: 3147		
		Service for the baby	Bonnie: 158-60; Ellie: 505; Laura: 1461-2; Olivia: 1869-70; Valentine: 2776; Xara: 3040-2; Yvonne: 3145-6		
		Giving the baby a social existence	Laura: 1424-5; Bonnie: 158-9; Penny: 2020-2; Justine: 1035-6		
	Use of rituals and token acts	Visiting places of cremation/burial	Gemma: 727-8; Xara: 3043; Zoe: 3235-6		
		Memory box	Anna: 41; Donna: 392-4; Ellie: 476; Gemma: 724, 780-2; Laura: 1470-1; Rose 2208-10; Sally 2356-8; Theresa 2521; Xara: 3043; Yvonne: 3147; Zoe: 3230-1; Beatrice: 3519-20		
		Photos	Bonnie: 157; Frances: 598; Laura: 1469; Megan: 1622; Ellie: 484-5; Penny: 2054; Zoe: 3231; Alison: 3329		
		Tattoos	Gemma: 729-31; Megan: 1622-3		
		Planting a tree	Bonnie: 167-9; Donna: 396-7; Keira: 1189; Ulrika: 2645-6		
		Receiving/providing support	Receiving support	Support from partner	Christine: 291-3; Sally: 2413; Theresa: 2559; Valentine: 2759; Xara: 3017
				Support from friends, family, colleagues	Frances: 601-2; Ellie: 500-1; Bonnie: 193-5; Isobel: 983-5; Laura: 1549-50; Penny: 2103-6; Alison: 3356; Beatrice: 3529-31
Religious support	Wendy: 2909-11; Yvonne: 3145-7				
Expectations of support	Bonnie: 164-7; Laura: 1467-8				
Support from health professionals	Bonnie: 147-9, 166-7; Laura: 1467-8				
Counselling	Anna: 42-3; Christine: 263-4, Keira: 1193, 1232; Laura: 1478-82; Sally: 2386-8; Yvonne: 3147				
Other forms of support	Olivia: 1892-5; Rose: 2250-5				
Receiving as well as providing support	Support groups – ARC	Christine: 291-3; Gemma: 739-41, 774-5; Justine: 1085-7; Keira: 1192; Laura: 1527-32, 1555; Bonnie: 178-80; Anna: 74-6; Donna: 422-3; Olivia: 1905-6; Isobel: 987-9; Ulrika: 2660-1, 2674-5; Beatrice: 3502-4; Penny: 2061-3. Theresa: 2553-4; Sally: 2373-4			
	Support groups - Sands	Frances: 601; Laura: 1555; Megan: 1645-7; Penny: 2069-71; Theresa: 2554-6; Ulrika: 2663-5			

Table 4.3. Coding table for women's coping strategies after the procedure (continued)

Superordinate themes	Themes	Codes	Quotations
Avoidance	Self-distraction	Going away	Rose: 2172-4; Christine: 259-60; Frances: 602-4
		Decorating the house/moving	Donna: 394; Keira: 1188; Valentine: 2776-7
		Keeping busy	Holly: 864-6; Isobel: 949; Natalie: 1750; Olivia: 1867-9; Keira: 1208-9; Frances: 618-9; Ulrika: 2658-9; Xara:3038-9; Yvonne: 3145; Alison: 3325; Keira: 1208-9
		Going back to work quickly	Holly: 833-4; Isobel: 949-50; Justine: 1082-3; Natalie: 1749-50
		Taking time off work	Bonnie: 160-1; Christine: 258; Laura: 1484-7;
	Blocking the emotional pain	Looking after existing children	Christine: 989; Donna: 1001; Megan: 1624-5; Olivia: 1867-9; Yvonne: 3145
		Try not to think about the baby	Olivia: 1873-4
		Thinking practically not emotionally	Isobel: 952-5; Natalie: 1743-4
		Drinking alcohol	Keira: 1193; Natalie: 1750
		Avoiding pregnant women/babies	Christine: 226-8; Frances: 582-3; Keira: 1236-8; Penny: 1995-2000
Looking to the future	Regaining a sense of normality	Going back to work	Penny: 2022-3; Frances: 617-8; Valentine: 2777-8; Beatrice: 3498-9
		Going back into a routine	Beatrice: 3344; Olivia: 1867-9
	Reaching a sense of closure	Long, uneven process of healing	Ellie: 448; Holly: 864; Olivia: 1872-3
		Important milestones: funeral, post mortem, due date, 1st birthday	Bonnie: 163-4; Frances: 598-600; Ellie: 491-3, 535-7; Donna: 413-4; Holly: 881-3; Alison: 3338-9; Beatrice: 3507-9; Gemma: 756-7; Ulrika: 2696; Ellie: 505-6
		Letting go of the baby	Gemma: 728; Laura: 1464-7; Theresa: 2524-6; Olivia: 1878-81; Alison: 3338-9
	Another pregnancy	Preparing for another pregnancy	Justine: 1046-9; Anna: 43-5; Beatrice: 3513-5
		Bittersweet experience	Bonnie: 139-40; Justine: 1050-1; Keira: 1166-70; Beatrice: 3516-8
	Looking for positives	Positives of the decision made	Bonnie: 103-7; Donna: 343-6; Laura: 1360-3
		Putting the experience to good use	Bonnie: 161-2,168; Laura: 1496-8; Sally: 2358, 2373-4; Justine: 1120-1
			Positive personal growth

Holding a service was, nevertheless, a way to give the baby social recognition. This was particularly important given that many women felt their loss was not fully sanctioned by society. Many reported feeling isolated and misunderstood in their grief: *“Nobody can understand the torture unless they have experienced it themselves as I don’t think it can be likened to anything else.”* (Justine)

Theme 2: Rituals and token acts

The use of rituals and token acts was widespread. Visiting a place of remembrance was common, and most women kept a memory box. In some cases, the memory box was provided by the hospital, in others it was sourced by the parents. One woman recalled her partner building the box over a period of time, almost mirroring his mourning process: *“My partner built a little box to put little mementos into. It took him many months to complete it as I think it was his time to think about the son he had lost.”* (Rose)

The memory box usually contained copies of the scans of the baby, photos of the baby, letters of condolence, poems, the baby’s hand and foot prints, toys, clothes, and other symbolic objects. Women reported initially looking at the box on a daily basis, but this need tended to lessen in time. One woman recalled the location of the box being a source of conflict with her partner, a possible reflection of grieving differences between them:

More recently he has been happier to talk about it; though he would prefer that her memory box was tucked away (it is on top of the unit in the living room and not obvious). But for a long time, he got cross. (Gemma)

Some women carried a photo album in their bag. Others displayed the baby’s photos next to photos of their other children. Other token acts included getting a tattoo or planting a tree - a permanent and ever-growing feature in the women’s lives: *“We planted an apple tree in our garden . . . this is [her] tree and she will always be part of our family.”* (Donna)

4.3.2.2 Superordinate theme 2: Receiving/providing emotional support

The second superordinate theme focused on receiving as well as providing support.

Theme 1: Receiving support

The majority of participants described the support received after the termination as essential to the way they coped. This support took many forms. Support from the woman's partner was essential and, in most cases, this support was available post termination. However, the nature of their partner's grieving process was often reported to differ significantly from the women's: *"My partner is very supportive, although he handles it differently to me - he just aims to keep as busy as possible!"* (Sally) Women may need more time to process the loss, and may be more willing to discuss it. In some cases, the perceived difference in grieving process could cause tensions in the relationship: *"The support from my partner was very good during the termination and for about 6 weeks afterwards. However, from that point our coping mechanisms have been very different and have put a massive strain on our relationship."* (Christine)

Emotional support was also sourced from friends and relatives, but its quality varied greatly, and most women indicated that it faded over time. A lack of support, particularly in the early stage, engendered much suffering:

I was horrified to spend a weekend with some of [my] closest friends, the week of the funeral, and not once did they ask about the funeral or how we were . . . remember feeling like a leper after that weekend and that people avoided talking to me. (Penny)

In rare instances, women chose to withdraw from their social network, particularly when friends went on to have successful pregnancies.

Support from health professionals was also important but, in many cases, this was limited post termination. Often, it was the interaction women had with health professionals during the procedure that had a lasting influence on the way they coped with the event.

Instances in which clinical care went beyond the traditional doctor–patient relationship were received with much gratitude and could have a soothing effect long after the termination:

I think of his words. He very kindly and reassuringly said that he would make the same decision in our position, something that he confessed he shouldn't say but something we found so helpful since he was the person who had the skill to "fix the problem." (Bonnie)

Support from health professionals post termination extended to other forms of care and communication, but in some cases, this support was deficient. One woman's district nurse had not read the paperwork prior to visiting her. The woman was particularly upset when the nurse came to obtain a blood sample from the baby: *"I had to tell her the baby had died. She hadn't read the notes properly! I was furious and very distressed."* (Rose) The language used to refer to the baby, particularly in post mortem reports, also influenced women's experiences:

All of her paperwork stated she was a "nonviable fetus." I felt she deserved to be recognised . . . because to us, she very much existed. P.S. - something that really doesn't help, is paperwork saying "non-viable fetus." Very upsetting to read. (Olivia)

Professional support was also dispensed in the form of counselling. Most women who received counselling found it helpful: *"Counselling was very helpful and I would recommend it to anyone in my position."* (Keira) However, the timing of the intervention was important. One participant reported receiving counselling too early in the process: *"The only thing that I found unhelpful was talking to a counsellor at the hospital immediately after the termination. I was too raw, and too numb, and felt I was being invited to think about things that I wasn't ready to think about."* (Sally)

Theme 2: Providing as well as receiving support

Support groups were another source of support, which is unsurprising given that the sample was drawn from ARC. Support groups form a distinctive category in that they involve a reciprocal support relationship based on a common experience. Most women considered the group email network/forum to be one of the most helpful elements in the coping process:

[It] has been the most amazing thing though as everyone really understands more than anyone else ever could. I still read the posts every day and have done some fund-raising for them. I would never, ever have done so well without their support.

(Gemma)

Being able to reciprocate, getting support as well as offering support, was of great benefit to the women:

Before the first anniversary, my husband and I attended an ARC meeting . . . It was so helpful to meet these people who also had to make a heart-breaking decision to end a pregnancy. We were able to support each other and give each other advice.

(Laura)

Being able to give 'something back' was also helpful to some women: "*I also volunteered as a parent contact for ARC sometime after the termination, and again it was good to feel that I was helping others.*" (Sally)

Reasons for using the group email network/online forum varied, but the underlying drive was to derive a sense of solidarity. For some women, the forum became the only opportunity to share their story: "*I feel completely alone in my grief as no one seems to understand just how profound it is. This includes my partner.*" (Christine) However, several participants reported having ambivalent feelings about using the forum. One woman saw the forum as a lifeline during dark days, but actively avoided it on good days to prevent being "*brought back to the darkness.*" (Ulrika) Another also expressed mixed feelings about the forum because some comments led her to believe that her way of grieving was inadequate:

Sometimes I found reading other people's accounts on the forum unhelpful as I felt guilty for not feeling as emotional or terrible as they did, but in time I was able to feel that this was positive, that I was coping and mentally strong. (Bonnie)

Meeting with other parents in a similar situation was another coping resource, and it provided women with a 'sense check' regarding where they were in the healing process: *"It made me realise how far I had moved on as some of the other members' loss and pain were still so raw."* (Laura) A few participants also used a support group focused specifically on stillbirth and neonatal deaths; some found it helpful, but others reported feeling uncomfortable given that this particular group only dealt with naturally occurring or accidental deaths rather than terminations: *"[Group] have also been good, although I feel a bit nervous at their meetings as I feel uncomfortable telling my story in front of people who have had stillbirths."* (Theresa)

4.3.2.3 Superordinate theme 3: Avoidance

'Avoidance' constituted another post termination coping strategy, although a less commonly used one. It comprised self-distraction and blocking the emotional pain.

Theme 1: Self-distraction

Avoidance usually involved self-distraction, such as going away after the termination or on the baby's due date, decorating, or moving house. Keeping busy was seen as an antidote to pain:

When it was most painful I kept myself busy so that I [made] an effort to put it to the back of my mind and made sure I was tired each evening so that I could get some sleep at night. (Holly)

Similarly, some women were eager to return to work soon after the termination. Although women reported that this initially helped, they also recognised that this strategy

might have pushed emotions aside and hampered the grieving process: *“Keeping busy and going back to work might have helped initially, but I think they stored up the emotions for later.”* (Keira) For some participants, concentrating on other children helped alleviate the pain by channelling their energy and deriving meaning: *“I kept myself busy with my other kids. I went into overdrive I think; almost like I had to prove my worth as a mum [mother].”* (Megan)

Theme 2: Blocking the emotional pain

Avoidance also meant actively trying to block the pain, which only a few participants mentioned. This strategy implied avoiding thinking about the baby and trying to rationalise the loss by framing it in a practical rather than an emotional way: *“I have never allowed myself to think as if I was having a baby. I’ve always thought it too good to be true so I have just not imagined a baby at the end. I think this has really helped.”* (Natalie) A minority of participants also recalled drinking heavily initially, in an attempt to block the pain. Avoidance could also extend to avoiding pregnant women or women with young babies, which some women admitted to: *“I avoid situations around pregnant women and little babies.”* (Christine)

4.3.2.4 Superordinate theme 4: Looking to the future

Most women reported that ‘looking to the future’ helped them cope with their loss. This involved regaining a sense of normality, getting closure, focusing on another pregnancy and looking for positives.

Theme 1: Regaining a sense of normality

One of the first steps in the coping process was to regain a sense of normality. This involved getting back into a routine, going back to work, and trying to function as normally as possible: *“I went back to work four weeks after the termination. I thought getting back into a routine would help the grieving process.”* (Beatrice);

I was always busy afterwards - we have a three year old (who was one and half at the time) - having her meant that time didn't really stand still, and although I cried lots, [I] still have to function with everyday things. (Olivia)

Theme 2: Reaching a sense of closure

Looking to the future was also linked to reaching closure. All women reported the process of healing as being uneven, similar to a roller-coaster, and lengthy. This process was usually punctuated by important milestones: *"As closure was provided through the funeral, post mortem, due date passing, the first birthday, now it is time to move on with our lives."* (Ellie)

The baby's funeral was usually the first milestone in the process, and generally provided some closure with the physical side of the loss, the loss of the 'actual' baby. The post mortem constituted a second milestone for those who requested it. Participants found the post mortem results helpful in reaching some closure on the decision they had made: *"The post mortem report also helped as it confirmed the diagnosis and put closure to that irrational fear that we might have made the wrong decision."* (Frances) The baby's due date was perhaps the most important milestone. It was often an anxious time because it directly confronted women with the reality of the loss: *"I will be mourning the loss of [baby] all over again."* (Ulrika) Many felt unable to 'let go' and 'move on' before the due date: *"I think once our baby's due date has gone and past [date] I may be able to move on more."* (Alison) The due date appeared to provide some closure on the pregnancy, the 'virtual' baby, and the hopes the pregnancy had brought.

The baby's first birthday was another significant milestone. It signalled the beginning of a new type of mourning process, which up to that point consisted of getting from one milestone to the other, each milestone bringing closure to some aspects of the loss. After the first birthday, the focus moved from grieving for the lost pregnancy, dream, and baby to a long-term grieving for the child. For one woman, birthdays were important and presented an opportunity to honour her daughter's memory: *"I celebrate [baby's] birthdays with cake, lantern, a card, and I often receive cards from lovely people who remember."* (Gemma)

Theme 3: Focusing on another pregnancy

Focusing on another pregnancy was another way of looking to the future and dealing with the loss: “*What helped me focus was that I desperately wanted a sibling for our daughter and so decided to try one last time for a baby.*” (Justine) This focus could, in some instances, be all-consuming and bittersweet. A new pregnancy was usually a source of worry, yet failure to become pregnant often led to feelings of despair:

The only time when I felt like I was unable to cope again was when it came to be nearly a year and half after the termination and I was still not pregnant. I felt that only having another baby would heal the wound which I still have, and a seeming inability to conceive again was almost like a punishment. (Keira)

Women who became pregnant stressed that their new baby was not a replacement for the baby they had lost.

Theme 4: Looking for positives

Finally, looking for positives in their experiences also contributed to women’s coping. Although women described the decision to end their pregnancy as the hardest they ever made, most were at peace with their decision. Some drew comfort from the fact that their baby’s condition was detected early enough to enable them to make a decision; for some, terminating the pregnancy was the only parental decision they could make:

I understood that as a mother, there are times when you have to make decisions for your children, on their behalf if it relates to safety, etc. Although this decision was a bit extreme, I felt that as a mother, I was making a decision to take away my child’s pain and it was for reasons out of love. (Laura)

Looking for positives also involved putting the experience to good use. Some participants donated money to a child sponsorship fund, some ran marathons to raise money

for charities specialising in their baby's condition, and others found solace in helping other women. For some participants, the termination also instigated personal positive growth, with some women reporting feeling stronger and more confident as a result:

This feeling of doing things in her memory and of using her memory to instigate positive things has also been hugely important in terms of ways of coping . . . I've been filled with an urge to do things that I hadn't been confident to do otherwise beforehand. It has made me realise the fragility of life, and it has made me want to treasure each day more, risk things more in order to live the life I really want to live.
(Theresa)

For others, the termination triggered a desire to explore new career paths and address unresolved issues, thus having a positive impact: "*Indirectly, through the counselling we sought after the termination, I have been able to deal with other personal issues and have become a much more forward looking person.*" (Keira)

4.4 Discussion

This study sought to explore women's coping strategies when undergoing TFA and assess whether these differ during and after the termination procedure. It provides novel insights into these coping processes, which had not been empirically researched in the context of TFA. The findings indicate that coping with the TFA procedure involved five processes: 'receiving and providing support,' 'acknowledging the baby,' 'problem solving,' 'dissociating oneself from the procedure,' and 'attributing meaning to the birth experience.' Regarding post termination coping, four processes were identified: 'remembering the baby,' 'receiving and providing emotional support,' 'avoidance' and 'looking to the future.' These findings suggest that women's coping strategies are similar across the two time periods. This possibly underlines the role of dispositional characteristics in the way women cope. Throughout the TFA process (during and after the procedure), four main coping structures

were identified as particularly relevant to women's experience: 'support,' 'acceptance,' 'avoidance,' and 'meaning attribution.' The coping strategy 'problem solving' was also important in coping with the procedure, whilst 'looking to the future' was more relevant to post termination coping. These findings are in line with some of the literature on coping, in particular with the review by Skinner et al. (2003) which identified five core categories of coping with a stressor: 'problem solving,' 'support seeking,' 'avoidance,' 'distraction,' and 'positive cognitive restructuring.' The four main coping structures identified in this study are discussed in the next sections alongside the study's limitations. The implications of the study in terms of theory, practice and future research are discussed in chapter 8.

4.4.1 Support

'Support' was the first essential coping structure present throughout the TFA process. This is consistent with group membership of a support organisation. The concept of support, in this study, involved two activities: receiving it and providing it. 'Receiving support' was considered crucial to women. Receiving support has been shown to contribute to general wellbeing (Lakey & Orehek, 2011). It is particularly important in the context of TFA because a lack of support has been associated with mood disturbances in women (Green & Statham, 2007). In this study, 'partner support' was critical to women because, in many cases, they only fully shared their experience with their partners. The reliance on the partner as a source of support was compounded by the fact that, in some instances, women did not feel that their loss was fully recognised by society. This corroborates existing findings suggesting that women who undergo TFA may feel alienated and stigmatised in their loss (Bryar, 1997; McCoyd, 2010a; Rillstone & Hutchinson, 2001). It is also consistent with the findings of the meta-ethnography (chapter 2). It is possible that the fact that, in some instances, TFA is conceptualised within the abortion paradigm contributes to women's sense of isolation (McCoyd, 2010a; see also chapter 2, section 2.4.3).

'Support from health professionals' was also considered essential to women's coping. This included providing compassionate and emotional support. Most women, in this

study, found the care in hospital satisfactory, which contributed to alleviating their distress. However, the aftercare was often seen as deficient and many women reported feeling unsupported post termination. Whilst there is limited evidence on this area of research, the recent publication of two studies on the experience of care support the findings of this study (Asplin et al., 2014; Fisher & Lafarge, 2015).

The women in this study were, to various degrees, active within the ARC's online forum and email network, and most considered their engagement with the group as an important coping strategy. This, in itself, may reflect their views of a limited aftercare. The reliance on 'support groups' as a coping strategy has also been observed in the context of other types of perinatal loss (Cacciatore, Schnebly, & Froen, 2009; Capitulo, 2004; Van & Meleis, 2003). The use of support groups as a coping strategy also underlines the importance of the reciprocal nature of support. The positive impact of being in a position to provide support to others has been reported in studies across various fields of psychology (Knoll, Kienle, Bauer, Pfüller, & Luszczynska, 2007; Warner, Schüz, Wurm, Ziegelmann, & Tesch-Römer, 2010). However, the study findings provide the first empirical evidence of such a relationship in the context of TFA. In this study, women found it helpful to support others and 'give something back' to the community (e.g. fund-raising for charities; see section 4.3.2.4). Comments provided by some participants at the end of the study corroborate this view. Supporting others seemed to enable women to transcend their pain, put it to good use, and frame it in a positive way.

4.4.2 Acceptance

'Acceptance' was another major coping structure used by women during and after the termination. It involved acknowledging and remembering the baby, and engaging in rituals and token acts, which many women found soothing. By contrast, trying not to think of the baby, blocking the pain, or busying themselves often resulted in short-term gain but long-term loss.

The findings also show that women who opted to see their baby after delivery found this comforting, although a minority found it disturbing. Whether or not to see or hold the baby in the context of perinatal loss has generated clinical discussions (Bennett, et al., 2005; Geerinck-Vercammen & Kanhai, 2003; Hughes, Turton, Hopper, & Evans, 2002; Kersting & Wagner, 2012; Sloan, Kirsh, & Mowbray, 2008). Until the mid-2000s, in the United Kingdom, parents were routinely encouraged to spend time with their baby on the assumption that doing so facilitated the grieving process (Bennett et al., 2005; Geerinck-Vercammen & Kanhai, 2003). However, a study by Hughes et al. (2002) on psychological adjustment to stillbirth found that women who choose to see their baby adjust to their loss less easily than those who choose not to. Seeing the fetus' physical anomalies has also been described as potentially traumatic for some parents (Kersting & Wagner, 2012). A literature review on the potential benefits of viewing the fetus following TFA concluded that there was no empirical evidence to support this practice, and that parents should decide for themselves whether viewing the fetus would be appropriate for them (Sloan et al., 2008). Similarly, Green and Statham (2007) suggested that women who do not seek care or engage in any form of ritual following TFA adjust better psychologically than those who do. Based on this evidence, NICE (2007, 2014) issued guidelines about care in perinatal loss, recommending not to routinely encourage parents to spend time with their baby, and leave the decision to the parents. By highlighting the range of emotions associated with spending time with the baby, the study findings support this clinical recommendation.

4.4.3 Avoidance

The third coping structure common to the procedure and its aftermath was 'avoidance.' This strategy was less commonly reported by participants than 'support' and 'acceptance.' It included strategies such as 'self-distraction,' 'dissociation,' and 'avoidance,' with the latter more prominent in post termination coping. It was the least homogeneous structure, with some elements experienced as helpful and others as unhelpful. Traditionally, 'self-distraction' and 'dissociation' have been linked to avoidant coping styles. Thus, they are

considered maladaptive strategies, primarily because they are difficult to sustain (Aldao & Nolen-Hoeksema, 2012; Folkman & Lazarus, 1988; Schnider et al., 2007). Nevertheless, in this study, both elements served an adaptive function, particularly during the procedure, by protecting women from further suffering. By contrast, most coping components of the avoidance theme in post termination coping involved various degrees of active denial and disengagement, which could be considered as maladaptive. These strategies are of limited use in the long term because they do not address the event and its impact upon an individual's life (Carver & Connor-Smith, 2010).

4.4.4 Meaning attribution

The fourth common coping structure was 'meaning attribution.' It covered 'attributing meaning to the birth experience,' but also 'experiencing growth' as a result of TFA. This coping structure is echoed in the concept of posttraumatic growth. As outlined in chapter 1 (section 1.3.3), research has shown that people can experience positive growth following a traumatic event, for example perinatal loss (Black & Wright, 2012; Bonanno, 2004). Research has established that the action of attributing meaning might lead to positive changes in people's lives (Helgeson et al., 2006; Tedeschi & Calhoun, 2004). Therefore, positive growth may be seen as a central part of the coping process rather than as a positive, and somewhat unexpected outcome of a difficult experience. This issue is discussed further in chapter 8 (section 8.4.1.3). This study shows that through the process of TFA, some women discovered strengths they were unaware of having; other women developed a drive to take control of their lives and fulfil their potential. These findings are consistent with those of the meta-ethnographic review (chapter 2, section 2.4.2).

4.4.5 Other coping strategies

The findings also uncovered several coping strategies specific to either the procedure or its aftermath. The first one, 'problem solving,' was exclusively used at the time of the procedure. Women who used this strategy usually sought information prior to the procedure in an

attempt to prepare themselves. Feeling prepared seemed to enable women to regain control over the situation. It is possible that it also contributed to lowering their anxiety levels. This would support existing evidence of the benefit of preoperative information on anxiety levels prior to surgery (McDonald, Hetrick, & Green, 2004) and on recovery (Shulldham, 1999). To make the procedure more manageable, some women also chose to focus on the task, rather than think about its meaning. Both strategies ('information seeking,' and 'focusing on the task') acted as buffers against the stress and pain of the procedure.

The second coping strategy, 'looking to the future,' predominantly belonged to post termination coping, although 'meaning attribution' was also relevant to the birth experience. This strategy involved a return to normality and/or focusing on another pregnancy, and reflected a drive to restore equilibrium and move forward. Focusing on a new pregnancy was an important coping strategy, but engendered ambivalent feelings. Women often experienced anxiety when planning or during their new pregnancy, which supports existing evidence about TFA (Rillstone & Hutchinson, 2001) and other perinatal losses (Blackmore, et al., 2011; Côté-Arsenault 2007). This finding raises a question about the recommended time between the termination and a subsequent pregnancy. Findings from a study by Hughes, Turton, and Evans (1999) on psychological adjustment to stillbirth suggest that women should preferably wait 12 months following their loss to conceive again. This has implications not only for the mother but also for the baby, because anxiety and distress during pregnancy can negatively affect pregnancy outcomes (e.g. pre-term birth [Hobel, Goldstein, & Barrett, 2008]), the wellbeing and development of the baby (Brouwers, van Baar, & Pop, 2001; Laplante, Brunet, Schmitz, Ciampi, & King, 2008). Such information applied in the context of TFA is lacking, and hence may need to be explored further.

4.4.6 Adaptive versus maladaptive coping strategies

This study revealed that women used coping strategies that are largely considered to be adaptive during and after the termination. According to the coping literature (Cartwright et al., 2009; Carver, 1997; Carver & Connor-Smith, 2010; Folkman & Lazarus, 1988; Moskowitz et

al., 2009), 'support,' whether instrumental (e.g. aspects of care being provided by health professionals) or emotional (e.g. derived from partner and/or friends), is an adaptive coping strategy. Similarly, acknowledging/remembering the baby, which is linked to the concept of 'acceptance,' and 'meaning attribution', which is related to positive reframing and growth, can also be considered adaptive (Aldao & Nolen-Hoeksema, 2012; Carver, 1997; Carver & Connor-Smith, 2010; Folkman & Lazarus, 1988). When strategies traditionally labelled maladaptive were used ('self-distraction,' 'dissociation,' and 'avoidance'), they either served an adaptive purpose of short-term protection and/or were used by only a few participants.

Whether a strategy is adaptive or not is subjective. Carver (1997) advised against classifying coping strategies into discrete categories, such as 'problem-focused' or 'emotional active/avoidant' coping. Instead, Carver recommended examining each aspect of coping independently. Similarly, it may be unhelpful to use classifications such as adaptive or maladaptive. Coping with a traumatic event is a personal process, determined by individual (e.g., personality, personal history, attitudes, and beliefs) and situational factors (e.g., type of stressor, timing of event; [Carver & Connor-Smith, 2010; Lazarus & Folkman, 1984]). Consequently, what is adaptive for some might not be so for others.

4.4.7 Limitations of the study

This study has several limitations. First, the sample was limited to women who were, to various degrees, active members of a support group. As indicated in section 3.2.1.2, the use of online groups can lead to personal empowerment, and act as a buffer against distress (Barak et al., 2008) but it can also lead to rumination (e.g. Malik & Coulson, 2008). Therefore, further research with women who are not using a support group would be beneficial as way of comparison. It is also likely that being members of a support organisation, participants were more likely to rely on 'support' as a coping strategy and regard their membership as a coping strategy in itself. In addition, as with other studies on TFA (Korenromp et al., 2009; McCoyd, 2007), the sample in this study predominantly comprised well-educated participants. It is possible that women who are less articulate might

find it more difficult to voice their feelings, which might influence the way they cope. Thus, widening the demographic profile of participants would be beneficial.

The fact that some accounts may have been subject to social desirability bias (van de Mortel, 2008) cannot be discarded, although this risk is minimised by the use of an asynchronous online methodology (see chapter 3, section 3.3.1.2). Nevertheless, some women may have underreported the use of maladaptive coping strategies. Similarly, some women may have felt under pressure to report their coping experience in a way they believed matches society's stereotypes of motherhood. Comments from one participant (Bonnie, p.166) suggest that some women may feel inadequate if they are not overwhelmed by sadness. Hochschild (1983) suggested that society is governed by "feeling rules," which are sets of beliefs about how people think they ought to feel. Feeling rules may also apply to TFA (McCoyd, 2009b) and influence the way coping processes are reported.

Finally, the retrospective nature of the study raised the possibility of *post hoc* rationalisation. Some women may have post rationalised their coping processes in light of the decision they made. Research in the field of abortion, antenatal screening, and prenatal sex identification has identified cognitive dissonance as a relevant concept to these life-events (Burke, 1992; Sandelowski & Barroso, 2005). Cognitive dissonance occurs when there is an uncomfortable conflict between ideas and feelings that are held simultaneously (Festinger, Riecken, & Schachter, 1956). The underlying assumption is that individuals are naturally driven to reduce this dissonance by either changing their attitudes, or rationalizing and justifying their actions. The concept of cognitive dissonance is pertinent to TFA (H. Statham, personal communication, July 4, 2011) given that the pregnancy is, in most cases, wanted. In some instances, the decision to terminate strongly conflicts with personal beliefs. Thus, when recalling their termination, some women may try to justify their decision by rationalising it, and the coping strategies they used. Ideally, further research would gather prospective data, from the time a fetal abnormality is detected to after the termination.

4.5 Conclusions and implications for the thesis

This qualitative study provides novel insights into women's coping strategies when dealing with TFA. It indicates that coping with TFA can be categorised into four main structures: 'support,' 'acceptance,' 'avoidance,' and 'meaning attribution.' It also shows that these coping structures are relevant during and after the procedure. The findings also reveal that women mostly used coping strategies generally considered as adaptive to deal with TFA, and that they reported inadequacies in aftercare, which challenged their resources.

These findings have three main implications for the development of the research reported in this thesis. Firstly, whilst they contribute to our understanding of what strategies women use when dealing with TFA, how these strategies relate to women's psychological adjustment remains to be ascertained. Given the role of 'adaptive' strategies in promoting psychological adjustment (Carver, 1997; Lazarus & Folkman, 1984) and the fact that women, in this study, mainly used such strategies, this group of women should, in theory, display relatively healthy levels of psychological wellbeing. The findings also suggest that the categorisation between 'adaptive' and 'maladaptive' strategies is somewhat ambiguous as 'maladaptive' strategies may serve an adaptive function. Therefore, it is important to measure both women's coping strategies and psychological adjustment following TFA and examine the relationship between the two to determine which strategies are more closely related to women's psychological adjustment following TFA. These analyses are undertaken in Study 2b (chapter 5).

Secondly, given the importance of receiving support from health professionals as a coping strategy, it seems imperative that health professionals have a comprehensive understanding of women's experience in order to care for them in the most appropriate way. This lends further support to the rationale for conducting Study 3 (chapter 6), which assesses health professionals' perceptions of women's coping.

Finally, the study findings corroborate those of the meta-ethnography of women's experiences of TFA (Study 1, chapter 2, section 2.4.2) in indicating that some women experience posttraumatic growth as a result of their termination. Whether the posttraumatic

growth experience is an outcome of TFA or part of the process of coping with it remains unclear. However, both studies highlight the importance of this concept in the context of TFA. The relationship between coping and posttraumatic growth is examined in Study 4 (see chapter 7).

Chapter 5 - Perinatal grief following termination of pregnancy for fetal abnormality:

The role of coping strategies

This chapter describes the research's second empirical study (Study 2b), which examines the relationship between the coping strategies women use when dealing with TFA and their levels of grief. The chapter outlines the methodology used in the study (discussed in more detail in chapter 3). It also provides a measure of the various coping strategies used by women when dealing with TFA and their levels of perinatal grief, and examines the relationship between the two sets of variables. In addition, a triangulation analysis pertaining to women's coping strategies is presented. This analysis is based on the comparison between the qualitative findings relating to women's coping strategies (Study 2a) presented in chapter 4 and the quantitative data relating to coping outlined in this chapter. A discussion of the findings and an evaluation of the study's limitations are provided at the end of the chapter. The analysis reported in this chapter has generated a research article (Lafarge, Mitchell, & Fox. [2013c] Perinatal grief following a termination of pregnancy for fetal abnormality: The impact of coping strategies) which has been published in the peer-reviewed journal Prenatal Diagnosis.

5.1 Introduction

The findings from Study 2a (chapter 4) revealed that women mostly use what are generally considered to be adaptive coping strategies (Aldao & Nolen-Hoeksema, 2012; Carver & Connor-Smith, 2010; Folkman & Lazarus, 1988; Moskowitz et al., 2009) to deal with the TFA procedure and its aftermath. However, the use of coping strategies in the context of TFA has yet to be examined in a large sample of women and using established psychometric measures. This approach is important to examine the extent to which the findings can be generalised. Furthermore, given the established link between coping strategies and psychological adjustment (Carver, 1997; Lazarus & Folkman, 2004, Moskowitz et al., 2009)

in a broad range of domains, it is important to investigate the relationship between the use of these strategies and women's psychological wellbeing. As discussed in chapter 1 (section 1.3.2) and chapter 3 (section 3.2.2.4.2), in the context of TFA, perinatal grief is an appropriate concept to investigate due to its established prevalence within this population of women (Hunfeld et al., 1994; Kersting et al., 2007, 2009; Korenromp et al., 2009; Toedter et al., 2001; Zeanah et al., 1993).

The objective of this study is twofold. Firstly, it aims to examine the coping strategies used by women when undergoing TFA quantitatively and triangulate these findings with the qualitative investigation (Study 2a, chapter 4) to obtain a comprehensive understanding of women's coping with TFA. Secondly, it aims to examine the relationship between the coping strategies used and levels of perinatal grief.

5.2 Methods

5.2.1 Summary of the methodology

The methodological elements of this study (Study 2b) have been described in chapter 3 (section 3.2). In brief, participants were women members of ARC. All were over 18 years old and had undergone TFA. Data were collected online using SurveyMonkey between April 2011 and July 2012. An interim analysis of the data based on 119 participants indicated that 12 predictors would be used in the statistical analyses. Using the power calculation tool G*Power described in chapter 3 (section 3.2.1.5), the required sample size was estimated at 127. More data were therefore needed, and a second message was posted by the ARC administrator on the email network and online forum. Once the minimum sample size required was reached, and after it became evident that no more questionnaires had been completed over a period of 14 days, the decision was made to close the survey.

As described in chapter 3 (sections 3.2.2.3 and 3.2.2.4), participants were asked to complete the Brief COPE (Carver, 1997) and the Short Perinatal Grief Scale ([Short PGS], Potvin et al., 1989). In addition, the questionnaire gathered information relating to the

terminated pregnancy (e.g. time elapsed since TFA) and obstetric history (e.g. number of pregnancies) as well as demographics.

5.2.2 Statistical data analysis

5.2.2.1 Statistical data analysis strategy

The statistical analysis of the data comprised seven steps. The data were verified for outliers and missing values. The subscales were then computed and their internal reliability examined. The data were subsequently examined to determine whether they were normally distributed or not. These steps are described in sections 5.2.2.2 to 5.2.2.5.

Descriptive and inferential statistics were used to analyse the data. Women's use of coping strategies and levels of perinatal grief were compared across groups based on demographic, obstetric and termination-related variables. Group differences were assessed through *t* tests and analyses of variance (ANOVA) followed by *post hoc* tests using the Bonferroni correction. Correlations and multiple regression analyses were also conducted to examine the relationship between coping strategies and perinatal grief. Variables exhibiting significant correlations with the grief variables were included in the regression analyses. A multiple hierarchical regression was run for each of the grief scales ('active grief,' 'difficulty coping,' 'despair' and 'total grief/PGS') individually. Coping strategies were entered first and other variables (all relating to the terminated pregnancy) second. The rationale for entering the variables in this order was based on the principle of research relevance (Cohen et al., 2003; see chapter 3 section 3.2.4.2). The Brief COPE subscales were used as predictors and the Short PGS scales as outcomes. These analyses are described in sections 5.3.2, 5.3.3 and 5.3.4. For all tests, *p*-values < 0.05 were considered statistically significant. Effect sizes were calculated using an online tool from the University of Colorado (n.d.). They were reported using the correlation coefficient *r* and the classification recommended by Cohen (1988): *r* = .10 (small effect), *r* = .30 (medium effect), *r* = .50 (large effect). Effect sizes for ANOVA were reported using the ω^2 statistic and the classification recommended by Field (2014): ω^2 = 0.01 (small effect), ω^2 = 0.06 (medium) and ω^2 = 0.14 (large effect).

5.2.2.2 Data verification

Data were analysed using SPSS (version 21, SPSS Inc, Chicago). Data were first verified for missing values. There were no missing data for any of the key variables (Brief COPE and Short PGS variables). Data were incomplete for the ethnicity question because this question had been introduced after data collection had started. Out of 166 participants, 134 completed this question.

Data were verified for outliers through visual examination of the box plots and by calculating z-scores, a method to standardise scores, which consists of dividing the score by its standard deviation (Field, 2009; Tabachnick & Fidell, 2007). z-scores that fall outside the -3.29/3.29 range are considered to be outliers (Field, 2009). Seven outliers were identified in the data, three for 'substance use' coping, three for 'behavioural disengagement' coping and one for 'active grief.' The outlying values for 'substance use' and 'behavioural disengagement' were high, indicating that women had made greater use of these coping strategies than other women in the sample. By contrast, the outlying value for 'active grief' was lower than the other scores. Potential patterns in the outliers were examined. All outlying values were within the range of scores available. Of the seven outlying values, only two (one for 'behavioural disengagement' and one for 'substance use') originated from the same participant.

A technique used to reduce the impact of outliers on the data is winsorising (Tabachnick & Fidell, 2007). This consists of converting the outlier score to the next highest or lowest score in the distribution. Given the small number of outliers, converting these scores to the next highest or lowest score did not significantly alter the variables' mean scores. Therefore, the decision was made to keep the original scores.

5.2.2.3 Scoring variables and computing the subscales

The Brief COPE data were scored and computed in accordance to the guidelines by Carver (1997). For each of the 13 Brief COPE subscales, participants were allocated a score between 2 (*I haven't been doing this at all*) and 8 (*I have been doing this a lot*). Mean scores for each subscale were calculated; the higher the mean score, the higher the usage of that particular coping strategy. The Short PGS subscales were scored and computed following the guidelines issued by Potvin et al. (1989). This involved reverse-coding two items and adding up scores, so that higher scores reflected higher levels of grief. The scores for the 'total grief' scale ranged from 33 to 165 (midpoint 99) and the scores for the 'active grief,' 'difficulty coping' and 'despair' subscales ranged from 11 to 55 (midpoint 33). The midpoints for each subscale were initially used as a threshold to distinguish between high and low levels of grief.

5.2.2.4 Subscale reliability

The subscales of both scales displayed satisfactory levels of internal reliability with Cronbach's alpha values for the Short PGS of 0.83 for 'active grief' and 'despair,' 0.86 for 'difficulty coping' and 0.93 for the 'total PGS' subscale. For the Brief COPE, Cronbach's alpha values ranged from 0.56 for 'behavioural disengagement' to 0.96 for 'substance use.' The subscale 'denial' did not satisfy the minimum requirement of 0.5 (Nunnally, 1978) with a value of 0.48, and thus was excluded from further analysis. The Cronbach's alpha values are shown in Table 5.4 (p.189) for the Brief COPE and Table 5.14 (p.204) for the Short PGS.

5.2.2.5 Data distribution

The distribution of scores was also assessed by visually examining histograms, calculating z-scores which are derived by dividing measures of skewness and kurtosis by their respective standard errors (Field, 2009), and by running the Shapiro-Wilk test on the variables. These analyses, displayed in Table 5.1, revealed that the scores were not

normally distributed, except for 'difficulty coping,' 'despair' and 'total PGS.' The histograms illustrating the data distribution are displayed in Appendix IX.

Table 5.1. Distribution of scores for the Brief COPE and the Short PGS based on the Shapiro-Wilk test

Variable	Statistic	df	p-value
Brief COPE			
Self-distraction	0.944	166	$p < 0.001$
Active coping	0.943	166	$p < 0.001$
Denial	0.799	166	$p < 0.001$
Substance use	0.634	166	$p < 0.001$
Emotional support	0.911	166	$p < 0.001$
Instrumental support	0.941	166	$p < 0.001$
Behavioural disengagement	0.717	166	$p < 0.001$
Venting	0.932	166	$p < 0.001$
Positive reframing	0.914	166	$p < 0.001$
Planning	0.937	166	$p < 0.001$
Acceptance	0.915	166	$p < 0.001$
Religion	0.710	166	$p < 0.001$
Self-blame	0.927	166	$p < 0.001$
Short PGS			
Active grief	0.969	166	$p = 0.001$
Difficulty coping	0.992	166	$p = 0.543$
Despair	0.991	166	$p = 0.396$
Total PGS	0.993	166	$p = 0.608$

$p < 0.05$ indicates that the data deviate significantly from normal

As an assumption for the use of parametric tests is a normal distribution of scores (Field, 2009; Tabachnick & Fidell, 2007), the violation of this assumption raised some questions about how to proceed with the data analysis. A number of considerations had to be taken into account, including: the potential benefit of transforming the data, the power of

non-parametric tests and the robustness of parametric tests to violation of normality, as well as the sample size.

The first consideration centred on the potential benefit of transforming the data. Whilst this strategy can be useful (Field, 2009), Tabachnik and Fidell (2007) also stated that transformed variables can become difficult to interpret and that this process may be less desirable if the measures are “widely used and meaningful” (Tabachnik & Fidell, 2007, p.86). In the case of the Brief COPE, one may argue that the abnormal distribution of the subscales is a meaningful finding in itself. For example, the skewness and kurtosis of the ‘substance use’ subscale indicates that this strategy is seldom used by women, an insightful finding in itself. Transforming the data could, therefore, result in weakening the results.

The second consideration concerned the power of non-parametric tests and the relative robustness of parametric tests to violation of normality. Non-parametric tests are generally considered less powerful than parametric ones due to the magnitude of the difference between scores being lost when the data are ranked (Field, 2009). Parametric tests are also known to be more sensitive in detecting real effects and thus, reducing the risk of Type I error (false positive [Tabachnick & Fidell, 2007]). In addition, the parametric tests considered most appropriate to analyse the data in this study, have been shown to be robust to violation of the assumption of normality (*t* test [Vickers, 2005]; ANOVA [Schmider, Ziegler, Danay, Beyer, & Bühner, 2010]; and Pearson’s correlations [Field, 2009; Havlicek & Peterson, 1977]). In the case of regression analyses, normality is generally assessed through the examination of the model’s residuals (Tabachnick & Fidell, 2007). Residuals correspond to the difference between the predicted and observed values in the data, and reflect ‘errors’ in the model (Field, 2009). These analyses, run along other diagnostic tests (e.g. homoscedasticity), assess the regression model’s goodness-of-fit and statistical predictive power beyond the sample used.

The sample size was also taken into account. Moderate to large sample sizes are known to be less sensitive to violation of normality. For example, it is estimated that positive kurtosis disappears with sample of over 100 participants (Tabachnick & Fidell, 2007). The

central limit theorem also posits that in samples greater than 30, the sampling distribution of the means is approximately normally distributed (Field, 2009). In this study, the sample was relatively large ($n = 166$) and many of the grouping variables contained more than 30 participants.

Based on these considerations, the decision was made to use parametric tests to analyse the data without transforming them. The analysis of group differences was, however, also run using non-parametric tests to check if there were any differences between the results obtained through parametric and non-parametric tests. No significant differences between the two sets of analyses were identified (see Appendix X for key termination-related variables). All statistical tests were run on a list-wise basis, meaning that participants for whom data were missing on any variable were excluded from the analysis for that particular variable.

5.3 Results

5.3.1 Participants' profile

Altogether, 215 participants agreed to participate in the study. Of those 38 (17.7%) did not complete the survey in full. A further 11 (5.1%) were identified as duplicates and were subsequently removed from the dataset. Thus, the total number of completed questionnaires is 166. It is not possible to calculate an exact response rate for this study. ARC has approximately 1,700 parent members, with approximately 1,000 and 1,400 members in the email and forum respectively. However, there are currently no data on the member's level of activity on the forum, nor on the number of members who were part of the email network prior to the forum's creation. Participants in this study were aged between 22 and 46 years old ($M = 34.5$, $SD = 4.9$), the majority (70.5%, $n = 117$) were university-level educated. All but one participant were married or in a relationship, and almost all (91.8%, $n = 123$ ¹) were

¹ Data on ethnicity are based on 134 responses. The question was added after the fieldwork had started.

White British. For 70 participants (42.2%), this was their first pregnancy. Pregnancies were terminated between 12 and 35 weeks of gestation ($M = 18.5$, $SD = 4.9$), with the majority terminated up to 24 weeks of gestation (89.8%, $n = 149$). For approximately half the participants (53.0%, $n = 88$), termination had occurred less than six months prior to study participation. Most terminations were medical (77.7%, $n = 129$). Participants' demographic and obstetric profiles are shown in Tables 5.2 and 5.3.

Table 5.2. Participants' demographic profile

	<i>N/n</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>
Age (years)	166		34.5	4.9	22-46
Education					
Secondary	49	29.5			
Graduate	67	40.4			
Postgraduate	50	30.1			
Socioeconomic status ²					
A	43	25.9			
B	86	51.8			
C1	21	12.7			
C2	11	6.6			
D	1	0.6			
Prefer not to answer	4	2.4			
Ethnicity ^a					
White British	123	91.8			
Other White background	7	5.2			
Other	4	3.0			
Marital status – Married/living together	165	99.4			

^a Data on ethnicity based on 134 participants

² The social grade definitions system (ABC1) is based on the National Readership Survey (NRS). It measures work status, which has often been used as a proxy for socioeconomic status (Adler, Boyce, Chesney, Cohen, Folkman, Kahn et al. 1994) including by the Office for National Statistics (Rose, Pevalin, & O'Reilly, 2005). This classification is widely used in market research and advertising (Market Research Society, n.d.).

Table 5.3. Participants' obstetric profile

	<i>N/n</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>
Time elapsed since TFA					
Up to 6 months	88	53.0			
7-12 months	35	21.1			
13-24 months	28	16.9			
24 months+	15	9.0			
Gestational age at TFA (weeks)	166		18.5	4.9	12-35
Method of detection					
Routine check	149	89.8			
Directed search	17	10.2			
Method of termination					
Medical	129	77.7			
Surgical	36	21.7			
Other	1	0.6			
Abnormality prognosis					
Incompatible with life	68	41.0			
Compatible with life	80	48.2			
Not sure	17	10.2			
Prefer not to answer	1	0.6			
Would make the same decision again					
Yes	122	73.5			
No	9	5.4			
Don't know	35	21.1			
Children at time of TFA – Yes	77	46.4			
First pregnancy – Yes	70	42.2			
First TFA – Yes	155	93.4			
Children since TFA - Yes/pregnant	53	31.9			

5.3.2 Women's use of coping strategies

Coping strategies were examined descriptively at an overall level. Group differences were also investigated in relation to demographic, obstetric and termination-related variables.

5.3.2.1 General use of coping strategies

The mean use of the coping strategies was examined through descriptive statistics. The highest usage was recorded for 'acceptance' ($M = 5.96$), 'emotional support' ($M = 5.93$), 'active coping' ($M = 5.35$), 'planning' ($M = 5.28$), 'self-distraction' ($M = 5.22$) and 'instrumental support' ($M = 5.21$). For these coping strategies, the mean score was above the midpoint value of 5. In comparison, the strategies 'behavioural disengagement' ($M = 2.82$), 'substance use' ($M = 2.88$) and religion ($M = 3.14$) recorded the lowest usage. The mean scores for each coping strategies are displayed in Table 5.4.

Table 5.4. Mean scores, standard deviations and Cronbach's values for the Brief COPE

Variables (N = 166)	Mean	SD	Cronbach's value
Self-distraction	5.22	1.71	0.61
Active coping	5.35	1.69	0.69
Denial ^a	3.04	1.20	0.48
Substance use	2.88	1.52	0.96
Emotional support	5.93	1.70	0.83
Instrumental support	5.21	1.68	0.69
Behavioural disengagement	2.82	1.18	0.56
Venting	4.77	1.75	0.68
Positive reframing	4.34	1.86	0.75
Planning	5.28	1.78	0.72
Acceptance	5.96	1.56	0.68
Religion	3.14	1.70	0.83
Self-blame	4.81	1.90	0.77

Values above the scale's midpoint (> 5) are highlighted in bold; ^a Variable removed from further analysis as $\alpha = 0.48$

5.3.2.2 Group differences in women's use of coping strategies

Differences in the use of coping strategies were assessed according to demographic, obstetric and termination-related variables. Demographic variables included: age, marital status, ethnicity, level of education and socioeconomic status. Obstetric and termination-related variables comprised: time elapsed since the termination, number of pregnancies, number of living children at the time of TFA, gestational age at TFA, method of abnormality detection, abnormality prognosis, method of termination, women's reproductive history post-TFA, and how women felt about their decision to terminate. These variables were analysed using either the categories of answers included in the questionnaire (described in chapter 3, section 3.2.2.3) or new categories which involved recoding. The rationale and procedure for recoding the data are presented in the relevant sections. Results pertaining to group differences in the use of coping strategies are detailed in the subsequent sections (5.3.2.2.1 and 5.3.2.2.2). Variables for which results are statistically significant are marked by asterisks in the tables (* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$).

5.3.2.2.1 Differences in the use of coping strategies by demographic variables

Demographic variables comprised age, marital status, ethnicity, level of education, and socioeconomic status. The sample almost exclusively comprised White British, married women or women living in a partnership (91.8% and 99.4% respectively). Consequently, the analysis of the coping strategies based on these variables was unlikely to differ from the analysis based on the whole sample (presented in section 5.3.2.1). It was, nevertheless, important to ascertain whether there were any significant differences in the use of coping strategies according to other demographic variables such as age, level of education and socioeconomic status.

Age

The age variable was examined in two different ways. It was initially grouped in three categories corresponding to the age groups represented in the sample: up to 30 years old (n

= 34), 31 to 40 years old ($n = 110$) and over 40 years old ($n = 22$). An unrelated one-way ANOVA revealed no significant effect of age on any of the coping variables. The data were subsequently recoded into two categories which generated groups of a more equivalent size: up to 34 years old ($n = 88$) and over 35 years old ($n = 78$). An unrelated t test was conducted using these new categories which did not reveal any significant difference between age groups. This grouping was, however, retained for the remainder of the analysis because it offered groups of an equivalent size. The results based on the two-category grouping are shown in Table 5.5.

Table 5.5. Differences in the use of coping strategies by age

Variables	Up to 34 years old	Over 35 years old	<i>t</i>-value	<i>p</i>-value
Coping strategies	<i>n</i> = 88 (53.01%)	<i>n</i> = 78 (46.98%)		
Self-distraction	5.33 (<i>SD</i> = 1.77)	5.12 (<i>SD</i> = 1.64)	0.804	$p = 0.423$
Active coping	5.20 (<i>SD</i> = 1.78)	5.51 (<i>SD</i> = 1.59)	-1.174	$p = 0.242$
Substance use	2.90 (<i>SD</i> = 1.49)	2.86 (<i>SD</i> = 1.57)	0.163	$p = 0.871$
Emotional support	5.86 (<i>SD</i> = 1.69)	6.00 (<i>SD</i> = 1.72)	-0.515	$p = 0.608$
Instrumental support	5.20 (<i>SD</i> = 1.68)	5.22 (<i>SD</i> = 1.69)	-0.051	$p = 0.959$
Behaviour. disengagement	2.88 (<i>SD</i> = 1.15)	2.76 (<i>SD</i> = 1.22)	0.644	$p = 0.521$
Venting	4.99 (<i>SD</i> = 1.73)	4.53 (<i>SD</i> = 1.76)	1.708	$p = 0.090$
Positive reframing	4.33 (<i>SD</i> = 1.82)	4.36 (<i>SD</i> = 1.92)	-0.101	$p = 0.920$
Planning	5.28 (<i>SD</i> = 1.87)	5.27 (<i>SD</i> = 1.70)	0.053	$p = 0.957$
Acceptance	5.81 (<i>SD</i> = 1.61)	6.14 (<i>SD</i> = 1.49)	-1.381	$p = 0.169$
Religion	3.15 (<i>SD</i> = 1.78)	3.13 (<i>SD</i> = 1.61)	0.074	$p = 0.941$
Self-blame	4.88 (<i>SD</i> = 1.95)	4.74 (<i>SD</i> = 1.86)	0.443	$p = 0.658$

Level of education

The variable 'level of education' was initially examined using the four categories of answer included in the questionnaire: 'GCSE,' 'A levels,' 'first degree' and 'postgraduate degree.'

The variable was recoded into two categories to examine these differences in terms of secondary education ($n = 49$) and higher education ($n = 117$) groupings. Analyses revealed

that the two-category grouping yielded statistically stronger results (i.e. ability to detect statistical significance) than the four-category and thus, was selected for the analysis. An unrelated *t* test was conducted to ascertain whether there was any significant difference in usage of coping strategies by level of education. The *t*-test analysis revealed that the mean use for 'instrumental support' in the higher education group ($M = 5.48$, $SD = 1.68$) was significantly higher than in the secondary education group ($M = 4.57$, $SD = 1.50$), $t(164) = -3.27$, $p < 0.01$, with a small to medium effect size ($r = 0.27$). A similar pattern was noted for 'planning' for which the mean score was significantly higher in the higher education group ($M = 5.46$, $SD = 1.79$) than the secondary education group ($M = 4.84$, $SD = 1.70$), $t(164) = -2.08$, $p < 0.05$ with a small effect size ($r = 0.17$). The result for 'active coping' approached significance in the same direction i.e. higher scores in the higher education than the secondary education group ($M = 5.51$, $SD = 1.65$ vs. $M = 4.96$, $SD = 1.74$, $t(164) = -1.94$, $p = 0.054$). The results are displayed in Table 5.6.

Table 5.6. Differences in the use of coping strategies by level of education

Variables	Secondary education	Higher education	<i>t</i>-value	<i>p</i>-value
Coping strategies	<i>n</i> = 49 (29.52%)	<i>n</i> = 117 (70.48%)		
Self-distraction	5.12 ($SD = 1.74$)	5.27 ($SD = 1.71$)	-0.52	$p = 0.605$
Active coping	4.96 ($SD = 1.74$)	5.51 ($SD = 1.65$)	-1.94	$p = 0.054$
Substance use	3.02 ($SD = 1.65$)	2.82 ($SD = 1.47$)	0.77	$p = 0.443$
Emotional support	5.61 ($SD = 1.53$)	6.06 ($SD = 1.76$)	-1.55	$p = 0.122$
Instrumental support	4.57 ($SD = 1.50$)	5.48 ($SD = 1.68$)	-3.27	$p = 0.001^{**}$
Behaviour. disengagement	2.69 ($SD = 1.21$)	2.87 ($SD = 1.17$)	-0.88	$p = 0.378$
Venting	4.45 ($SD = 1.77$)	4.91 ($SD = 1.74$)	-1.54	$p = 0.126$
Positive reframing	4.61 ($SD = 1.93$)	4.23 ($SD = 1.83$)	1.20	$p = 0.230$
Planning	4.84 ($SD = 1.70$)	5.46 ($SD = 1.79$)	-2.08	$p = 0.039^*$
Acceptance	5.82 ($SD = 1.55$)	6.03 ($SD = 1.57$)	-0.79	$p = 0.432$
Religion	2.88 ($SD = 1.48$)	3.25 ($SD = 1.78$)	-1.28	$p = 0.201$
Self-blame	5.08 ($SD = 2.00$)	4.70 ($SD = 1.86$)	1.18	$p = 0.241$

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Socioeconomic status

The variable socioeconomic status, which initially included six categories of answer was recoded into two categories: AB ($n = 129$) and C1C2D ($n = 33$). The variable was recoded because the lower categories comprised few participants (11 for C2, one for D and none for E). Therefore, these categories were aggregated with the mid-category C1. An unrelated t test was run to check for any significant difference in the use of coping strategies according to socioeconomic status. The results showed that the AB group ($M = 6.07$, $SD = 1.64$) made greater use of 'emotional support' compared to the C1C2D group ($M = 5.27$, $SD = 1.86$), $t(160) = 2.42$, $p < 0.05$. The difference in 'substance use' was significant in the opposite direction, with use of this strategy lower in the AB group than the C1C2D group ($M = 2.76$, $SD = 1.48$ vs. $M = 3.42$, $SD = 1.66$, $t(160) = -2.24$, $p < 0.05$). Group differences had small to medium effect sizes ($r = 0.22$ and $r = 0.21$ respectively). Results are shown in Table 5.7.

Table 5.7. Differences in the use of coping strategies by socioeconomic status

Variables	AB	C1C2D	<i>t</i>-value	<i>p</i>-value
Coping strategies	$n = 129$ (79.62%)^b	$n = 33$ (20.37%)^b		
Self-distraction	5.21 ($SD = 1.68$)	5.18 ($SD = 1.91$)	0.082	$p = 0.935$
Active coping	5.50 ($SD = 1.69$)	4.88 ($SD = 1.63$)	1.887	$p = 0.061$
Substance use	2.76 ($SD = 1.48$)	3.42 ($SD = 1.66$)	-2.241	$p = 0.026^*$
Emotional support	6.07 ($SD = 1.64$)	5.27 ($SD = 1.86$)	2.423	$p = 0.017^*$
Instrumental support	5.31 ($SD = 1.70$)	4.72 ($SD = 1.61$)	1.777	$p = 0.077$
Behaviour. disengagement ^a	2.77 ($SD = 1.06$)	3.09 ($SD = 1.59$)	-1.108	$p = 0.275$
Venting	4.81 ($SD = 1.73$)	4.67 ($SD = 1.91$)	0.427	$p = 0.670$
Positive reframing	4.28 ($SD = 1.85$)	4.55 ($SD = 1.95$)	-0.731	$p = 0.466$
Planning	5.35 ($SD = 1.84$)	4.97 ($SD = 1.57$)	1.088	$p = 0.278$
Acceptance	6.01 ($SD = 1.64$)	5.84 ($SD = 1.30$)	0.518	$p = 0.605$
Religion	3.11 ($SD = 1.68$)	3.15 ($SD = 1.73$)	-0.130	$p = 0.897$
Self-blame	4.74 ($SD = 1.88$)	5.09 ($SD = 2.00$)	-0.934	$p = 0.352$

^a Equality of variance not assumed, ^b Percentages based on participants who could be classified in either category ($n = 162$); * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

5.3.2.2.2 Differences in women's use of coping strategies by obstetric and termination-related variables

Obstetric and termination-related variables comprised: time elapsed since TFA, number of pregnancies, number of living children at the time of TFA, gestational age at TFA, method of abnormality detection, abnormality prognosis, method of termination, women's reproductive history post-TFA, and how women felt about their decision to terminate. Similarly to the demographic variables of ethnicity and marital status, the sample almost exclusively comprised women for whom the fetal abnormality had been detected through a routine check (89.8%). Therefore, the analysis of the coping strategies based on this variable was likely to follow the same pattern as the analysis based on the whole sample (presented in section 5.3.2.1). Consequently, group differences were not examined for this variable.

Time elapsed since TFA

Women's use of coping strategies was examined according to the time elapsed since the termination. This variable comprised four categories of answer: up to six months prior to study participation ($n = 88$), 7 to 12 months ($n = 35$), 13 to 24 months ($n = 28$), over 24 months ($n = 15$). An unrelated one-way ANOVA was run to assess the main effect of time elapsed since the termination on the use of coping strategies. The data revealed a main effect of time elapsed on the use of 'instrumental support' $F(3,162) = 3.03$ $p < 0.05$ and 'venting' $F(3,162) = 3.61$, $p < 0.05$, both with a small to medium effect size ($\omega^2 = 0.04$ and $\omega^2 = 0.05$). *Post hoc* tests with the Bonferroni correction established that women who had a termination up to six months prior to study participation made greater use of 'instrumental support' and 'venting' compared to those who had had their termination 13 to 24 months prior ('instrumental support': $M = 5.51$, $SD = 1.65$ vs. $M = 4.46$, $SD = 1.75$, $p < 0.05$; 'venting': $M = 5.08$, $SD = 1.71$ vs. $M = 3.86$, $SD = 1.76$, $p < 0.05$). The results are displayed in Table 5.8.

Despite exhibiting significant group differences, homogeneity of variance could not be established for 'emotional support.' Therefore a Kruskal-Wallis test was used to analyse

this variable. It revealed that the use of this strategy was significantly affected by time elapsed since the termination, $H(3) = 13.69$, $p < 0.01$. Pairwise comparisons with adjusted p -values showed significant differences in the use of 'emotional support.' Women whose termination had occurred up to six months prior to study participation made greater use of this strategy than those whose termination had occurred 13-24 months prior ($p = 0.007$, $r = 0.30$).

Table 5.8. Differences in the use of coping strategies by time elapsed since TFA

Variables	Up to 6 months	7-12 months	13-24 months	24 + months
Coping strategies	$n = 88$ (53.01%)	$n = 35$ (21.08%)	$n = 28$ (16.87%)	$n = 15$ (9.04%)
Self-distraction	5.36 ($SD = 1.74$)	5.37 ($SD = 1.65$)	4.86 ($SD = 1.82$)	4.80 ($SD = 1.47$)
Active coping	5.32 ($SD = 1.75$)	5.37 ($SD = 1.72$)	5.11 ($SD = 1.66$)	5.93 ($SD = 1.33$)
Substance use	2.92 ($SD = 1.61$)	3.09 ($SD = 1.76$)	2.64 ($SD = 1.13$)	2.60 ($SD = 1.06$)
Emotional support ^{ab}	6.41 ($SD = 1.39$)	5.60 ($SD = 1.72$)	5.00 ($SD = 2.07$)*	5.60 ($SD = 1.72$)
Instrumental support	5.51 ($SD = 1.65$)	5.03 ($SD = 1.69$)	4.46 ($SD = 1.75$)*	5.27 ($SD = 1.28$)
Behaviour disengag.	2.90 ($SD = 1.32$)	2.94 ($SD = 1.19$)	2.43 ($SD = 0.63$)	2.80 ($SD = 1.01$)
Venting	5.08 ($SD = 1.71$)	4.74 ($SD = 1.65$)	3.86 ($SD = 1.76$)*	4.73 ($SD = 1.79$)
Positive reframing	4.38 ($SD = 1.84$)	4.51 ($SD = 2.03$)	3.89 ($SD = 1.75$)	4.60 ($SD = 1.84$)
Planning	5.47 ($SD = 1.77$)	5.20 ($SD = 1.80$)	4.75 ($SD = 1.78$)	5.33 ($SD = 1.84$)
Acceptance	5.98 ($SD = 1.57$)	5.80 ($SD = 1.73$)	6.07 ($SD = 1.44$)	6.07 ($SD = 1.44$)
Religion	3.10 ($SD = 1.65$)	2.74 ($SD = 1.36$)	3.82 ($SD = 2.11$)	3.00 ($SD = 1.36$)
Self-blame	4.65 ($SD = 1.96$)	4.77 ($SD = 1.77$)	5.14 ($SD = 1.86$)	5.27 ($SD = 1.98$)

Groups were compared against the group whose loss was most recent (up to six months), * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. ^a Equality of variance not assumed; ^b Kruskal-Wallis test run with pairwise comparison

Children at the time of TFA

Differences in the use of coping strategies were examined according to whether women had children at the time of TFA. This variable was coded into two categories, 'children' (irrespective of the number of children) and 'no children' because this grouping captured the main difference of interest and generated groups of a similar size ('children' $n = 77$ and 'no

children' $n = 89$). An unrelated t test indicated that women who had no children at the time of TFA ($M = 5.54$, $SD = 1.71$) made greater use of 'planning' than women who had children ($M = 4.97$, $SD = 1.84$), $t(164) = 2.06$, $p < 0.05$ but the effect size was small ($r = 0.16$). Similarly, women who had no children at the time of TFA made greater use of 'venting' than those who already had children, although the difference only approached significance ($M = 5.01$, $SD = 1.77$ vs. $M = 4.49$, $SD = 1.70$, $t(164) = 1.91$, $p = 0.058$). The results are shown in Table 5.9.

Table 5.9. Differences in the use of coping strategies by whether women had children at the time of TFA

Variables	No children	Children	t-value	p-value
Coping strategies	$n = 89$ (53.61%)	$n = 77$ (46.39%)		
Self-distraction	5.34 ($SD = 1.68$)	5.10 ($SD = 1.75$)	0.875	$p = 0.383$
Active coping	5.51 ($SD = 1.60$)	5.17 ($SD = 1.78$)	1.282	$p = 0.202$
Substance use	2.98 ($SD = 1.61$)	2.77 ($SD = 1.42$)	0.890	$p = 0.375$
Emotional support	6.07 ($SD = 1.73$)	5.77 ($SD = 1.66$)	1.139	$p = 0.256$
Instrumental support	5.35 ($SD = 1.65$)	5.05 ($SD = 1.71$)	1.135	$p = 0.258$
Behaviour. disengagement	2.93 ($SD = 1.21$)	2.69 ($SD = 1.14$)	1.331	$p = 0.185$
Venting	5.01 ($SD = 1.77$)	4.49 ($SD = 1.70$)	1.912	$p = 0.058$
Positive reframing	4.38 ($SD = 1.79$)	4.30 ($SD = 1.96$)	0.286	$p = 0.775$
Planning	5.54 ($SD = 1.71$)	4.97 ($SD = 1.84$)	2.056	$p = 0.041^*$
Acceptance	5.92 ($SD = 1.54$)	6.01 ($SD = 1.59$)	-0.376	$p = 0.707$
Religion ^a	3.27 ($SD = 1.82$)	2.99 ($SD = 1.54$)	1.08	$p = 0.281$
Self-blame	4.99 ($SD = 1.95$)	4.61 ($SD = 1.84$)	1.280	$p = 0.202$

^a Equality of variance not assumed; * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Children following TFA

A similar analysis was run on women's obstetric history following the termination. The variable initially comprised five categories of answer: 'had another child since TFA,' 'expecting another child,' 'suffered another loss,' 'not pregnant but would like another child' and 'decided not to have another child.' This variable was recoded into two categories to illustrate the 'presence versus absence' of children: 'children since TFA' ($n = 53$) and 'no

children since TFA' ($n = 113$). The first category comprised women who had children since TFA or were pregnant at the time of the study. The second category included women who, at the time of the study, wished to be pregnant and women who did not want another baby. Unrelated t tests revealed that the use of 'planning,' was, again, higher in the 'no children' category ($M = 5.48$, $SD = 1.66$), than in the 'children' category ($M = 4.85$, $SD = 1.97$), $t(164) = 2.01$, $p < 0.05$, $r = 0.16$. Results are shown in Table 5.10.

Table 5.10. Differences in the use of coping strategies by whether women had children following TFA

Variables	No children	Children	t-value	p-value
Coping strategies	$n = 113$ (68.07%)	$n = 53$ (31.93%)		
Self-distraction ^a	5.35 ($SD = 1.61$)	4.96 ($SD = 1.89$)	1.302	$p = 0.196$
Active coping	5.41 ($SD = 1.68$)	5.23 ($SD = 1.73$)	0.641	$p = 0.523$
Substance use	2.91 ($SD = 1.63$)	2.81 ($SD = 1.27$)	0.394	$p = 0.694$
Emotional support	6.08 ($SD = 1.63$)	5.60 ($SD = 1.81$)	1.690	$p = 0.093$
Instrumental support	5.31 ($SD = 1.69$)	5.00 ($SD = 1.66$)	1.108	$p = 0.269$
Behaviour. disengagement	2.89 ($SD = 1.22$)	2.66 ($SD = 1.09$)	1.188	$p = 0.237$
Venting ^a	4.84 ($SD = 1.64$)	4.62 ($SD = 1.98$)	0.697	$p = 0.488$
Positive reframing	4.30 ($SD = 1.90$)	4.43 ($SD = 1.80$)	-0.428	$p = 0.669$
Planning ^a	5.48 ($SD = 1.66$)	4.85 ($SD = 1.97$)	2.009	$p = 0.048^*$
Acceptance	5.98 ($SD = 1.59$)	5.92 ($SD = 1.52$)	0.222	$p = 0.825$
Religion	3.17 ($SD = 1.68$)	3.08 ($SD = 1.75$)	0.327	$p = 0.744$
Self-blame	4.71 ($SD = 1.90$)	5.04 ($SD = 1.91$)	-1.041	$p = 0.299$

^a Equality of variance not assumed; * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Feeling about the decision to terminate the pregnancy

The use of coping strategies was assessed according to the way women felt about their decision to end the pregnancy. The variable initially comprised three categories of answer: 'would make the same decision again,' 'would not make the same decision' and 'don't know.' This variable was recoded into two categories: 'comfortable with decision' and

'uncomfortable with decision' because it captured the main difference of interest. The first category encompassed women who stated that they would make the same decision again ($n = 122$), whilst the second comprised women who stated that they would not make the same decision again or were unsure about it ($n = 44$). An unrelated t test revealed that the mean score for 'emotional support' among women 'comfortable with their decision' ($M = 6.21$, $SD = 1.59$) was significantly higher than among women who were 'uncomfortable with their decision' ($M = 5.14$, $SD = 1.77$), $t(164) = 3.74$, $p < 0.001$ with a medium effect size ($r = 0.30$). Similarly, women in the 'comfortable' category made greater use of 'venting' ($M = 4.94$, $SD = 1.75$) compared to those in the 'uncomfortable' group ($M = 4.30$, $SD = 1.71$), $t(164) = 2.12$, $p < 0.05$, $r = 0.18$. The use of 'planning' and 'instrumental support' followed a similar pattern although the results only approached significance ($M = 5.43$, $SD = 1.77$ vs. $M = 4.84$, $SD = 1.76$, $t(164) = 1.91$, $p = 0.058$ and $M = 5.36$, $SD = 1.70$ vs. $M = 4.80$, $SD = 1.56$, $t(164) = 1.93$, $p = 0.055$ respectively). The use of 'self-blame' showed significant results in the opposite direction. Women 'uncomfortable' with their decision ($M = 5.77$, $SD = 1.74$) made greater use of this strategy than women who were 'comfortable' with it ($M = 4.47$, $SD = 1.85$), $t(164) = -4.08$, $p < 0.001$, with a medium effect size $r = 0.34$. The results are shown in Table 5.11.

Table 5.11. Differences in the use of coping strategies by feeling about the decision

Variables	Comfortable with decision	Uncomfortable with decision	t-value	p-value
Coping strategies	<i>n</i> = 122 (73.49%)	<i>n</i> = 44 (26.51%)		
Self-distraction ^a	5.33 (<i>SD</i> = 1.77)	4.95 (<i>SD</i> = 1.52)	1.333	<i>p</i> = 0.186
Active coping	5.46 (<i>SD</i> = 1.73)	5.05 (<i>SD</i> = 1.55)	1.395	<i>p</i> = 0.165
Substance use	2.85 (<i>SD</i> = 1.55)	2.95 (<i>SD</i> = 1.46)	-0.380	<i>p</i> = 0.705
Emotional support	6.21 (<i>SD</i> = 1.59)	5.14 (<i>SD</i> = 1.77)	3.740	<i>p</i> < 0.001***
Instrumental support	5.36 (<i>SD</i> = 1.70)	4.80 (<i>SD</i> = 1.56)	1.929	<i>p</i> = 0.055
Behaviour. disengagement	2.79 (<i>SD</i> = 1.22)	2.91 (<i>SD</i> = 1.07)	-0.587	<i>p</i> = 0.558
Venting	4.94 (<i>SD</i> = 1.75)	4.30 (<i>SD</i> = 1.71)	2.121	<i>p</i> = 0.035*
Positive reframing	4.44 (<i>SD</i> = 1.92)	4.07 (<i>SD</i> = 1.69)	1.143	<i>p</i> = 0.255
Planning	5.43 (<i>SD</i> = 1.77)	4.84 (<i>SD</i> = 1.76)	1.907	<i>p</i> = 0.058
Acceptance	6.10 (<i>SD</i> = 1.60)	5.59 (<i>SD</i> = 1.39)	1.863	<i>p</i> = 0.064
Religion	3.02 (<i>SD</i> = 1.58)	3.45 (<i>SD</i> = 1.97)	-1.445	<i>p</i> = 0.150
Self-blame	4.47 (<i>SD</i> = 1.85)	5.77 (<i>SD</i> = 1.74)	-4.083	<i>p</i> < 0.001***

^a Equality of variance not assumed; * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

Method of termination

The variable method of termination was recoded into two categories corresponding to the two methods of termination available: medical and surgical. 'Medical termination' included termination involving medication and induction of labour, with or without feticide. Using a *t* test, group differences were identified for 'emotional support.' Women who had undergone a medical termination (*M* = 6.05, *SD* = 1.71) made greater use of this strategy than women who had had a surgical termination (*M* = 5.42, *SD* = 1.57, *t*(164) = 2.01, *p* < 0.05, with a small effect size *r* = 0.17). Results are displayed in Table 5.12.

Table 5.12. Differences in the use of coping strategies by method of termination

Variables	Medical	Surgical	t-value	p-value
Coping strategies	<i>n</i> = 129 (77.71%)	<i>n</i> = 36 (21.69%)^b		
Self-distraction	5.17 (<i>SD</i> = 1.68)	5.44 (<i>SD</i> = 1.84)	-0.846	<i>p</i> = 0.399
Active coping	5.23 (<i>SD</i> = 1.63)	5.72 (<i>SD</i> = 1.88)	-1.543	<i>p</i> = 0.125
Substance use ^a	2.95 (<i>SD</i> = 1.63)	2.64 (<i>SD</i> = 1.05)	1.392	<i>p</i> = 0.168
Emotional support	6.05 (<i>SD</i> = 1.71)	5.42 (<i>SD</i> = 1.57)	2.011	<i>p</i> = 0.046*
Instrumental support	5.25 (<i>SD</i> = 1.67)	5.03 (<i>SD</i> = 1.73)	0.695	<i>p</i> = 0.488
Behaviour. disengagement	2.85 (<i>SD</i> = 1.23)	2.69 (<i>SD</i> = 0.98)	0.674	<i>p</i> = 0.501
Venting	4.77 (<i>SD</i> = 1.76)	4.72 (<i>SD</i> = 1.75)	0.137	<i>p</i> = 0.891
Positive reframing	4.36 (<i>SD</i> = 1.87)	4.22 (<i>SD</i> = 1.82)	0.383	<i>p</i> = 0.703
Planning	5.30 (<i>SD</i> = 1.82)	5.11 (<i>SD</i> = 1.63)	0.570	<i>p</i> = 0.570
Acceptance	5.93 (<i>SD</i> = 1.55)	6.08 (<i>SD</i> = 1.63)	-0.518	<i>p</i> = 0.605
Religion	3.14 (<i>SD</i> = 1.74)	3.06 (<i>SD</i> = 1.49)	0.263	<i>p</i> = 0.793
Self-blame	4.91 (<i>SD</i> = 1.92)	4.44 (<i>SD</i> = 1.84)	1.310	<i>p</i> = 0.192

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category (*n* = 165); * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

Other obstetric and termination-related variables

Group differences were assessed according to gestational age. The variable was coded into two categories corresponding to the first and second half of the pregnancy, and which generated groups of a similar size ('up to 20 weeks' *n* = 84 and '20 weeks and over' *n* = 82).

The analysis carried out using *t* test did not reveal any significant differences in the use of coping strategies based on gestational age. Similar patterns were noted for group differences according to the abnormality prognosis (incompatible vs. compatible with life) and whether it was a woman's first pregnancy (Yes vs. No), which were not statistically significant (*p* > 0.05). Results for these variables are displayed in Table 5.13.

Table 5.13. Differences in the use of coping strategies by other termination-related variables

Variables	Categories		t-value	p-value
Gestational age	Up to 20 weeks	Over 20 weeks		
Brief COPE	n = 84 (50.60%)	n = 82 (43.39%)		
Self-distraction	5.23 (SD = 1.74)	5.23 (SD = 1.69)	-0.02	p = 0.984
Active coping	5.46 (SD = 1.81)	5.23 (SD = 1.56)	0.885	p = 0.377
Substance use ^a	2.71 (SD = 1.23)	3.05 (SD = 1.77)	-1.41	p = 0.160
Emotional support	5.74 (SD = 1.83)	6.12 (SD = 1.54)	-1.46	p = 0.146
Instrumental support	5.15 (SD = 1.69)	5.27 (SD = 1.68)	-0.43	p = 0.665
Behaviour. disengagement	2.79 (SD = 1.05)	2.85 (SD = 1.30)	-0.37	p = 0.712
Venting	4.57 (SD = 1.85)	4.98 (SD = 1.63)	-1.49	p = 0.138
Positive reframing	4.40 (SD = 1.88)	4.28 (SD = 1.85)	0.428	p = 0.669
Planning	5.23 (SD = 1.67)	5.33 (SD = 1.90)	-0.37	p = 0.711
Acceptance	6.04 (SD = 1.62)	5.89 (SD = 1.51)	0.60	p = 0.550
Religion ^a	2.94 (SD = 1.48)	3.34 (SD = 1.89)	-1.52	p = 0.130
Self-blame	4.58 (SD = 1.90)	5.05 (SD = 1.88)	-1.58	p = 0.115
First pregnancy	First pregnancy	Not first pregnancy		
Brief COPE	n = 70 (42.17%)	n = 96 (57.83%)		
Self-distraction	5.27 (SD = 1.60)	5.20 (SD = 1.80)	0.273	p = 0.786
Active coping	5.49 (SD = 1.61)	5.25 (SD = 1.75)	0.886	p = 0.377
Substance use	2.76 (SD = 1.46)	2.97 (SD = 1.57)	-0.882	p = 0.379
Emotional support	6.03 (SD = 1.74)	5.85 (SD = 1.67)	0.651	p = 0.516
Instrumental support	5.31 (SD = 1.71)	5.14 (SD = 1.66)	0.676	p = 0.500
Behaviour. disengagement	2.86 (SD = 1.08)	2.79 (SD = 1.26)	0.351	p = 0.726
Venting	5.03 (SD = 1.76)	4.58 (SD = 1.73)	1.624	p = 0.106
Positive reframing ^a	4.19 (SD = 1.70)	4.46 (SD = 1.98)	-0.953	p = 0.342
Planning	5.59 (SD = 1.72)	5.05 (SD = 1.81)	1.918	p = 0.057
Acceptance	5.79 (SD = 1.56)	6.09 (SD = 1.56)	-1.258	p = 0.210
Religion	3.34 (SD = 1.82)	2.99 (SD = 1.59)	1.327	p = 0.186
Self-blame	4.97 (SD = 1.94)	4.70 (SD = 1.88)	0.914	p = 0.362

Table 5.13. Differences in the use of coping strategies by other termination-related variables (continued)

<i>Variables</i>	<i>Categories</i>		<i>t-value</i>	<i>p-value</i>
<i>Abnormality prognosis</i>	<i>Incompatible with life</i>	<i>Compatible with life</i>		
Brief COPE	<i>n = 68 (45.36%)^b</i>	<i>n = 81 (54.36%)^b</i>		
Self-distraction	5.35 (<i>SD</i> = 1.86)	5.38 (<i>SD</i> = 1.59)	-0.11	<i>p</i> = 0.916
Active coping	5.50 (<i>SD</i> = 1.82)	5.22 (<i>SD</i> = 1.64)	0.98	<i>p</i> = 0.329
Substance use	2.83 (<i>SD</i> = 1.51)	3.05 (<i>SD</i> = 1.63)	-0.81	<i>p</i> = 0.418
Emotional support	5.96 (<i>SD</i> = 1.62)	5.84 (<i>SD</i> = 1.75)	0.418	<i>p</i> = 0.677
Instrumental support	5.24 (<i>SD</i> = 1.60)	5.20 (<i>SD</i> = 1.72)	0.138	<i>p</i> = 0.891
Behaviour. disengagement ^a	2.96 (<i>SD</i> = 1.43)	2.70 (<i>SD</i> = 0.98)	1.232	<i>p</i> = 0.221
Venting	4.85 (<i>SD</i> = 1.81)	4.65 (<i>SD</i> = 1.67)	0.694	<i>p</i> = 0.489
Positive reframing	4.47 (<i>SD</i> = 1.95)	4.20 (<i>SD</i> = 1.71)	0.911	<i>p</i> = 0.364
Planning	5.47 (<i>SD</i> = 1.74)	5.21 (<i>SD</i> = 1.77)	0.904	<i>p</i> = 0.368
Acceptance	6.10 (<i>SD</i> = 1.69)	5.81 (<i>SD</i> = 1.48)	1.11	<i>p</i> = 0.270
Religion	3.35 (<i>SD</i> = 1.78)	3.01 (<i>SD</i> = 1.66)	1.21	<i>p</i> = 0.229
Self-blame	4.97 (<i>SD</i> = 1.80)	4.68 (<i>SD</i> = 1.97)	0.936	<i>p</i> = 0.351

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category (*n* = 149)

5.3.2.2.3 Summary of the results pertaining to women's use of coping strategies

Women used mainly strategies considered to be adaptive (Aldao & Nolen-Hoeksema, 2012; Carver, 1997; Lazarus & Folkman, 2004) to cope with TFA. These included: 'acceptance,' 'emotional support,' 'active coping,' 'planning,' 'instrumental support.' Women also made use of 'self-distraction,' a strategy often considered as maladaptive. Group differences were noted according to demographic, obstetric and termination-related variables, but all were of a small to medium magnitude. Women who were educated at university level were more likely to seek 'instrumental support' and 'plan' a strategy on how to deal with TFA. Women of higher socioeconomic status made greater use of 'emotional support,' whilst those of lower socioeconomic status were more likely to rely upon 'substance use.' Women who had terminated their pregnancy most recently (up to six months prior to study participation) made

greater use of 'instrumental support,' 'emotional support' and 'venting' than those whose loss was less recent. The results also indicate that the absence of children at the time of TFA and following TFA was associated with greater use of 'planning.' Women who underwent a medical termination reported greater use of 'emotional support' than those who had a surgical termination. Women who felt comfortable with their decision to terminate relied more on 'emotional support' and 'venting' and less on 'self-blame' than women uncomfortable with their decision. The latter finding may indicate the importance of the concept of guilt as an influential element in the process of TFA. There were no significant differences according to gestational age, abnormality prognosis, or whether this was a woman's first pregnancy.

5.3.3 Women's levels of perinatal grief

Similarly to the coping strategies, women's levels of perinatal grief were examined descriptively at the overall level and according to demographic, obstetric and termination-related variables.

5.3.3.1 General levels of perinatal grief

The analysis revealed that the mean scores for the three grief subscales decreased progressively indicating incremental levels of pathological grief. Mean scores for 'active grief' ($M = 41.5$) and 'total PGS' ($M = 104.1$) were above the midpoint (33 and 99 respectively), whereas mean scores for 'difficulty coping' ($M = 33.1$) and 'despair' ($M = 29.5$) were on or below the midpoint. Mean scores for the grief variables are shown in Table 5.14.

Table 5.14. Mean scores, standard deviations and Cronbach's values for the Short PGS

Variables	Mean	SD	Cronbach's values
Short PGS (N = 166)			
Active grief (11-55)	41.53	7.08	0.83
Difficulty coping (11-55)	33.11	8.62	0.86
Despair (11-55)	29.49	7.99	0.83
Total PGS (33-165)	104.14	21.58	0.93

Values above the scales' midpoints are highlighted in bold; active grief, difficulty coping and despair: > 33 and total PGS: > 99

5.3.3.2 Group differences in women's levels of grief

Similarly to the coping strategies, women's levels of perinatal grief were examined for differences according to demographic, obstetric and termination-related variables.

5.3.3.2.1 Differences in levels of perinatal grief by demographic variables

Differences in levels of perinatal grief were assessed in relation to age, level of education and socioeconomic status. Differences in levels of grief according to age were assessed using the two-category grouping described in section 5.3.2.2.1, which comprised 'up to 34 years old' and '35 years old or older.' An unrelated *t* test showed that women aged up to 34 years old ($M = 42.58$, $SD = 6.52$) displayed significantly higher levels of 'active grief' than women aged 35 and above ($M = 40.35$, $SD = 7.53$), $t(164) = 2.05$, $p < 0.05$, $r = 0.16$. Levels of perinatal grief were also examined by level of education and socioeconomic status through unrelated *t* tests. No significant differences in grief levels were observed across these groups ($p > 0.05$). These results are displayed in Table 5.15.

Table 5.15. Differences in levels of perinatal grief by demographic variables

Variables	Categories		t-value	p-value
Age	Up to 34 years old	35 years and above		
Short PGS	n = 88 (53.01%)	n = 78 (46.97%)		
Active grief	42.58 (SD = 6.52)	40.35 (SD = 7.53)	2.049	p = 0.042*
Difficulty coping	34.06 (SD = 8.25)	32.05 (SD = 8.96)	1.502	p = 0.135
Despair	30.22 (SD = 8.42)	28.68 (SD = 7.44)	1.239	p = 0.217
Total PGS	106.85 (SD = 20.89)	101.08 (SD = 22.07)	1.731	p = 0.085
Level of education	Secondary education	Higher education		
Short PGS	n = 49 (29.51%)	n = 117 (70.48%)		
Active grief	42.14 (SD = 6.76)	41.27 (SD = 7.22)	0.721	p = 0.472
Difficulty coping	32.57 (SD = 8.88)	33.45 (SD = 8.54)	-0.524	p = 0.601
Despair	30.65 (SD = 8.99)	29.01 (SD = 7.52)	1.211	p = 0.227
Total PGS	105.37 (SD = 23.08)	103.62 (SD = 21.01)	0.474	p = 0.636
Socioeconomic status	AB	C1C2D		
Short PGS	n = 129 (79.62%)^b	n = 33 (20.37%)^b		
Active grief	41.19 (SD = 6.98)	42.42 (SD = 7.69)	-0.891	p = 0.375
Difficulty coping	32.91 (SD = 8.37)	33.52 (SD = 9.84)	-0.359	p = 0.720
Despair	29.22 (SD = 7.88)	30.73 (SD = 8.66)	-0.962	p = 0.337
Total PGS	103.31 (SD = 21.14)	106.67 (SD = 24.06)	-0.791	p = 0.430

^b Percentages based on participants who could be classified in either category (n = 162);

* p < 0.05, ** p < 0.01, *** p < 0.001

5.3.3.2.2 Differences in levels of perinatal grief by obstetric and termination-related variables

Differences in levels of perinatal grief were examined according to time elapsed since TFA, number of pregnancies, number of children at the time of TFA, gestational age at TFA, abnormality prognosis, method of termination, women's reproductive history post-TFA, and how women felt about their decision to terminate. The variables exhibiting at least one significant group difference are presented first. These include: time elapsed since TFA,

children at the time of TFA, first pregnancy, children following TFA and feeling about the decision to terminate. The results for these variables are shown in Table 5.16.

Time elapsed since TFA

Women's levels of grief were analysed according to the 'time elapsed since TFA' using a one-way unrelated ANOVA. The analysis indicated a main effect of time elapsed on 'active grief' $F(3,162) = 8.41$ $p < 0.001$, 'difficulty coping,' $F(3,162) = 3.10$, $p < 0.05$, and 'total PGS' $F(3,162) = 3.64$, $p < 0.05$, all with a small to medium effect size ($\omega^2 = 0.12$, $\omega^2 = 0.04$ and $\omega^2 = 0.05$ respectively). *Post hoc* tests with the Bonferroni correction revealed that women who had terminated their pregnancy up to six months prior to study participation displayed significantly higher levels of 'active grief' than women who had terminated their pregnancy 13-24 months ($M = 43.80$, $SD = 6.13$ vs. $M = 38.64$, $SD = 6.61$, $p < 0.01$) or over 24 months prior to taking part in the study ($M = 43.80$, $SD = 6.13$ vs. $M = 36.53$, $SD = 9.36$, $p < 0.01$). They also displayed significantly higher levels of 'total PGS' compared to women in the 13-24 months category ($M = 108.66$, $SD = 20.41$ vs. $M = 96.39$, $SD = 19.76$, $p < 0.05$). There were no significant pairwise differences for 'difficulty coping.'

Children at the time of TFA

Levels of grief varied according to whether women had children at the time of the termination. Women who were childless at the time of TFA displayed significantly higher levels of grief on all grief variables. Effect sizes were, however, of a small to medium magnitude: 'active grief' $r = 0.18$, 'difficulty coping' $r = 0.20$, 'despair' $r = 0.25$ and 'total PGS' $r = 0.23$.

First pregnancy

Comparable patterns were noted according to whether this was a woman's first pregnancy or not. Women for whom this was the first pregnancy exhibited significantly higher levels of

grief on all grief variables. Effect sizes were also of a small to medium magnitude 'active grief' $r = 0.22$, 'difficulty coping' $r = 0.18$, 'despair' $r = 0.22$ and 'total PGS' $r = 0.22$.

Children following TFA

Grief levels were compared according to whether women had had children since the termination (or were pregnant at the time of the study) or not. Women who had not had children since TFA displayed significantly higher levels of grief compared to women who had had children/were pregnant following the termination on all grief variables except 'despair.' Effect sizes were of a medium magnitude for the three variables: 'active grief' $r = 0.29$, 'difficulty coping' $r = 0.26$ and 'total PGS' $r = 0.27$.

Feeling about the decision to terminate

Group differences were noted based on women's feeling about their decision to terminate. Women 'uncomfortable' with their decision scored significantly higher on the 'difficulty coping,' 'despair' and 'total PGS' subscales than women 'comfortable' with their decision. These differences were of small to medium magnitude ($r = 0.23, 0.35$ and 0.26 respectively).

Table 5.16. Differences in levels of perinatal grief by time since TFA, children at TFA, first pregnancy, children following TFA and feeling about the decision to terminate

Variables	Categories			
Time since TFA	Up to 6 months	7-12 months	13-24 months	24+
Short PGS	n = 88 (53.01%)	n = 35 (21.08%)	n = 28 (16.87%)	n = 15 (9.04%)
Active grief	43.80 (SD= 6.13)	40.29 (SD = 6.58)	38.64 (SD=6.61)**	36.53(SD=9.36)**
Difficulty coping ⁺	34.72 (SD= 8.56)	33.00 (SD = 8.25)	30.14 (SD= 8.24)	29.53 (SD=8.78)
Despair	30.15 (SD= 7.74)	29.71 (SD = 9.07)	27.61 (SD = 7.20)	28.67 (SD=8.33)
Total PGS	108.66 (SD=20.41)	103.00 (SD= 22.09)	96.39 (SD=19.76)*	94.73 (SD=24.83)
Children at TFA	No children	Children	t-value	p-value
Short PGS	n = 89 (53.61 %)	n = 77 (46.39%)		
Active grief	42.73 (SD = 6.56)	40.14 (SD = 7.44)	2.382	p = 0.018*
Difficulty coping	34.75 (SD = 8.24)	31.22 (SD = 8.71)	2.681	p = 0.008**
Despair	31.34 (SD = 7.99)	27.36 (SD = 7.49)	3.289	p = 0.001**
Total PGS	108.82 (SD=20.58)	98.72 (SD=21.58)	3.081	p = 0.002**
First Pregnancy	Yes	No		
Short PGS	n = 70 (42.17%)	n = 96 (57.83%)		
Active grief	43.33 (SD = 6.11)	40.22 (SD = 7.46)	2.856	p = 0.005**
Difficulty coping	34.86 (SD = 7.93)	31.84 (SD = 8.92)	2.251	p = 0.026*
Despair	31.50 (SD = 7.85)	28.03 (SD = 7.81)	2.820	p = 0.005**
Total PGS	109.69 (SD=19.69)	100.09 (SD=22.10)	2.890	p = 0.004**
Children since TFA	No children	Children		
Short PGS	n = 113 (68.07%)	n = 53 (31.93%)		
Active grief	42.52 (SD = 6.40)	39.42 (SD =8.00)	2.686	p = 0.008**
Difficulty coping	34.26 (SD = 8.20)	30.68 (SD = 9.06)	2.533	p = 0.012*
Despair	30.18 (SD = 7.58)	28.04 (SD = 7.58)	1.16	p = 0.108
Total PGS	106.96 (SD=19.98)	98.13 (SD=23.75)	2.494	p = 0.014*
Feeling about decision	Comfortable	Uncomfortable		
Short PGS	n = 122 (73.49%)	n = 44 (26.51%)		
Active grief	41.10 (SD = 7.02)	42.73 (SD = 7.18)	-1.312	p = 0.191
Difficulty coping	32.05 (SD = 8.39)	36.07 (SD = 8.67)	-2.701	p = 0.008**
Despair	27.98 (SD = 7.58)	33.68 (SD = 7.66)	-4.262	p < 0.001***
Total PGS	101.13 (SD= 20.73)	112.48 (SD= 21.95)	-3.064	p = 0.003**

⁺Groups compared against the group whose loss was most recent (up to six months), * p < 0.05, ** p < 0.01, *** p < 0.001.

Other obstetric and termination-related variables

Analyses were also carried out by gestational age (up to 20 weeks vs. over 20 weeks), abnormality prognosis (incompatible vs. compatible with life) and termination method (medical vs. surgical). These did not show any significant group differences in grief levels. Results for these variables are displayed in Table 5.17.

Table 5.17. Differences in levels of perinatal grief by other termination-related variables

Variables	Categories		t-value	p-value
Gestational age	Up to 20 weeks	Over 20 weeks		
Short PGS	n = 84 (50.60%)	n = 82 (43.39%)		
Active grief	41.06 (SD = 6.94)	42.01 (SD = 7.23)	-0.867	p = 0.387
Difficulty coping	32.07 (SD = 8.38)	34.18 (SD = 8.78)	-1.585	p = 0.115
Despair	29.14 (SD = 8.39)	29.85 (SD = 7.60)	-0.572	p = 0.568
Total PGS	102.27 (SD = 21.54)	106.05 (SD = 21.59)	-1.128	p = 0.261
Abnormality prognosis	Incompatible with life	Compatible with life		
Short PGS	n = 68 (45.36%)^b	n = 81 (54.36%)^b		
Active grief	41.87 (SD = 6.90)	41.75 (SD = 6.65)	0.103	p = 0.918
Difficulty coping	33.56 (SD = 8.00)	33.11 (SD = 9.10)	0.316	p = 0.753
Despair	30.72 (SD = 8.09)	28.57 (SD = 7.90)	1.639	p = 0.103
Total PGS	106.15 (SD = 20.73)	103.43 (SD = 21.72)	0.776	p = 0.439
Termination method	Medical	Surgical		
Short PGS	n = 129 (77.71%)^b	n = 36 (21.69%)^b		
Active grief	41.64 (SD = 7.26)	40.86 (SD = 6.33)	0.587	p = 0.558
Difficulty coping ^a	33.25 (SD = 9.03)	32.44 (SD = 7.09)	0.564	p = 0.574
Despair	29.42 (SD = 7.93)	29.67 (SD = 8.38)	-0.164	p = 0.870
Total PGS	104.31 (SD = 22.33)	102.97 (SD = 18.95)	0.328	p = 0.743

^a Equality of variance not assumed; Percentages based on participants who could be classified in either category: abnormality prognosis (n = 149), termination method (n = 165)

5.3.3.2.3 Summary of the results pertaining to women's levels of grief

Despite using mainly adaptive coping strategies (see section 5.3.2), women's levels of grief were high and above the midpoint for 'active grief' and 'total PGS.' There were also significant group differences in women's levels of grief according to obstetric and termination-related variables, but these were of a small to medium size. Significantly higher levels of grief were noted among women who were childless at the time of TFA (all four grief variables), for whom it was the first pregnancy (all four grief variables), who had not had children/were not pregnant following TFA ('active grief,' 'difficulty coping,' 'total PGS'), who were uncomfortable with their decision ('difficulty coping,' 'despair' and 'total PGS') and whose termination occurred up to six months prior to study participation ('active grief' and 'total PGS'). Thus, time and the presence of children may contribute to mitigating psychological distress. Importantly, women uncomfortable with their decision to terminate displayed higher levels of grief than those who were comfortable, particularly on the 'despair' subscale. This emphasises the importance for women to reach a decision they feel comfortable with. Differences across age groups were also noted, with women under 35 years old displaying higher levels of 'active grief' than women aged over 35. However, these differences were of a small magnitude. No significant group differences in levels of grief were observed according to education level, socioeconomic status, termination method, gestational age or abnormality prognosis. Collectively, these results indicate that women's personal and familial circumstances may influence levels of grief to a greater extent than factors directly related to the terminated pregnancy (e.g. gestational age, termination method).

5.3.4 Relationship between coping strategies and perinatal grief

Analyses were run to examine the relationship between women's use of coping strategies and their levels of perinatal grief and to ascertain which coping strategies predicted women's levels of grief.

5.3.4.1 Correlations between variables

Pearson's correlations indicate that scores on the grief subscales were highly inter-correlated (ranging from $r = 0.70$ to 0.93). Coping strategies generally considered to be adaptive were positively correlated with each other (e.g. 'positive reframing' and 'acceptance' $r = 0.43$, $p < 0.01$) and negatively correlated with grief scales (e.g. 'acceptance' and 'total PGS' $r = -0.47$, $p < 0.01$). Similarly, strategies generally considered to be maladaptive were also correlated with each other (e.g. 'behavioural disengagement' and 'self-blame' $r = 0.22$, $p < 0.01$) and positively correlated with grief (e.g. 'behavioural disengagement' and 'total PGS' $r = 0.44$, $p < 0.01$).

Correlations between grief variables and coping strategies followed a similar pattern. 'Behavioural disengagement,' 'venting,' 'planning,' 'religion' and 'self-blame' were significantly positively correlated with all/some grief variables ($p < 0.05$). 'Behavioural disengagement,' 'planning' and 'self-blame' exhibited significant positive correlations with all four grief variables, whilst 'venting' was positively correlated with 'active grief,' 'difficulty coping' and 'total PGS,' and 'religion' with 'active grief' and 'total PGS' ($p < 0.05$). Negative correlations between 'positive reframing' and 'acceptance' were significant for all four grief variables ($p < 0.05$). 'Emotional support' was also negatively correlated with 'despair' ($p < 0.05$). Results of the correlation analyses are displayed in Table 5.18.

Correlations between grief variables and age exhibited a weak, but significant, negative correlation with 'active grief' ($r = -0.19$, $p < 0.05$) and 'total PGS' ($r = -0.17$, $p < 0.05$) indicating that as women's age increases, their levels of 'active grief' decrease. Significant negative correlations were also observed between the 'time elapsed since TFA' and 'active grief,' 'difficulty coping' and 'total PGS' ($p < 0.01$), indicating that with the passing of time, grief levels for these variables decrease. Correlation between levels of grief and gestational age were not significant ($p > 0.05$). Point-biserial correlations were also run between grief variables and dichotomous obstetric and termination-related variables (Cohen et al., 2003). These included whether the terminated pregnancy was women's first pregnancy (Yes/No), whether they had children at the time of TFA (Yes/No) or since TFA

(Yes/No), abnormality prognosis (incompatible/ compatible with life), termination method (medical/surgical), and how they felt about their decision to terminate the pregnancy (comfortable/uncomfortable). Point-biserial correlations were also run on demographic variables which used a two-category coding: e.g. education level (secondary/higher education) and socioeconomic status (AB/C1C2D). The results showed significant negative correlations between the grief variables and the presence of children suggesting that grief levels decrease with the presence of children at TFA and afterwards ($p < 0.05$). The results also indicated that, as women are more comfortable with their decision to terminate, levels of grief decrease ($p < 0.05$). Correlation analyses between grief variables and demographic, obstetric and termination-related variables are displayed in Table 5.19.

Table 5.18. Correlations between the Brief COPE and Short PGS scales

Subscales	Self distr.	Active cop.	Sub. use	Emo sup.	Instru sup.	Behav diseng	Ven-ting.	Posit. refra.	Plan-ning	Accep-tance	Reli-gion	Self-blame	Acti-grief	Diff. cop.	Des-pair
Active coping	.169*														
Substance use	.043	-.002													
Emot. support	.131	.397**	-.013												
Instru. support	.057	.401**	-.037	.610**											
Behav. diseng.	-.096	-.014	.095	-.112	.013										
Venting	.070	.324**	.008	.438**	.391**	.155*									
Positive refram	.129	.352**	.059	.276**	.228**	-.120	.046								
Planning	.172*	.474**	.019	.274**	.361**	.156*	.305**	.061							
Acceptance	.235**	.386**	.024	.358**	.181*	-.201**	.055	.425**	.141						
Religion	.016	.055	-.038	-.013	.036	.010	.015	.180*	.049	.034					
Self-blame	.075	.092	.126	-.117	-.071	.217**	.103	-.069	.210**	-.186*	.222**				
Active grief	.024	-.043	-.032	.050	.099	.344**	.246**	-.211**	.267**	-.383**	.199*	.404**			
Difficulty coping	-.040	-.092	.036	-.037	.066	.466**	.272**	-.330**	.242**	-.438**	.122	.477**	.755**		
Despair	-.015	-.045	.011	-.187*	-.076	.372**	.132	-.244**	.182*	-.446**	.152	.540**	.704**	.769**	
Total PGS	-.013	-.067	.008	-.068	.031	.437**	.238**	-.291**	.252**	-.466**	.170*	.523**	.890**	.931**	.908*

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 5.19. Correlations between the Short PGS scales and demographic, obstetric and termination-related variables

<i>Variables</i>	<i>Active grief</i>	<i>Difficulty coping</i>	<i>Despair</i>	<i>Total PGS</i>
Age	-.194*	-.130	-.149	-.171*
Education level†	-.056	.041	-.094	-.037
Socioeconomic status†	.091	.045	.065	.072
Time since TFA	-.362**	-.229**	-.101	-.248**
Gestational age†	.068	.123	.045	.088
First pregnancy†	-.218**	-.173*	-.215**	-.220**
Children at time of TFA†	-.183*	-.205**	-.249**	-.234**
Children since TFA†	-.273**	-.244**	-.166*	-.248**
Feeling about decision†	.102	.206**	.316**	.233**
Abnormality prognosis†	-.008	-.026	-.134	-.064
Termination method†	-.046	-.039	-.013	-.026

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; † Point-biserial correlations

5.3.4.2 Predicting levels of grief: regression analyses

5.3.4.2.1 Methodological elements

Multiple hierarchical regression analyses were run to predict which coping strategies predicted levels of perinatal grief and to ascertain whether demographic, obstetric and termination-related variables had any predictive value above and beyond the coping strategies (see chapter 3, section 3.2.4.2 for further details on regression analyses).

Variables showing a significant correlation with grief variables were used as predictors in the multiple regression analyses (Field, 2009; Tabachnik & Fidell, 2007). Individual models were run for each grief variable based on their own set of predictors as identified by the correlation analyses. For example, the model for 'active grief' used the predictors 'behavioural disengagement,' 'venting,' 'positive reframing,' 'planning,' 'acceptance,' 'religion,' 'self-blame,' 'time elapsed since TFA,' 'children at the time of TFA,' 'children since TFA,' 'feeling about the decision' because these variables exhibited significant correlations with this variable (see Tables 5.18 and 5.19).

Although the 'first pregnancy' variable was significantly correlated with all grief variables, it was excluded from the analysis because it was highly correlated with the 'having children at the time of TFA' variable ($r = 0.81, p < 0.001$) and found to be statistically less powerful in detecting significant differences. Furthermore, the variable 'having children at the time of TFA' reflects women's obstetric history more accurately than the 'first pregnancy' does because the number of pregnancies does not necessarily equate to the number of living children. Similarly, although 'age' was significantly negatively correlated with 'active grief' and 'total PGS' ($p < 0.05$), its predictive value was weak and thus, this variable was removed from the analysis. As one of the aims of regression analysis is to identify the minimum number of predictors with the highest predictive value (Tabachnick & Fidell, 2007), the removal of these two variables enhances the analysis.

5.3.4.2.2 Results from regression analyses

The regression results are displayed in Table 5.20. 'Active grief' was positively predicted by 'self-blame,' 'religion,' 'planning' and 'behavioural disengagement' and negatively predicted by 'acceptance' and 'longer time elapsed since termination.' 'Difficulty coping' was positively predicted by 'self-blame,' 'behavioural disengagement,' 'venting' and 'feeling uncomfortable about the decision;' 'difficulty coping' was negatively predicted by 'acceptance,' 'positive reframing,' 'longer time elapsed since termination,' 'having living children at the time of TFA' and by 'having had children/being pregnant following TFA.'

'Despair' was positively predicted by 'self-blame,' 'behavioural disengagement' and 'feeling uncomfortable about the decision' and negatively predicted by 'acceptance,' 'having living children at the time of TFA' and 'having had children/being pregnant following TFA.' 'Total PGS' was positively predicted by 'self-blame,' 'behavioural disengagement,' 'venting,' 'planning,' 'religion' and 'feeling uncomfortable about the decision' and negatively predicted by 'acceptance,' 'positive reframing,' 'longer time elapsed since termination,' 'having living children at the time of TFA' and 'having had children/being pregnant following TFA.'

Overall, 'time elapsed since TFA' was a significant predictor of 'active grief,' 'difficulty coping' and 'total PGS.' The absence of children at the time of TFA and since TFA (or being pregnant), alongside feeling uncomfortable with the decision to terminate, were significant predictors of the more pathological levels of grief ('difficulty coping' and 'despair'). Both 'self-blame' and 'acceptance' were strong predictors of high and low levels of grief respectively for all four grief variables.

The total amount of variance explained by the models was high; 50.5% for 'active grief,' 59.7% for 'difficulty coping,' 53.3% for 'despair' and 64.6% for 'total PGS.' Variables related to the terminated pregnancy contributed to explaining between 8.6% of the variance for 'difficulty coping,' and 'despair,' 10.8% of the variance for 'total PGS' and 13.1% of the variance for 'active grief' in addition to the coping strategies. Thus, the main contribution to predicting levels of grief was accounted for by the coping strategies.

Table 5.20. Results of multiple regression analyses for the Short PGS active grief, difficulty coping, despair and total PGS scales

Variables	Active grief	Difficulty coping	Despair	Total PGS
Step 1 - Coping predictors	β	β	β	β
Behavioural disengagement	0.17*	0.27***	0.19**	0.24***
Venting	0.16*	0.18**	n/a	0.14*
Planning	0.19**	0.13*	0.12	0.15**
Religion	0.17*	n/a	n/a	0.12*
Self-blame	0.21**	0.31***	0.41***	0.33***
Positive reframing	-0.09	-0.17**	-0.06	-0.14*
Acceptance	-0.31***	-0.28**	-0.32***	-0.33***
Emotional support	n/a	n/a	-0.02	n/a
<i>F</i> model	15.33***	30.50***	23.73***	28.91***
R^2 on step 1	0.38	0.52	0.45	0.54
Step 2 – Other predictors				
Behavioural disengagement	0.13*	0.24***	0.17**	0.20***
Venting	0.09	0.16**	n/a	0.12*
Planning	0.13*	0.10	0.09	0.12*
Religion	0.17**	n/a	n/a	0.11*
Self-blame	0.27***	0.30***	0.37***	0.33***
Positive reframing	-0.11	-0.18**	-0.06	-0.14**
Acceptance	-0.28***	-0.25***	-0.29***	-0.30***
Emotional support	n/a	n/a	-0.02	n/a
Time since TFA	-0.33***	-0.17**	n/a	-0.22***
Children at TFA	-0.11	-0.12*	-0.18***	-0.15**
Children since TFA	-0.07	-0.14*	-0.20***	-0.13*
Feeling about TFA	n/a	0.15**	0.18**	0.16**
<i>F</i> model	17.86***	25.41***	21.92***	28.36***
R^2 on step 2	0.51	0.60	0.53	0.65
^a Change in R^2	0.13***	0.09***	0.09***	0.11***

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; ^a difference in R^2 on steps 1 and 2, and the significance of *F* change.

5.3.4.2.3 *Evaluating the regression models*

A number of diagnostic tests were used to evaluate the regression model. The first step was to establish whether the model was a good fit for the data. To this aim, the residuals and influential cases were examined (Field, 2009; Tabachnick & Fidell, 2007). As residuals represent the differences between predicted and observed values (Field, 2009), a model that accurately fits the data should theoretically have small residual values. Residuals were examined using z-scores (residual values divided by their standard deviation). It is recommended that 99.9% of scores should fall between -3.29 and +3.29. All z-scores were within these ranges.

The regression models were subsequently examined to identify individual cases that may unduly influence the results, using three commonly used influence statistics (Field, 2009; Tabachnick & Fidell, 2007). These are Cook's distance, leverage and DFBeta. Cook's distance values indicate the influence of a single case on the model. It is generally accepted that scores should fall below 1 (the greater the value, the stronger the influence [Field, 2009]). In this analysis, Cook's distance scores all fell within the recommended range of 1.

Next, leverage values were used to evaluate the influence of outcome cases on the predicted values. Leverage values estimates the influence of the observed value of the outcome on the predicted value (Field, 2009; Tabachnick & Fidell, 2007). Similarly to Cook's distance, the higher the leverage value is, the more influence a case may have on the data. The range for leverage values varies according to the number of predictor and the sample sizes. A simple equation is used to calculate this value. It takes into account the number of predictors plus one, divided by the sample size ($(k+1/n)$), where k is the number of predictors and n the sample size. To indicate the absence of an unduly influential case, leverage values should be lower than three times the calculated value (Field, 2009). Leverage values were calculated for each regression model as the number of predictors varied ('active grief' and 'difficulty coping' had 10 predictors: $10+1/166 = 0.066$, then $\times 3 = 0.20$; 'despair' had 9 predictors: $9+1/166 = 0.060$, then $\times 3 = 0.18$; 'total PGS' had 11 predictors: $11+1/166 = 0.072$, then $\times 3 = 0.22$). All values fell within the recommended range except for one value in

the 'active grief,' 'difficulty coping' and 'despair' models, which originated from the same participant. However, given that these values were only marginally above the maximum value (0.21 instead of 0.20 for 'active grief' and 'difficulty coping,' and 0.20 instead of 0.18 for 'despair') and that other diagnostic tests revealed no unduly influential cases, this record was kept in the data. In addition, considering that leverage values are measured using the outcomes and not the predictors, they can only provide an estimation of what the influence of predicting variables may be (Field, 2009).

Finally, DFBeta values were examined. These values estimate the model based on whether individual cases are included and excluded from the analysis (Field, 2009; Tabachnick & Fidell, 2007). Cases for which DFBeta value is greater than 1 are considered to exert a large influence in the model (Field, 2009). All DFBeta values were within the acceptable parameter (up to 1). Collectively, these influence tests showed that no individual case had an excessive influence on any of the regression models.

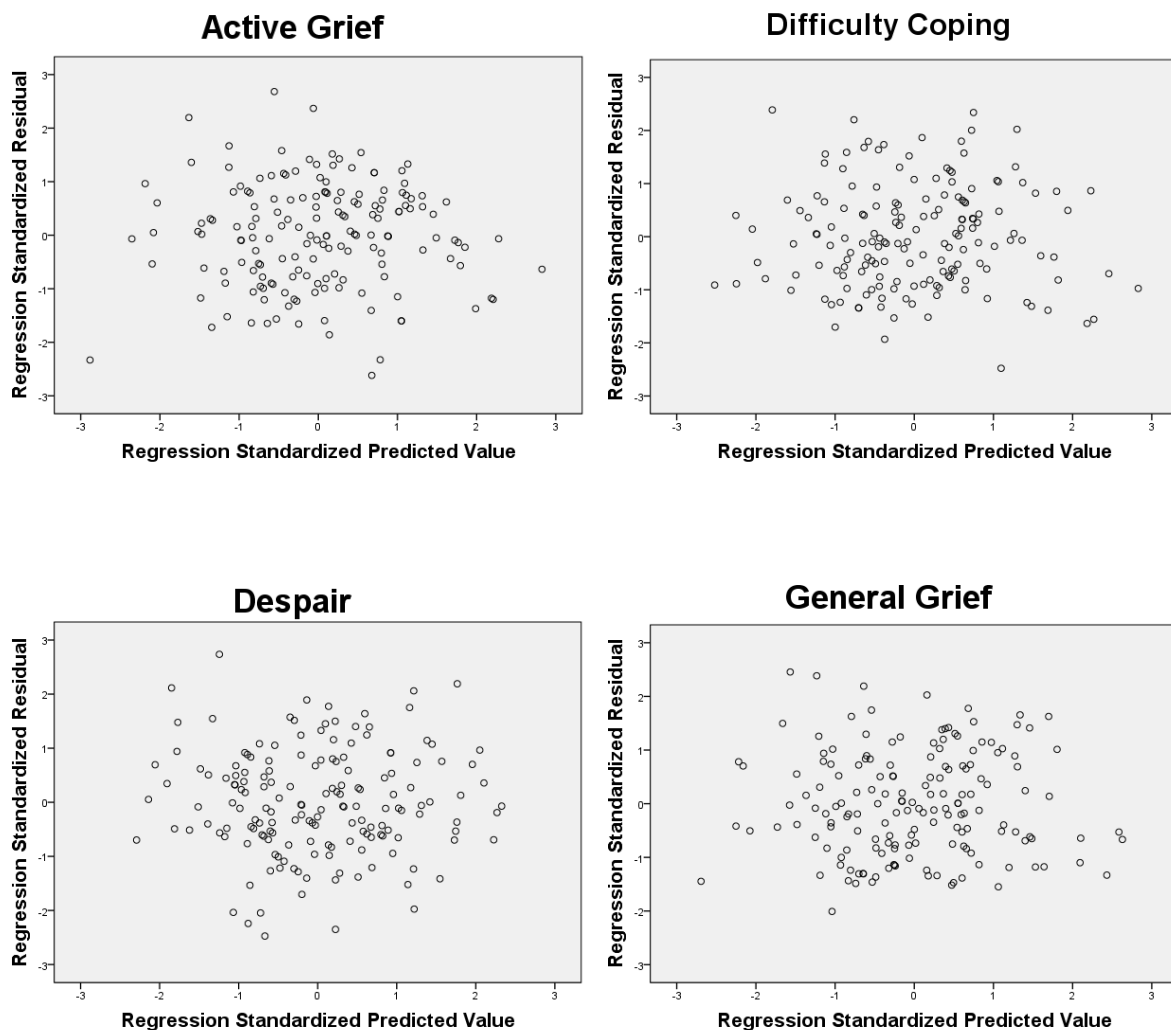
The next step was to assess whether the model could be generalised beyond the sample used in the study. This was achieved by checking a number of assumptions, which underpin the statistical robustness of regression analyses (Tabachnick & Fidell, 2007). First, the model was checked for multicollinearity, which indicates high inter-correlations between the predictor variables. The variance inflation factor (VIF) value is generally used to assess multicollinearity. It is recommended that VIF values should be below 10 and that the average VIF should not be "substantially" greater than 1 (Field, 2009, p.343). All VIF values in the models satisfied these criteria as they ranged between 1.06 and 1.55 and averaged 1.26 for 'active grief,' 1.23 for 'despair' and 1.28 for both 'difficulty coping' and 'total PGS.'

The models were also checked for independent errors, which indicate a lack of correlation between the residuals in the models. This is assessed using the Durbin-Watson statistics which run serial correlations between residuals. Values above 2 indicate a positive correlation and values below 2 a negative correlation; values less than 1 and greater than 3 are considered problematic (Field, 2009). The analyses revealed that the Durbin-Watson values for the four regression models were close to 2 (2.05 for 'active coping,' 2.1 for

'difficulty coping,' 1.92 for 'despair' and 2.03 for 'total PGS') leading to the conclusion that the residuals were not inter-correlated in any significant way.

Finally, the models were checked for linearity and homoscedasticity, which are important assumptions in regression analyses. Linearity assumes that the outcome variable is linearly related to the predictors, whilst homoscedasticity implies that the residuals (or errors in the model) have similar variance (Field, 2009; Osborne & Waters, 2002). If these assumptions are violated, they may weaken the statistical power of the model (Field, 2009; Tabachnick & Fidell, 2007). Linearity and homoscedasticity were assessed through the visual examination of the *ZRESID against *ZPRED scatterplot (Field, 2009; Osborne & Waters, 2002), which display the standardised predicted value against the standardised residual. The points on the plot should be randomly and evenly dispersed and there should not be any apparent curve in the graph. The plots for the four regression models showed linearity and homoscedasticity (see Figure 5.1). Finally, normality of the residuals was assessed through visually examining histograms and normal P-P plots. These plots revealed a fairly normal distribution of the residuals both on the histograms and the P-P plots.

Figure 5.1. Scatterplots illustrating the relationship between the standardised predicted values and the standardised residuals for each of the grief variables



5.3.4.2.4 Summary of the results pertaining to the relationship between coping strategies and perinatal grief

The results show that a relationship exists between the coping strategies used by women when dealing with TFA and their levels of perinatal grief. Women who used adaptive coping strategies such as 'acceptance' and 'positive reframing' reported lower levels of grief than those who used more maladaptive strategies such as 'self-blame' or 'behavioural disengagement.' Overall, 'acceptance,' 'self-blame,' 'behavioural disengagement' and 'time

elapsed since TFA' were the most significant and consistent predictors of grief. 'Venting,' 'planning' and 'positive reframing' also predicted grief but to a lesser extent. 'Acceptance,' 'positive reframing' and 'time elapsed since TFA' had a negative relationship with grief, indicating that these measures predicted lower levels of grief. By contrast, the other variables ('self-blame,' 'behavioural disengagement,' 'venting' and 'planning') all had a positive relationship with grief. 'Not having children at the time of TFA', 'not having had children/not being pregnant following TFA' and 'feeling uncomfortable' with the decision, also had significant positive relationships with grief, particularly with the more pathological levels of grief such as 'difficulty coping' and 'despair.' The amount of variance explained by the regression models was high (50.5-64.6%), which alongside the statistically significant reports of analysis of variance in the models, indicates that coping strategies are strong predictors of grief. Termination-related variables contributed to explaining between 9 and 13 % of the variance, which, although much smaller than the coping strategies still represents a sizeable contribution to the model. The regression models generated by the analysis were statistically robust and had strong predictive power indicating that the regression models may be generalisable to different samples.

5.3.5 Comparison between the qualitative findings and quantitative results on women's coping strategies

At the inception of this research programme, the topic of women's coping strategies when dealing with TFA had not been examined. Therefore, a robust way to gain a comprehensive understanding of what women's coping with TFA involves was to triangulate the results of the quantitative study with the findings of the qualitative investigation (Study 2a, chapter 4).

The quantitative study described in this chapter has shown that women relied upon coping strategies generally considered to be adaptive to cope with TFA, rather than on maladaptive ones. This is consistent with the findings of the qualitative investigation (Study 2a, chapter 4). The coping strategies mostly used by women ('acceptance,' 'emotional support,' 'active coping,' 'planning,' 'self-distraction,' 'instrumental support') in the quantitative

study correspond to some of the themes identified in the qualitative data. Indeed, 'active coping' and 'planning' relate to the themes of 'problem solving,' 'self-distraction' and 'avoidance.' Similarly, 'emotional and instrumental support' can be linked to the theme of 'support.' Finally, 'acknowledging and remembering the baby' relates to the theme of 'acceptance.' Although 'positive reframing' was not one of the most commonly used coping strategies in the quantitative study, it was a significant negative predictor of grief. As such, it is an important coping strategy for women, which can find its equivalent in the qualitative theme of 'meaning attribution.' This triangulation analysis shows that there are significant overlaps between the qualitative findings and the quantitative results on women's use of coping strategies, which adds credence to the overall finding that women undergoing TFA tend to rely more upon coping strategies considered to be adaptive than maladaptive ones. Comparisons between the women's coping strategies as identified by the qualitative and quantitative investigations are presented in Tables 5.21 and 5.22.

Table 5.21. Comparison between women's coping strategies used at the time of the procedure and the Brief COPE subscales

Superordinate themes	Themes	Codes	Brief COPE subscale
Receiving/providing support	Receiving support	Support from partner	Emotional support
		Support from family members	Emotional support
		Support from health professionals	Emotional support, instrumental support
		Religious support	Religion
	Providing support	Supporting partner	No equivalent
		Being strong for the baby	No equivalent
Acknowledging the baby	Spending time with the baby	The baby is real	Acceptance
		Bonding with the baby	Acceptance, positive reframing
		Baby belongs to the family	Acceptance, positive reframing
		Seeing the baby's anomalies	Acceptance
	Conferring an identity on the baby	Naming the baby	Acceptance, positive reframing
		Photos	Acceptance, positive reframing
		Clothes/teddy	Acceptance, positive reframing, active coping
	Saying goodbye	Funerals	Planning, active coping
		Having the baby blessed	Acceptance, positive reframing, religion
		Teddy/photos with the baby	Acceptance, positive reframing

Table 5.21. Comparison between women's coping strategies used at the time of the procedure and the Brief COPE subscales (continued)

Superordinate themes	Themes	Codes	Brief COPE subscale
Problem solving	Preparation	Seeking factual information	Planning, instrumental support, active coping
		Experiential knowledge	Instrumental support, emotional support, active coping
		Time to prepare	Planning, active coping
	Focusing on the task	Focusing on delivery	Planning, active coping
		Taking one step at a time	Active coping
Dissociating oneself from the procedure	Self-distraction	Watching TV	Self-distraction
		Reading newspapers/magazines	Self-distraction
	Blocking the pain	Out of body experience	Behavioural disengagement, denial
		Going on autopilot/focusing on task	Behavioural disengagement, planning, active coping
		Relying upon pain relief	Behavioural disengagement, substance use
Attributing meaning to the birth experience	Attributing meaning to the birth experience	Pain as punishment	Self-blame
		Cathartic pain	Positive reframing
		Pain as a bonding process	Positive reframing
		Expectation of a dignified birth	N/A
		Final act as a mother	Positive reframing

Table 5.22. Comparison between women's coping strategies used after the procedure and the Brief COPE subscales

Superordinate themes	Themes	Codes	Equivalent Brief COPE subscale	
Remembering the baby	Acknowledging the baby	Talking about the baby	Acceptance, venting	
		Service for the baby	Acceptance, planning, active coping	
		Giving the baby a social existence	Acceptance, positive reframing	
	Use of rituals and token acts	Visiting places of cremation/burial	Acceptance, positive reframing	
		Memory box	Acceptance, positive reframing	
		Photos	Acceptance, positive reframing	
		Tattoos	Acceptance, positive reframing	
		Planting a tree	Acceptance, positive reframing	
	Receiving/ providing support	Receiving support	Support from partner	Emotional support, instrumental support
			Support from friends, family, colleagues	Emotional support, instrumental support
Religious support			Religion	
Expectations of support			N/A	
Support from health professionals			Emotional support, instrumental support	
Counselling			Emotional support, instrumental support	
Other forms of support		Emotional support, instrumental support		
Receiving as well as providing support		Support groups - ARC	Emotional support*, instrumental support*, venting	
		Support groups - Sands	Emotional support*, instrumental support*, venting	

*Brief COPE subscales that focus on receiving support rather than providing it

Table 5.22. Comparison between women's coping strategies used after the procedure and the Brief COPE subscales (continued)

Superordinate themes	Themes	Codes	Equivalent Brief COPE subscale
Avoidance	Self-distraction	Going away	Self-distraction
		Decorating the house/moving	Self-distraction
		Keeping busy	Self-distraction
		Going back to work quickly	Self-distraction
		Taking time off work	Self-distraction
		Looking after existing children	Self-distraction
	Blocking the emotional pain	Try not to think about the baby	Denial
		Thinking practically not emotionally	Denial, active coping
		Drinking alcohol	Substance use, denial, behavioural disengagement
		Avoiding pregnant women/babies	Denial, behavioural disengagement
Looking to the future	Regaining a sense of normality	Going back to work	Active coping
		Going back into a routine	Active coping
	Reaching a sense of closure	Long and uneven process of healing	N/A
		Important milestones:	Acceptance
		Letting go of the baby	Acceptance
	Another pregnancy	Preparing for another pregnancy	Active coping, planning
		Bittersweet experience	
	Looking for positives	Positives of the decision made	Acceptance, positive reframing
		Putting the experience to good use	Acceptance, positive reframing, active coping
Positive personal growth		Acceptance, positive reframing, active coping	

5.4 Discussion

This study sought to measure the coping strategies used by women when undergoing TFA among a large sample through using psychometric measurements, and examine the relationship between the coping strategies used and women's levels of perinatal grief. The results suggest that women used coping strategies that are considered to be adaptive to deal with TFA. Yet their levels of perinatal grief were high. The results also indicate a strong relationship between the coping strategies used by women and their levels of grief. Coping strategies such as 'acceptance' and 'positive reframing,' as well as 'longer time elapsed since TFA' had a negative relationship with grief. By contrast, 'self-blame,' 'behavioural disengagement,' and to a lesser extent, 'venting,' 'planning' and 'religion' positively predicted grief. 'Not having living children at the time of TFA,' 'not having children/being pregnant following TFA' and 'feeling uncomfortable about the decision to terminate' also had a positive predictive value on grief. These findings are discussed in the next sections. An evaluation of the study's limitations is presented at the end of the discussion section. The study's implications in terms of theory, practice and further research are discussed in detail in chapter 8.

5.4.1 Women's use of coping strategies

The findings of the study indicate that to cope with TFA women relied to a greater extent on coping strategies generally considered to be adaptive than maladaptive. This finding is consistent with the findings of Study 2a (chapter 4). The triangulation analysis between the two studies therefore provides robust evidence of women's coping processes when dealing with TFA. The pattern of scores for the use of coping strategies observed in this study, were comparable to other studies using the Brief COPE (Perczek, Carver, Price, & Pozo-Kaderman, 2000). Higher scores for strategies such as 'acceptance,' 'support,' 'planning' and 'active coping,' and lower scores for strategies such as 'behavioural disengagement' and 'substance use,' were observed. These patterns were comparable with a study about coping with abortion (Major, Richards, Cooper, Cozzarelli & Zubek, 1998). Although the

Major et al. study (1998) used the long version of the COPE measure (Carver et al., 1989), it suggested that to cope with abortion, women rely more upon 'acceptance' and 'positive reframing' than on avoidant strategies (e.g. 'denial' and 'disengagement'). A recent study addressing coping with TFA (Nazaré et al., 2013) shows a similar pattern. The study by Nazaré et al. (2013), which looked at gender differences in coping with TFA and levels of grief, also indicates that women coping with TFA use 'acceptance,' 'positive reframing,' 'active coping' and 'emotional support' to a greater extent than 'denial.' However, given that several of the Brief COPE subscales were excluded from the analysis due to having low internal reliability, it is difficult to make a direct comparison between the two studies. Participants' reliance on emotional and instrumental support is also consistent with their membership of ARC and the fact that women may view their engagement with this support group as a coping strategy in itself.

5.4.2 Women's levels of perinatal grief

The mean scores for the three Short PGS subscales, which reflect incremental levels of pathological grief, decreased progressively. The scores for 'active grief,' which corresponds to 'uncomplicated grief,' were higher than the scores for 'difficulty coping,' which themselves were higher than the scores for 'despair.' Both 'difficulty coping' and 'despair' characterise 'complicated grief,' with 'despair' being a more severe outcome than 'difficulty coping.' This pattern of scores is consistent with other studies using the Short PGS in the context of perinatal loss (Toedter et al., 2001), TFA (Hunfeld et al., 1994; Nazaré et al., 2013) and pregnancy following perinatal loss (Gaudet et al., 2010).

However, despite the use of adaptive coping strategies, women's levels of grief in this study were higher than in other studies using the Short PGS (Hunfeld et al., 1994; Lasker & Toedter, 1991; Nazaré et al., 2013; Toedter et al., 2001). Furthermore, a significant proportion of participants displayed pathological levels of grief meeting the criteria for complicated grief as defined by Toedter and colleagues (2001). In their review of 22 studies using the Short PGS, Toedter and colleagues suggested that scores above 34 for 'active

grief,' 30 for 'difficulty coping,' 27 for 'despair' and 91 for 'total PGS' indicated 'complicated grief' (Toedter et al., 2001). In this study, 79.5% ($n = 132$) of the women scored above 34 for 'active grief,' 59.6% ($n = 99$) above 30 for 'difficulty coping,' 56.6% ($n = 94$) above 27 for 'despair' and 69.9% ($n = 116$) above 91 for 'total PGS.' Similarly, in a study by Hunfeld et al. (1994) into women's emotional responses to induced delivery following a diagnosis of severe fetal abnormality, the mean scores for the 'total PGS' scale ranged between 76 and 85, well below the levels observed in this study (104.1). This finding is clinically relevant given that 'complicated grief' has recently been added to the *DSM-V* (APA, 2013) as a distinct disorder. Whilst some researchers have argued that this inclusion is necessary to ensure that those suffering receive help (Shear et al., 2011), others have raised issues of false-positive diagnosis and warned against the medicalisation of normal human emotions (Wakefield, 2012). The implications of this finding are further discussed in chapter 8 (8.4.2.1).

5.4.3 The relationship between coping strategies and levels of perinatal grief

This study also demonstrates that a relationship exists between the coping strategies used by women when dealing with TFA and their levels of grief. Women who reported using strategies such as 'acceptance' and 'positive reframing' reported lower levels of grief than those who used more maladaptive strategies such as 'self-blame' or 'behavioural disengagement.' This finding supports the view that the use of maladaptive strategies may lead to poorer psychological outcomes (Aldao & Nolen-Hoeksema, 2012; Cartwright et al., 2009; Carver & Connor-Smith, 2010; Lazarus & Folkman, 1984; Moskowitz et al., 2009). It is also consistent with the Nazaré et al. study (2013), which shows that 'self-blame' predicts higher levels of 'active grief,' 'difficulty coping' and 'despair.'

The importance of 'self-blame' may reflect characteristics unique to TFA, as seen in the study by Nazaré et al. (2013). In a separate investigation, Nazaré et al. (2014) examined trauma following TFA and found that 'guilt,' a construct close to 'self-blame,' significantly influenced grief symptomatology. Indeed, it may be unsurprising that some women

experience a degree of 'self-blame' given that they, and their partners, bear the responsibility for terminating their pregnancy. Thus, in the context of TFA, 'self-blame' may reflect a feeling inherent to the nature of the loss rather than a coping strategy *per se*.

The high levels of grief observed in the presence of adaptive coping strategies also calls into question the rationale for categorising coping strategies into adaptive versus maladaptive. This issue has been discussed at the end of chapter 4 (section 4.4.6) and the theoretical implications of such a distinction are discussed in chapter 8 (section 8.4.1.1).

5.4.4 Other factors contributing to women's high levels of grief

Levels of grief in this study varied on the basis of obstetric and termination-related variables, with higher levels of grief recorded among women who had undergone TFA more recently (six months prior to study participation), those who were childless at the time of TFA, those who were not pregnant or had not had children since TFA and those who were uncomfortable with the decision to terminate their pregnancy. Similar findings have been reported in the TFA literature (Fisher & Statham, 2009; Korenromp et al., 1992; Statham et al., 2001; Statham, 2002). Whilst it is impossible to modify some of these factors (women's past and current obstetric situation, time elapsed since TFA), it may be possible to help women reach a decision they feel comfortable with and help them accept their decision in the long-term. This is particularly important given that, in this study, over a quarter of the women were categorised as being 'uncomfortable' with their decision.

The high levels of grief observed in this study may be explained by a number of factors. Firstly, over half of the participants had experienced their loss up to six months prior to participating in the study, and evidence has shown that emotional distress peaks in the first year following TFA (Korenromp et al., 2009). This study supports this finding as levels of grief were lower as time elapsed. Secondly, the use of a support group may also be related to levels of grief as all participants were, to some degree, active on the support group email network or forum. It is plausible that women who experience high levels of emotional distress may be more likely to use an online support group. However, it is also possible that women

who do not seek online support may experience even higher levels of grief. There is currently no evidence to indicate the direction of the relationship, if any.

Thirdly, it is also possible that the way in which people use an online support group may influence their emotional wellbeing. The health benefits of self-disclosure, a central component of using online support groups, have been well-documented (Pennebaker, 1989; Stanton et al., 2002). However, direct evidence of the psychological benefits of engagement with online support groups is inconclusive (Eysenbach et al., 2004). Some studies suggest that using an online support group may provide a forum for self-expression, social support and a sense of empowerment, which collectively act as a buffer against distress (Barak et al., 2008; Coulson & Shaw, 2013). However, another line of evidence suggests a more complex relationship. A study of peer-to-peer interactions in an online support group for women with breast cancer indicates that members who concentrate on their own story tend to experience more psychological distress than those open to the story of other members (Han et al., 2008). Although the causal direction of this relationship is difficult to determine, this may support the study's finding linking venting to poorer psychological adjustment.

Other studies have also underlined the potential for the use of online support groups to lead to rumination (Eysenbach et al., 2004; Malik & Coulson, 2008). Thus, the nature of interactions and the depth of involvement in the support group may influence women's psychological adjustment. In line with this hypothesis, evidence suggests that women who do not seek professional help following TFA and do not engage in bereavement ritual adjust better than those who do (Green & Statham, 2007).

5.4.5 Limitations of the study

This study has several limitations. The first three have been partly discussed in chapter 4 section 4.4.7. The first limitation relates to the type of sample used and the participants' membership of an online support group, and whether this may lead to better psychological adjustment following life events (also see section 5.4.4) and over-representation of some coping strategies (i.e. emotional and instrumental support). The second limitation concerns

the retrospective nature of the study and raises the potential for cognitive dissonance (Festinger et al., 1956) and *post hoc* rationalisation. The third limitation lies in the participants' demographic profile. The majority of women were educated at university-level, which may impact upon their experience and the answers they provide. Furthermore, a clear bias towards the White British ethnic group was evident in this study. Although this profile may be a valid reflection of ARC's support group's membership, it may not be representative of all women experiencing TFA. However, given that no demographic profile of the ARC members or of the population of women undergoing TFA as a whole is available, it is not possible to ascertain the extent of this potential bias. In addition, some TFA studies have reported similar sampling issues (Korenromp et al., 2009; McCoyd, 2007). It is possible that it may be a reflection of the women who choose to participate in research on TFA.

A final limitation of the study concerned the research design. Given that a cross-sectional design was used in this study, it is not possible to identify the directional causality between women's coping strategies and their grief levels. It would be needed to gain insights into these questions. A longitudinal design would also enable the cross-validation of self-reports to address possible *post hoc* rationalisation or social desirability bias in women's responses.

5.5 Conclusions and implications for the thesis

This study indicates that women used mostly strategies that are considered to be adaptive to cope with TFA. Yet their levels of grief were high and varied according to demographic, obstetric and termination-related variables. The study also shows that the use of strategies such as 'acceptance' and 'positive reframing' is associated with lower levels of grief, and that 'self-blame' plays an important part in the process of coping with TFA. These findings have a number of practical implications for theory, practice and further research, which are discussed in detail in chapter 8.

The findings of this study have two main implications for the development of the research reported in this thesis. Firstly, by identifying that coping strategies such as 'acceptance' and 'positive reframing' may mitigate distress following TFA, it further supports the rationale for investigating the concept of posttraumatic growth in the context of TFA. This rationale was already underpinned by the findings from the meta-ethnography (Study 1, chapter 2) and the qualitative investigation into women's coping strategies (Study 2a, chapter 4). Posttraumatic growth is associated with the process of finding meaning (Linley & Joseph, 2011), and implies high levels of cognitive processing (Tedeschi & Calhoun, 2004). It is likely that 'acceptance' and 'positive reframing' may be part of that cognitive processing. The concept of posttraumatic growth is examined more fully in Study 4 (chapter 7).

Secondly, collectively the findings of Studies 2a and 2b provide comprehensive insights into the way women cope with TFA, which should be informative to health professionals involved in caring for these women. However, little is known about how much health professionals understand of what coping with TFA involves for these women. This question is important because to provide appropriate care to women undergoing TFA, health professionals need to understand what women may be experiencing and what their coping strategies may be. This may require training health professionals in this area. Chapter 6 focuses on health professionals' perceptions of women's coping. It describes a qualitative study, which examines the congruence between health professionals' and women's accounts of coping with TFA with a view to identify any commonalities and differences between the two groups.

Chapter 6 - Health professionals' perceptions of women's coping with pregnancy termination for fetal abnormality

This chapter describes the research's third empirical study (Study 3), which investigates health professionals' perceptions of women's coping with TFA and assesses to what extent these perceptions are congruent with women's accounts. The chapter provides an overview of the qualitative methodology used in the study (discussed in more detail in chapter 3, section 3.3.2). It contains a detailed profile of the participants and presents the themes identified in the data. The findings section is organised in three parts. The first part centres on health professionals' reflexions about coping with TFA and their role in supporting women. The second part focuses specifically on health professionals' perceptions of the coping strategies used by women. The third part presents a comparative analysis between the health professionals' and women's accounts. A discussion of the findings is provided alongside an evaluation of the study's limitations at the end of the chapter.

6.1 Introduction

The literature review presented in chapter 1 (section 1.2) demonstrates that TFA is a traumatic event, which can have long-term consequences for the women involved, including depression and posttraumatic stress (Fisher & Statham, 2009; Green & Statham, 2007; Iles & Garth, 1993; Kersting et al., 2005, 2009; Korenromp et al., 2007a, 2009; Mirlesse et al., 2011; Salvesen, et al., 1997; Statham et al., 2001) and complicated grief (Kersting et al., 2007; Nazaré et al., 2013, 2014; Zeanah et al., 1993). Research also suggests that women's experience of healthcare, in particular the provision of compassionate care, may influence the way they adjust to TFA (Asplin et al., 2014; Fisher & Lafarge, 2015; McCoyd, 2009a; Statham et al., 2001). Yet caring for women in these circumstances presents challenges for health professionals. These challenges have been described in chapter 1 (sections 1.1.4.2.2, 1.1.5 and 1.2.3.3.1). They include: health professionals' own moral dilemmas, the

complexity of making TFA-related decisions within the existing legal framework, the intensity of the emotions displayed by patients, the difficulty in carrying out specific duties such as breaking bad news, and the fact that given the stressful nature of TFA, some women may feel unsatisfied with the care they received, however well managed (e.g. Dommergues et al., 2010; Fisher et al., 2015; Guerra et al., 2011; Menezes et al., 2013). These challenges may also relate to health professionals' understanding of women's coping. This study is the first to empirically investigate health professionals' perceptions of women's coping with TFA and compare these to women's accounts of their own coping processes (Study 2a, chapter 4). The aim of the study is to identify commonalities and differences between accounts, as these may have implications for improving healthcare and health outcomes for women following TFA.

6.2 Methods

6.2.1 Summary of the methodology

The methodological elements of this study have been described in detail in chapter 3 (sections 3.3.2.2 to 3.3.2.5). Participants were health professionals (e.g. consultants, midwives, sonographers) caring for women who presented to hospital with a suspected or confirmed fetal abnormality. Participants were recruited from three hospitals in England. Data were collected through face-to-face semi-structured interviews conducted between May and July 2013. Interview duration ranged between 25 and 65 minutes and averaged 49 minutes. Approximately a third to one half of the interview was dedicated to exploring the health professionals' perceptions of women's coping with TFA, covering the time of diagnosis, the procedure and post termination. The remainder of the interview focused on exploring the practice of prenatal diagnosis, which was the topic of the international research project this investigation was a part of (for more detail, see chapter 3, section 3.3.2.1). The analysis of the data pertaining to the practices of prenatal diagnosis is not reported in this

thesis. Ethical approval was obtained from the University of West London Ethics Committee and from a NHS Research Ethics Committee prior to the fieldwork starting.

6.2.2 Participants' profile

Any health professionals involved in the management of pregnancy of women referred to the fetal medicine units or the obstetrics and gynaecology department were eligible to take part in the study. The objective of the study was to gather data from a range of professionals (e.g. consultants, midwives, sonographers) with various levels of clinical experience, to sample a range of perceptions (see chapter 3, section 3.3.2.2.1 for more detail on the recruitment of participants).

In total, 15 health professionals participated in the study. One professional declined to take part, citing time pressures. Data analyses indicated that data saturation had been reached at 15 interviews. Seven interviews were carried out with consultants. Of those, four were conducted with fully qualified fetal medicine consultants, one with a registrar who was within a year of completing a sub-speciality in fetal medicine, one with a genetic counsellor and one with a fetal cardiologist. In addition, four interviews were conducted with midwives, two with sonographers, one with a specialist nurse and one with a healthcare assistant. Ten of these interviews were conducted with participants recruited from Site 1, four from Site 2, and one from Site 3. Sites 1 and 3 were large fetal medicine referral centres, whilst Site 2 was a local obstetrics and gynaecology unit, providing standard fetal medicine services (e.g. amniocentesis). More detail on the clinical sites is provided in chapter 3, section 3.3.2.2. Twelve participants were female and three were male. They were aged between 24 and 55 years old (average: 42 years old). Nine of them were classified as 'senior' based on their job title, years of practice and level of responsibility within the units. The participants' profile is shown in Table 6.1.

Table 6.1. Participants' profile

Notation	Job type	Level	Gender	Age
Site 1				
C1	Consultant	Senior	Male	44
C4	Consultant	Senior	Male	49
C5	Fetal cardiologist	Senior	Female	55
Reg	Registrar	Junior	Female	38
Mid1	Midwife	Senior	Female	49
Mid6	Midwife	Junior	Female	33
SNur	Specialist nurse		Female	36
Son1	Sonographer	Senior	Female	54
Son3	Sonographer	Senior	Female	52
HCA	Health care assistant	Junior	Female	24
Site 2				
C6	Consultant	Senior	Female	44
C7	Consultant	Junior	Male	38
Mid10	Midwife	Junior	Female	31
Screen	Senior screening coordinator	Senior	Female	49
Site 3				
Gen	Geneticist	Senior	Female	47

All Consultants were Obstetrics and Fetal Medicine consultants

6.2.3 Data analysis

The data were transcribed verbatim, line-numbered and analysed using thematic analysis (TA). TA's precepts have been discussed in chapter 3, section 3.3.2.5. TA was selected because it can be used both deductively and inductively (Braun & Clarke, 2006) as required in this study. The analytical process closely followed the guidelines provided by Braun and Clarke (2006). This involved data familiarisation by reading the transcripts several times, generation of initial codes, identification of themes, revision and refinement of themes, definition and naming of themes, and report writing. The analysis was iterative, in that codes and themes were refined throughout the analysis.

The analytical process first consisted of identifying themes in the health professionals' data using an inductive (bottom-up) approach. This approach enabled the researcher to fully explore the data and preserve the originality and richness of individuals' accounts. The data were also analysed using a deductive (top-down) approach, in which data were coded using the coding frameworks derived from the women's data (Study 2a, chapter 4). This approach enabled the identification of commonalities and differences between the health professionals' and the women's accounts. However, to ensure that the full range of participants' accounts was represented, care was taken not to force the data into existing codes. Disconfirming cases, whereby evidence that contradicts an established or emergent code is sought and coded (Pope, Ziebland, & Mays, 2000), were also included in the analysis. To enhance rigour and validity, randomly selected sections of text were independently co-coded by the researcher's second supervisor. The level of agreement between the two researchers was high and resulted in very minor changes being made to the coding framework.

6.3 Findings

The findings section is organised in three parts. The first part focuses on the themes identified as a part of the inductive analysis. They depict health professionals' reflexions about coping with TFA and their role in supporting women. The second part deals specifically with health professionals' perceptions of the coping strategies used by women. These themes were identified through the deductive process of coding the health professionals' data using the coding frameworks generated from the women's data. The third section presents a comparative analysis between the two datasets and identifies the commonalities and differences between the health professionals' and women's accounts.

6.3.1 Health professionals' reflexions about coping with TFA and their role in supporting women

The inductive analysis identified four themes, which depict health professionals' reflexions and assumptions about coping with TFA and their own role in supporting women. These included: 'the nature of coping with TFA,' 'the idiosyncrasies of women's coping,' 'helping women cope' and 'the limitations to health professionals' understanding of women's long-term coping.' The coding framework is displayed in Table 6.2.

6.3.1.1 Theme 1: The nature of coping with TFA

The first theme identified in the inductive analysis of the health professionals' accounts focused on the nature of coping with TFA. Health professionals equated TFA to a unique grieving process and commented on the 'burden of choice.'

Subtheme 1: TFA as a unique grieving process

Most professionals considered TFA as a unique grieving process that can be difficult and lengthy: "*I do see them post termination and, you know, they may be in tears the whole consultation, you know, they're struggling, they haven't coped with the problem.*" (C5) The difficulty with coping with the termination can sometimes be evidenced later post termination, when women return to hospital for a subsequent pregnancy: "*They don't cope because it's a grieving process that goes on for a long time, and even when they come back for the next pregnancy, they bring it up.*" (Mid1) Professionals remarked that women may appear to be coping well, when the reality may be different:

From the outside, they seem over it. I mean often when I see them, for example, for the next pregnancy, they may admit it's been harder than their friends realise for example, because they have put on this normal face. (Gen)

Table 6.2. Health professionals' reflexions about coping with TFA and their role in supporting women

Themes	Sub-themes	Codes	Quotations
Nature of coping with TFA	Unique grieving process	A long grieving process	Mid1: 598-9; C4: 556, 620-7; C1: 419, 423-6, 663-6; C6: 541-2, 545-6; Screen: 537-45
		A difficult process	SNur: 657-61; Mid1: 598; HCA: 218; Son1: 683-4; Son3: 324; C5: 411-5, 418-20, 462; Gen: 460-1
		Grieving the many losses Unique type of death	C1: 423-6; Screen: 542-5; C4: 620-7, 753-7 Mid6: 651-3; C1: 508-9, 511-4
	The burden of choice	Guilt	SNur: 669-70, 679-80, 682-3; Mid1: 604-8; C1: 514-5; C5: 420, 463; Mid6: 563-4, 567-8; Son1: 627-34
		Stigma	Screen: 584-5
Idiosyncrasies of women's coping	Personal characteristics	Individual differences	SNur: 618-9, 621-3, 729; C4: 518; C5: 463-4, 469, 483-6, 500-14; C6: 341-2, 544-5; C7: 604-10, 611-4; Son1: 686-7, 747; Son3: 299; Gen: 402-6, 419-28; Screen: 601-2
		Dispositional characteristics	C1: 624-8; Mid6: 615-7
		Coping styles	C1: 522, 526-8; C7: 604-10; Son3: 299-303
		Support needs	C1: 565-7, 571-8; Gen: 402-6, 419-28; Screen: 647-78; Reg: 488-95
	Termination-related variables	Termination-related variables	SNur: 681-2; C4: 750-5; Mid10: 298-309; Mid6: 627-32
	Women's environment	Family situation	C5: 461; Mid10: 314-6
Cultural differences		Son1: 638-9, 650-2, 657-61; Gen: 419-28	
Support available		Son1: 686-7	

Table 6.2. Health professionals' reflexions about coping with TFA and their role in supporting women (continued)

Themes	Sub-themes	Codes	Quotations	
Helping women cope	The right decision as central to the coping process	The importance of the right decision	SNur: 688-91, 701-18; Mid1: 635-6, 674-5; Mid6: 593-6, 598-601, 604-6; Screen: 549, 552-5; C4: 435-8, 442-8, 456-9, 461; C6: 359-60, 372-4; C1: 435-8, 442-52, 456-9	
		Information provision	Sonographer Consultant Midwives Follow-up appointment Signposting	Son1: 639-46; Son1: 688-9 C1: 448-50, 467-70, 472-4, 489-91; C6: 374-88, 469-70; C5: 382-403 SNur: 690-9; Mid1: 674-5 SNur: 643-6; C1: 583-4; C5: 417-30; Gen: 393, 397-403, 409-12 C1: 579-83; HCA: 282
	Providing emotional support	Midwives provide more support after TFA	Midwives provide more support after TFA	SNur: 655, 739-40; Son1: 752-5; Reg: 473-7
		Compassion	Compassion	Mid : 139-46; SNur: 860-1; Gen: 397-401; Son1: 170, 293-5; Reg: 566-7; C1: 687-91
		Alleviating guilt	Alleviating guilt	C5: 423-30; C1: 514-5
		Promoting acceptance	Promoting acceptance	C1: 617-20, 629-32, 649-54
	Aftercare	Limited aftercare	Limited aftercare	SNur: 654-5; Mid6: 344-57; Reg: 486-7; C4: 612-4; C1: 538-42; C6: 598-600
		Availability of aftercare	Availability of aftercare	Screen: 561-4; C1: 553; C5: 434-46; Gen: 480-2
		Challenges in providing aftercare	Challenges in providing aftercare	SNur: 734-7; HCA: 287-91; Reg: 466-9; C1: 542-53, 565-83
		Self-referral	Self-referral	Mid1: 610-6; Reg: 524-31; C4: 691-716; C5: 434-46

Table 6.2. Health professionals' reflexions about coping with TFA and their role of in supporting women (continued)

Themes	Sub-themes	Codes	Quotations
Limitations to understanding women's long-term coping	Limitations to understanding women's long-term coping	Lack of insights into long-term coping	SNur: 631-6, 640-1, 652-3, 720-2, 731-4; Mid6: 588-9, 606-7, 636-8, 657-8; Mid10: 336-9; HCA: 226; Screen: 561; Son1: 686-7, 724-6; Son3: 325; Reg: 453-4, 458; C4: 549-52, 610-4; C5: 456-60; C6: 543-4; C7: 573-6, 623-4, 637-40
		Lack of personal experience	SNur: 685-8; Son1: 682-4

Most health professionals compared the experience of coping with TFA with a grieving process, which can generate a range of emotions such as “denial”, “anger” and, eventually, “acceptance.” (C1) Some professionals considered this grieving process to start from the time of diagnosis, when the woman begins grieving the loss of the “ideal” (Screen) and “healthy” (C1) baby:

How you respond to finding out that your baby, for example, has a severe disorder is, I suspect, very similar to formal grieving process as if, you know, someone died. Because you do lose something of that concept of a healthy baby, even if ultimately your decision is to continue. (C1)

All professionals recognised that the loss of the baby lies at the centre of the grieving process. However, some also pointed to other losses the woman may experience when terminating her pregnancy, such as the loss of ‘potential,’ which may complicate the process of coping:

I don't think it can be very different from the grief that you would have from losing a brother or a sister, a father or a mother, whatever, and I often believe it to be harder, because at least with your parents or your relatives or your friends you have good memories . . . With the baby you're grieving for the loss of potential, and I think it's harder to grieve for that loss of potential than it is for somebody who you know and who you can say, well they had a good innings. (C4)

Therefore, the loss of ‘potential’ and alongside it, the loss of dreams and hopes that may have accompanied the pregnancy, may be experienced as acutely as the loss of the baby itself. Professionals also considered TFA to be a unique type of bereavement because parents make the decision to terminate a pregnancy which, in most cases, is wanted. They believed that some parents may never be able to fully ‘accept’ their loss:

It's a death, it's your baby, it's all about you, it's not like a death of someone else . . . I don't think that ever happens with this kind of death because it was wanted and they made a decision to terminate. (Mid6)

Subtheme 2: The burden of choice

Many health professionals indicated that the process of coping with TFA may be complicated by the fact that women have made the decision to end the pregnancy. References to women's potential for experiencing feelings of guilt were common among health professionals: *"I think everybody probably feels guilty because you never know whether it was the right decision."* (SNur) This was contrasted by one professional who considered the decision to terminate almost as secondary to the grieving process. In this instance, the process of coping with TFA was likened to coping with a stillbirth:

I mean it's like a stillbirth isn't it? You are losing the baby . . . so I think I would imagine or, you know, at least in my experience, it's actually very difficult to distinguish women who have an unexpected stillborn but normal baby from women who have had a baby that had abnormality they have had to kill. (C1)

Other professionals stated that the guilt experienced by some women may not relate exclusively to the decision to terminate the pregnancy, but also to causing the abnormality in the first place:

And they bring it up and they always want to think had I done this or had I done that, or did I do this, should I have come to the hospital earlier, you know, should I had eaten this, should I had eaten, any little thing that they can think that they didn't do right, some women really beat themselves up about it. (Mid1)

In addition, some professionals mentioned women's fear of being judged: *"Parents feel that they might be judged by other people around them, especially if they're saying that they've had a termination."* (Screen) In some cases, they reported women justifying their decision to

them: *"They will try and justify it [the decision] to make it seem better, I guess, for them."*

(Mid6)

6.3.1.2 Theme 2: The idiosyncrasies of women's coping

Health professionals reported many individual differences in the way women cope with TFA. This formed the second theme of the inductive analysis. All participants acknowledged that *"people are very different"* (Son3) and that coping is a very individual process. Health professionals made several assumptions about what may influence women's coping. These related to women's personal characteristics, termination-related variables and women's environment:

I think again it [the process of coping] would be very individual and I think it depends on how much support they've got from their families and their partner as well as professionals' support, completely being open about what the problem is, what the prognosis for the baby is, etc. (Son1)

Subtheme 1: Personal characteristics

Health professionals suggested that women's personal characteristics such as women's personality and beliefs, coping styles and capacity for self-regulation influence the way they cope. Several health professionals cited dispositional or personality characteristics as an influential factor in the way women cope with TFA, for example: *"How sentimental you are as a person."* (C1) How extrovert or introvert a person is was also thought to influence the way women cope, which related to women's willingness or ability to seek support: *"It depends on how you are, if you're someone that is very much not emotional, you know, that they're keeping ... keep it quite close."* (Mid6) Religious beliefs were also mentioned as a significant individual difference: *"There are some people who just think that's God's will and they accept it and they just cope with it."* (Son3) Differences in coping styles, from active to passive coping or engagement to avoidance coping, were also mentioned as influencing the coping process:

Some people are very actively involved and sort of want to know everything and, you know, even want to see the baby after birth and take pictures etcetera and other people just sort of want to have nothing to do with it . . . so I think that's very individual. (C1)

Differences in women's capacity for self-regulation were also cited as having a bearing on women's coping, with some professionals emphasising some of the women's resilience and natural ability to recover: *"I don't know how women cope. Most of them seem to, somehow."* (C7) *"Some people, they just think that's happened, it's done, let's get on with it."* (Son3)

Health professionals also noted differences in support needs, which could also influence coping:

I don't think everyone necessarily wants huge amounts of support shoved at them because I think that in a way it can become counter-productive as well. You know if your coping mechanisms are working well, and it's just, okay I'm going to deal with this and then put it behind me and move on, then actually you know having huge amounts of leaflets and follow-up phone calls and counselling visits and whatever aren't necessarily helpful. I think it's got to be very individual. (Reg)

Subtheme 2: Termination-related variables

Another factor believed to influence women's coping relate to the women's personal circumstances with regards to the terminated pregnancy, in particular gestational age. However, accounts of how gestational age may impact upon women's coping were contrasted. Some professionals believed that women may find it more difficult to cope with TFA as gestational age increases. For example, referring to a woman who was 36 weeks pregnant when she terminated her pregnancy, the specialist nurse stated: *"I think her being so late on in her pregnancy is going to have a massive effect on how she copes now."* (SNur) For other professionals, gestational age seemed irrelevant to how well women may

adjust. Rather, they suggested that it may be people's expectations of how women 'should cope' that may impact upon how well they adjust:

I think it's equally hard to lose a baby at 12 weeks as it is at 9 months . . . I think that the people who have an early loss, often have a harder time because everyone else presumed it's easier to lose a baby at 12 weeks than it is at nine months. (C4)

The baby's prognosis was also believed to influence the way women cope with TFA, the assumption being that it may be easier to cope with the termination if the prognosis is incompatible with life:

I think certain conditions, I think women, it's easier for them to cope with. So, like making that decision, for example we have a lady, the baby had acrania [partial or complete absence of the top portion of the skull]. So obviously she was devastated but she understood that the baby was not compatible with life. (Mid10)

Subtheme 3: Women's environment

Women's environment, including their family situation, culture and beliefs were also thought to impact upon the way they cope with TFA. This was often linked to the support women could receive:

I think maybe there is a cultural difference in that often people who have large families like, for example, Indians and so on, they live with their aunts and uncles and the parents and the cousins and the nephews, so there is a lot of people who know and who support and really it's a nice network and it's rare that they come back for more counselling. I think Caucasian people or professional people are more likely to have moved around, maybe not know anybody, there's no other family in the city, they may have a few good friends who know, but it's not the same kind of close-knit support system. (Gen)

Having children to look after was considered as another possible factor in helping women cope with TFA: *"I think sometimes when parents have other children, that helps them to cope and, in some ways, they've got a little child, smiley happy child that keeps them busy, distracted."* (Mid 10) Cultural differences in attitudes towards adversity were also reported. One professional suggested that women in the UK may feel pressured into hiding their emotions: *"Pressure on them to stiff upper lip, be British and not cry."* (Son1)

6.3.1.3 Theme 3: Helping women cope

The third theme identified in the inductive analysis of the health professional's accounts was their role in helping women cope with TFA. Most health professionals considered helping women reach a decision that is right for them to be their main prerogative. This process involved providing information and emotional support to women through the decision-making process and the termination procedure. It also involved the provision of aftercare although health professionals were often unclear on what the aftercare should consist of and how it should be provided.

Subtheme 1: The right decision as central to the coping process

Regardless of the point at which health professionals intervened in women's care, all participants mentioned that they saw their primary role as providing information to enable women to reach a decision that feels right to them. They believed that women's chances of adjusting well to the termination were greatly increased if they felt that they had made the right decision: *"[what helps women cope is] knowing that, you know, it's the right thing because either the baby wouldn't have survived or would have been distressed so they, you know they just keep on reminding themselves that this is the right thing to do"* (C6); *"I think [what helps them] it is the belief that they're doing the right thing."* (Screen) Consequently, health professionals considered the provision of clear, comprehensive and balanced information as paramount.

Subtheme 2: Providing information

Depending on when health professionals intervened in women's care, the nature of the information they provided varied. Sonographers reported giving women as much information as possible at the time of the ultrasound examination. However, they also acknowledged that it falls within the consultants' remit to make full sense of the abnormality that has been detected and counsel the woman accordingly:

I'll tell them as much as I can but sometimes I will say, listen, I'm not the expert, the doctors will tell you a little bit more, but if they ask, I try and tell them as much as I feel confident. (Son3)

Being at the forefront of the process of diagnosing fetal abnormalities, sonographers were acutely aware of the importance of delivering the news to women in a sensitive way:

I think how they cope is depending on how your behaviour is as a sonographer as well. I think there is a direct communication in body language and your voice actually, because I think if you're scared as a sonographer in how you're going to deliver this news, you won't deliver it well. (Son1)

Consultants also considered information provision as their key responsibility towards women: "*My responsibility is to make sure they're making the right decision for them.*" (C6)

Another consultant stated:

I see there is a problem, there isn't anything I can do about that. I can't take the problem away, so the best I can do is try and make sure the patient understands what the problem [is] . . . because everything they do will be based on what the problem is, will be based in what I tell them. (C5)

Some consultants emphasised the importance of providing comprehensive and balanced information: "*[I explained the problem] but I also explain to them what the termination would involve, because people don't have any idea, you know, they don't know that they're going to*

go through a feticide.” (C5) One consultant also referred to his role as a guide through a shared decision-making process: “It’s not me counselling the parents. It’s us having a conversation almost about what we’ve found and making a decision together, and agreeing an action plan.” (C1)

If reaching the right decision was seen as essential in helping women cope with the termination, it was also important to health professionals who have a legal obligation to sanction the termination: *“If I’m going to sign the blue form [the HSA4 form sanctioning the termination] then I have to be happy in my own mind that they have made the right decision.”*

(C6) Most consultants also considered the follow-up appointment offered to women as an important milestone in women’s coping process. The follow-up appointment was seen as an opportunity for women to ask questions and for health professionals to assess how well women are adjusting:

Overall I think they like that sense of closure to have a place to re-discuss it, talk about next time, but really just review it, with a health professional, have a chance maybe to vent about the problem, that nurse was awful, or whatever. (Gen)

Midwives were also involved in providing information, whether this was on diagnostic tests, the termination procedure or some of the fetal conditions suspected or diagnosed. The importance of providing balanced information was, again, emphasised:

The way you counsel a woman, you tell her the whole picture, you tell her everything about that situation, whether you feel biased about it or not, you tell her I’ve seen this, I’ve seen this, I’ve seen this, and you know, at the end of the day, it’s your decision. (Mid1)

In some cases, midwives admitted to having limited information about some conditions. A lack of personal experience also resulted in some of them finding it challenging to give comprehensive information:

There's not much I can give [in terms of information] because I personally don't have any experience in my personal life or professionally because I don't work with people with learning disabilities or any kind of disorder, and so generally I just give them lots of information, just to point them in the right direction. (Mid6)

The provision of information also involved signposting women to organisations or support groups which, in some cases, could complement the information received at the hospital: “*here they give out the ARC leaflet.*” (HCA)

Subtheme 3: Providing emotional support

Health professionals also saw their role as providing emotional support to women, but this was usually considered as secondary to the information giving role. This role mainly fell within the remit of the midwives: “*[the midwives] potentially will see them [the women] and they'll speak to them on phone, and they are very good and I think quite often they will phone and see how they are doing.*” (Reg) Midwives were aware of the importance of supporting women through this difficult time: “*I can give them the best that I can and be as supportive as I can. I can't change it for them. I can only try and make it bearable.*” (Screen)

Compassion was seen as an important element in supporting women:

I couldn't just sit here to you and say, okay, your baby's got Exomphalos [a condition of the abdominal wall, where abdominal contents protrude outside the abdominal cavity], do you know what that means, and you're crying your eyes out, and I'm sitting here watching you, do you understand, so I would have to get up from my seat and come round to you and say, you know, this is the situation, I know this is not what you were expecting today . . . they need the time, they need the empathy.

(Mid1)

Compassion also translated into acts of kindness which could help alleviate women's distress: “*Sometimes I'll pop in [into the room] and say are you alright, can I make you a drink, that's like ... offering [a] calming [presence].*” (HCA)

Health professionals also viewed their supporting role as attempting to alleviate feelings of guilt they believe some women experience: *“I tell them anybody could have a child with Down’s syndrome so don’t feel guilty that you’re the one that’s had this diagnosis.”*

(HCA) Another professional reported:

I always try to say to them, as well, coming back to the consultation, that’s not their fault, you know, because they tend to feel it’s me, or I’ve had to say, you know, it’s not something you did, didn’t do, should have done, could have done differently, it’s one of those things. (C5)

Reassuring women that they are making the right decision could be challenging for health professionals, who are bound by the principle of non-directedness (RCGO, 2010). There were, however, instances when this could occur. For example, the specialist nurse described a consultation during which a senior consultant openly supported a couple’s decision to terminate their pregnancy, having established for himself that the parents were considering this outcome:

I had Consultant X with me once and he just made it, it was, he really personalised you know, without. I can’t even remember what he said but it was something like, you know, if it were me, would you want a child that was this, this and this, and this, but he’d obviously assessed from them that they were gearing towards that anyway, because you can’t say that if you’re unsure. (SNur)

Some professionals also sought to promote women’s acceptance of their situation: *“I try to encourage people to accept that, you know, they’ve had a baby, you know, that they lost and that is not going to go away.”* (C1) Generally health professionals considered themselves to be supportive of the parents. One particular professional described going ‘the extra mile’ in providing emotional support to women: *“At work I get very emotionally involved with my parents, with my parents and my couples actually yeah, you know, frequently sort of hugged and cried together.”* (C1) However, this was an isolated comment.

Subtheme 4: The aftercare

The aftercare was regarded as another factor important in women's coping. Many professionals commented on the aftercare provided to women and the majority considered it to be "patchy" (Reg). Some professionals remarked on the sense of isolation women may feel following the termination: "*I often feel when they have a termination and they just go home and they're left to deal with it.*" (SNur) This was thought to be particularly difficult for women because it contrasts with the intense level of care they receive up to the termination:

There is a sort of cliff-edge effect that we have discussed many times in that, you know, you find a baby with an abnormality and you know, you see them every week in the fetal medicine unit, and you get counselled by 6000 people and then you have a termination and then go home and you don't see anyone anymore. (C1)

Several professionals, nonetheless, commented that support is available to women after the termination: "*At the same time, there are services available to them. We have a counsellor.*" (C1);

I do say to the couples that I come in contact with, if you want to ever phone up and talk to me, you're more than welcome to. So I think, sometimes, they need to know that they've got somebody they can talk to. (Screen)

Healthcare professionals also questioned the best way to provide aftercare given the varied nature of women's needs: "*Whether there needs to be some follow-up, but then again, they might not want to be just randomly called by someone they've met once or twice.*" (SNur) Furthermore, some professionals believed that they are not necessarily best placed to provide this care, particularly because women may find it difficult to resume contact with the team that managed the termination: "*I don't necessarily think we are the right people to provide support afterwards, because quite often people do not want to come back here.*" (Reg) Health professionals were also aware that this difficulty may resurface when women return to the hospital for a subsequent pregnancy:

They might not want [to see me again]. I say, you know, I know that when you see me, it might bring back a lot of bad memories, so I always ask the woman, do you want to see me again or do you to see somebody else. (Mid1)

Some professionals commented on the benefits of offering women the option to self-refer to the unit during a subsequent pregnancy, which enables women to be in control of their care:

So if you're anxious, you come. And that's much easier for us, much easier for them, it's better for them and it doesn't propagate their anxiety . . . So it's not a problem. And you'll be surprised that when we do that, they often don't need to come. They know they can, but that's good enough. (C4)

6.3.1.4 Theme 4: Limitations to health professionals' understanding of women's long-term coping

The last theme of the inductive analysis centred on health professionals' limitations to their understanding of the way women cope long-term with TFA. These limitations were twofold. Firstly, as the health professionals who participated in this study worked in secondary or tertiary care settings, their interactions with women did not usually go beyond the termination or the follow-up appointment, which usually takes place six weeks after the termination:

"They [the women], they are going to go off and you don't see them again." (Reg) "We're focused on the immediate, but actually it's the immediate to long-term changes and I, you and I, have no access to that in general." (C4) "It's difficult because I think the actual procedure itself, when they are tertiary-referred, the feticide is done in the unit and then before they start off labour, they go back to their hospital of origin." (Son 1)

Secondly, based on their differing clinical roles, health professionals intervened at different points in the process of diagnosing the abnormality and managing the pregnancy. The process of identifying the abnormality usually started with the sonographers. These professionals were the first to raise the issue of an abnormality being present. However, they

usually did not see the women again beyond this point as women are referred to a midwife or a consultant. This limited their understanding of women's coping processes: "*We don't really deal with that part of it [thinking about long-term process]; but I think they do get counselling here.*" (Son3)

Consultants were involved in the diagnosis of the abnormality and, if a feticide was required, in the termination procedure itself. They often did not see the woman after this point:

How they cope, I don't know. Do you? I don't go home with them, I don't know who their friends are, I don't know who their family are, I don't know whether they take drugs, I don't know whether they have hobbies, I have no idea how they cope. I know how I cope with mine [bad news], but I have no idea [about them]. (C4)

In some cases, consultants saw women at their follow-up appointment six weeks after the termination. However, this did not necessarily provide them with insights into the way women had coped between the termination and the follow-up appointment:

Apart from seeing these women for a sort of debrief, I don't know what's going on in the background. You know I don't know how much care they are getting from the GPs or from midwives here in the hospital, from nursing staff. (C7)

Therefore, consultants also acknowledged limitations to their understanding of women's long-term coping processes. The only exception was the genetic counsellor who sometimes had a longer-term involvement with the women. This could be because women requested additional counselling sessions following the termination, or because they wished to undergo genetic testing in a subsequent pregnancy: "*The majority are okay, appropriate, and I don't see them again. Some people say they need more and then either I offer to see them again or refer them to their GP or somebody else.*" (Gen)

Midwives generally had a broader understanding of women's long-term coping processes as they usually were involved in caring for women from the women's first

appointment in the unit to after the termination. Their involvement could involve having a one-to-one consultation (e.g. before a diagnostic test), giving women the test results, giving them the medication for a medical termination or assisting the consultant during a feticide procedure. Midwives in senior positions were usually responsible for coordinating women's care after discharge. In some cases, midwives offered on-going support over the phone:

There's one lady that had a really difficult one, late diagnosis, at 37 weeks, and I still talk to her at least two or three times a week sometimes, until she has that post mortem, she just can't stop calling, and I understand that, because I was very close to her then. (Mid1)

The specialist nurse had a similar involvement with the women as the midwives. In some cases, she visited women at home to discuss their options. However, she too admitted that her understanding of women's long-term coping processes was somewhat incomplete: "*I don't see what happens from when they've decided, to when they go.*" (SNur) This professional also believed that her limited insight into women's long-term coping also related to her lack of experiential knowledge: "*I sometimes wish I had gone through it to know, to get me a bit more insight into how it must feel.*" (SNur) The healthcare assistant's involvement with the women was more sporadic, varying from accompanying women in the ultrasound room to offering them drinks as they wait for the consultants. Although she was able to identify several women's coping strategies, similarly to her colleagues, she was more hesitant about the long-term coping processes that may be involved.

6.3.2 Health professionals' perceptions of women's coping strategies

This section focuses specifically on the health professionals' perceptions of women's use of coping strategies when dealing with TFA. The themes identified derived from the deductive analytical process, which consisted of using the coding frameworks generated from the women's data to code the health professionals' accounts. The analysis of the professionals' perceptions of the coping strategies used by women closely matched women's accounts. Six

themes identified in the health professionals' data were also represented in the women's accounts. Similarly to the women's data, the themes identified in the health professionals' dataset spread across time periods (diagnosis, procedure and post termination). Therefore, these are presented as general coping strategies rather than being specific to any time period. The themes included: 'support,' 'acceptance,' 'problem solving,' 'avoidance,' 'another pregnancy' and 'meaning attribution.' The coding framework is displayed in Table 6.3.

6.3.2.1 Theme 1: Support

Many health professionals underlined 'receiving support' as an important coping strategy for women during the procedure. Women drew support from several sources including their partners, friends and families, their own spiritual beliefs, health professionals and support organisations.

Subtheme 1: Individual-based support

Women's partners were identified as an essential source of support, particularly on the day of the termination:

They're often more physically approximate [close] to their partner than [they] ever been before. I think that's noticeable so usually when they come for previous consultations, let's say they are not distant, [but] you know I have to encourage people to hold hands in the room, they rarely do. But when they come for their termination, they're often sitting together and holding hands. They're often, their manner and demeanour are very different. (C4)

Table 6.3. Health professionals' perceptions of women's coping strategies

Themes	Sub-themes	Codes	Quotations
Support	Individual-based support	Support from partner	Son1: 688-9; Gen: 386-8; Mid1: 634-6; C4: 571-80; Mid10: 316; C6: 372
		Support from friends/family	Son1: 688-9; Screen: 556-7; Gen: 368-71; C5: 460; C6: 548; Mid10: 324; C6: 372
		Spiritual support	HCA: 239-50, 253-4; Screen: 602-4; C4: 644, 652-64
	Professional-based support	Support from HP Counselling	Son1: 688-9; Screen: 557-9 SNur: 656; Mid6: 637; Mid10: 352; Son1: 684-5; C4: 647; C1: 553; C5: 416; Gen: 391
Support groups		SNur: 655; Mid6: 354; Mid10: 321-3; HCA: 282-5, 293; Son1: 752-5; Son3: 349-52, 357-63; Reg: 477-8; Gen: 389-90, 473-80, 482-4; C6: 393-5	
Acceptance	Accepting the situation	Accepting/talking about the situation	Mid10: 325-7; Reg: 449; Mid6: 677-87, 692-4
	Acknowledging the baby	Taking pictures, memory box A grave/shrine/burial/remembrance service	HCA: 265-78 Mid6: 666, 676; HCA: 256-7; Screen: 605; Gen: 413; Screen: 606-7, 610
		Celebrating milestones Personifying the baby	Mid6: 667 Mid1: 625-7

Table 6.3. Health professionals' perceptions of women's coping strategies (continued)

Themes	Sub-themes	Codes	Quotations
Problem solving	Problem solving	Information gathering	C6: 423-9; Gen: 362-5, 367-8, 381-2; Screen: 518-23, 526-9, 530-4; C1: 522-4; Reg: 436-8
		Being involved	C4: 580-95; C1: 522-4
		Focusing on the task	Mid6: 578-80, 584-6, 638; Screen: 551-2; Reg: 438-44
Avoidance	Procedure	Avoiding information	Gen: 365-7
		Autopilot/Dissociating	Reg: 438; C1: 524-6
	Post termination	Blocking, forgetting, not disclosing	Mid6: 623-6, 632, 635-6; HCA: 276-7; Son3: 326-9; Gen C: 379-80
		Keeping busy - work/routine	Mid10: 310, 312-3; Screen: 612-3; C7: 599-605
		Keeping busy - looking after existing children	Mid10: 314-6; Reg: 446-8; C6: 546-7
Partial disclosure	Screen: 586-90; Mid6: 624-5		

Table 6.3. Health professionals' perceptions of women's coping strategies (continued)

Themes	Sub-themes	Codes	Quotations
Another pregnancy	Focus on another pregnancy	Thinking about another pregnancy	Mid6: 622-3; HCA: 231; Reg: 450-1; C6: 553-4
		Another pregnancy helps	C6: 565-74, 592-3; C7: 649-50, 657-8
		The danger of 'replacement baby'	C1: 613-28, 629-32, 639-52
	Challenges of caring for women in subsequent pregnancy	Anxiety in subsequent pregnancy	SNur: 748-51,754-80, 792-5; Mid6: 640-1, 646-9; Mid10: 340, 345-7; Screen: 627-8, 656-8; Son1: 742-7; Reg: 536-55; C4: 681-6, 689-90; C5: 476-81; C6: 557-9, 594-603; C7: 610-1,613-5; Gen: 490-532, 539
		Reliving the trauma and new fears	Mid1: 599-600, 621; Mid6: 648-9, 655-6; Mid10: 341-2; Screen: 624-6, 640-1, 652-3; Reg: 501-9; C6: 585-90; Gen: 464-7, 469-71
		Sensitive care in next pregnancy helps	C7: 650-2
Meaning attribution	Meaning of birth experience	Meaning of birth process	C7: 577-9

A few participants also commented on the reciprocal nature of support with women supporting their partner through the process of TFA: *“I think at the time that it happens both seem to be in the same place of grieving and just getting through this, so they support each other a lot.”* (Gen)

Support from friends and relatives was also mentioned as important in helping women cope: *“I think it's really supportive to have your own family and friends that can be there to just pick you up”*. (Screen) Religious support was also cited by a few health professionals who reported women bringing spiritual items during the procedure (e.g. candles), saying prayers, or having the baby blessed immediately after the birth:

I took a lady, it was very late [in pregnancy] actually, but she came along with a friend and they brought a candle, and they sat there and they were saying some prayers, and then I took them afterwards to the chapel and they said some prayers. (HCA)

Subtheme 2: Professional-based support

Health professionals believed that the support they provide to women whilst in their care also influenced the way women coped: *“The staff obviously, the midwives that are looking after you, they tend to be supportive and not judgemental, just being there to get you through the best that we can.”* (Screen) Professional support could also take the form of counselling, which some participants believed to be a coping strategy used by women post termination: *“They sometimes have looked for help. They have seen a counsellor. Sometimes we organise with them.”* (C5) Health professionals did acknowledge, however, that counselling may not be appropriate for all women: *“I know some people will take up counselling, some people are not ready for it when we first see them.”* (SNur)

Professional support also included the use of support organisations. Most health professionals spontaneously mentioned several of these organisations, which they considered to be an effective source of support for women: *“I hope maybe by going on a website or a support group or something, that [seeking support] is much easier to do. You can do it in the evening at home, they may do that.”* (Gen) Health professionals also relied

on these organisations to deliver accurate information to women, which could complement the information they, themselves, provided. They also considered these organisations to be helpful in counter-balancing information women may have sought independently, which some professionals believed to be potentially inaccurate:

There's also a very good organisation in the UK called ARC. They're very good and they will be, patients will be pointed in that direction so they don't, as I said earlier, Google everything on site and get the awful scenarios and the wrong information, so we try and tailor it to them. (Son1)

6.3.2.2 Theme 2: Acceptance

Acceptance was identified as another important coping strategy for women, particularly by the midwives. It involved accepting the situation and acknowledging the baby.

Subtheme 1: Accepting the situation

Some professionals, particularly the midwives, specialist nurse, screening coordinator and healthcare assistant, considered acceptance of the situation as a prerequisite of coping: *"If you acknowledge it, you can grieve. If you don't acknowledge it, you just can't, can you?"* (Mid6). Accepting the situation involved talking about it and some health professionals believed that having the opportunity to talk about their situation can be beneficial to women.

This opportunity may be provided by support organisations:

Sometimes people want to talk to other people who have been through the same. And we're like a hospital system that we can give as much; some people don't want to have that connection with the hospital, they want somebody completely separate that has or is aware of that experience. (HCA)

Subtheme 2: Acknowledging the baby

Acknowledging the baby was regarded as equally important. This could involve naming the baby: *"Other women they gradually get over it. Some of them, they've named that baby,*

especially if they've terminated." (Mid1) Taking pictures and using a memory box were also seen as helpful coping strategies:

"They [at the hospital] do it very well, but the pictures are nice, as nice as you can have I imagine and they give them special memory . . . they do it really nicely. They give that to a patient so they've got, you know, a little bit of a picture and the blanket they had that they [the baby] were wrapped in, but for some people that's really nice because they can go home, and some people I suppose want to go home, they just want to forget, but some people don't. They want to go home and they want to have something with them that reminds them of what was I suppose." (HCA)

Attending a "remembrance service" (Screen) or having a burial were also considered to be helpful for some women and provide them with a sense of closure: *"I think if they went for cremation, for example, many people find that very helpful. Again it helps a little bit with grieving and closure."* (Gen) Celebrations of milestones were also reported as beneficial:

I heard that one of them . . . they celebrate with a birthday every year. I thought that was really nice. I thought because, as painful and as horrible as it all was, and there probably wasn't much of a memory, because you've never met the baby, and the baby that you knew was a baby with an abnormality, they still had a tie. (Mid6)

6.3.2.3 Theme 3: Problem solving

Adopting a practical, active, 'problem solving' approach to the termination was another of women's coping strategies reported by health professionals. This involved actively gathering information: *"There are some people who will cope by trying to fix or solve the problem, and will go and get a second opinion or do lots of research, or come up with lots of information."* (Reg) Some professionals also regarded this approach as a way for women to regain some control over the situation:

I think many people will seek more information to try and get a bit more control over, understanding it better because this thing is thrown at them. . . . so by reading up on it, I think they can put it a bit better into perspective. (Gen)

Similarly, a few health professionals reported women wishing to be involved in the termination procedure, for example by expressing a desire to look at the screen during the procedure of feticide and requesting ultrasound photographs of the baby:

In general we turn off the screens and I know, they don't want to see what we're doing, but you know people are different. Some people have asked to see . . . Ask to see and some people will ask for images and pictures and stuff, even at the time of termination. (C4)

The coping strategy of problem solving could also involve women focusing on the medical task and regarding the procedure as a medical intervention they had to go through rather than reflecting on its meaning:

Just that for that moment in time they [the women] need to just not think about it in a certain way. Think about it as a procedure, that this is what I need to do, you're going to give me instruction, I'm just going to do what [you tell me]. (Mid6)

6.3.2.4 Theme 4: Avoidance

In contrast to those engaging with the process of termination, health professionals reported that some women appeared to rely upon various avoidant strategies to cope with TFA at the time of the procedure and afterwards.

Subtheme 1: Avoidance at the time of the procedure

Avoidant strategies were reported at the time of the procedure. This could include avoiding information about the fetal condition or the procedure: *"We have a few people who say on*

purpose they didn't read up at all. They don't want to know more." (Gen) Avoidance was also manifest in women's attempts to dissociate from the procedure: "*I think a lot of people just go on to autopilot*" (Reg) or avoid any involvement in it: "*[some people] close their eyes and say 'you know, just let me know when it's all done and then we can get out of here.'*" (C1)

Subtheme 2: Avoidance post termination

Avoidant strategies were also reported after the termination. Health professionals described women's attempts to keep busy and "*get on with it.*" (Mid6) Health professionals also mentioned that some women choose to return to work quickly after the termination: "*I've seen a woman today who wants to go back to work as soon as possible . . . because she feels she will cope better if she's busy.*" (C7) Having other children to look after was also seen as a possible welcome distraction for some women: "*I think distraction probably, you know, if you have other kids, your life has to go on, you still have to make tea, you still have to get your kids to school.*" (Reg) Actively avoiding thinking about the termination was another coping strategy mentioned by professionals: "*I think there are some people who actually want to put that behind them and don't want to be reminded of it.*" (Son3)

One health professional considered partial disclosure about what caused the loss of the baby to be useful, and actively recommended it:

I always say you don't have to tell anybody what happened. It's not a big secret but, actually, this is something that's gone on between you as a couple . . . So you can tell them that the baby died, because the baby has died, but you don't have to go the ins and outs of what happened and why it died. (Screen)

However, other professionals regarded partial disclosure as a possible impediment to women's coping process: "*Not grieving. Not realising that actually . . . What is hard is that sometimes they don't want to tell people that they're terminating.*" (Mid6)

6.3.2.5 Theme 5: Another pregnancy

Focusing on another pregnancy was another coping strategy health professionals believed women relied on to cope with TFA. They also acknowledged that caring for women at that time could present some challenges.

Subtheme 1: The focus on another pregnancy

Another pregnancy was often seen by health professionals as a way of coping for women, whether women simply thought about the pregnancy or actively planned it: “*Most people want to get on with the next pregnancy straight away actually . . . by the time we’ve got to six weeks, [they are] looking forward to the next pregnancy.*” (C6) Planning for another pregnancy was seen as a positive step by some health professionals and an indication of women’s readiness to move on: “*I say to them [the women] you know if you feel psychologically ready then there is no advantage of waiting. I think that [for] most people it’s better for them to get on and try again.*” (C6) Similarly, a positive pregnancy outcome could be considered as an indication that women had adjusted well to the termination: “*I think most women seem to recover quite well when they’ve had a happy pregnancy outcome.*” (C7)

One professional, however, raised potential issues with seeking a new pregnancy too quickly after the termination in what he described as a “replacement strategy:”

Some people have this sort of replacement strategy in their head. You lost a baby, so I must get pregnant as soon as possible in order to, and, you know, I don’t think that’s valuable in my experience . . . The fact that they had a pregnancy they’ll have a due date, they’ll remember the due date five years from now. They’ll have a day that the baby was born and they will cry on the day that the baby would have been 18 or whatever. And I don’t think that they should try to go away from that because I don’t think it’s very successful when you try to do that. (C1)

Subtheme 2: Challenges in caring for women in subsequent pregnancies

Most healthcare professionals acknowledged that a subsequent pregnancy is often a time of heightened anxiety for women and that many of them relive their difficult experience: “*When they're booking that scan [in the next pregnancy], they will get all emotional. And like a choking thing, it's all coming back again.*” (Mid1) Health professionals also acknowledged that returning to the hospital where they underwent the termination may be challenging for some women:

It's a huge physical sort of memory . . . I think they are very, very vivid memories for, you know, the place, so you imagine memory, the smell of the room or the fact that it's cold or, you know, probably is about [all] sorts of sensory things. (Reg)

Sensitive care in subsequent pregnancy was, therefore, considered to be essential to women: “*I think giving them supportive care in subsequent pregnancies, I think is very important.*” (C7) Many professionals also commented on the challenges in managing women’s levels of anxiety during subsequent pregnancies, as many women find it difficult to trust statistics that indicate a low risk of the abnormality re-occurring:

They're left in this limbo, although we give them the risk of re-occurrence being quite low, I think they focus on what the, if you reverse, you know 96% likely you'll be absolutely fine; they still can't focus on that. They've been in that 4%. (SNur)

6.3.2.6 Theme 6: Meaning attribution

Meaning attribution as a potential coping strategy used by women was seldom mentioned by health professionals. However, one professional reported some women deriving meaning from the birth experience. This consultant believed that for some of the women undergoing a medical termination (which implied giving birth to the baby), the birth could have a symbolic meaning: “*A few women who I've seen for counselling afterwards have said that whilst the experience was unpleasant, horrible or awful, they've felt that they needed to go through it to sort of as part of their grieving or something.*” (C7)

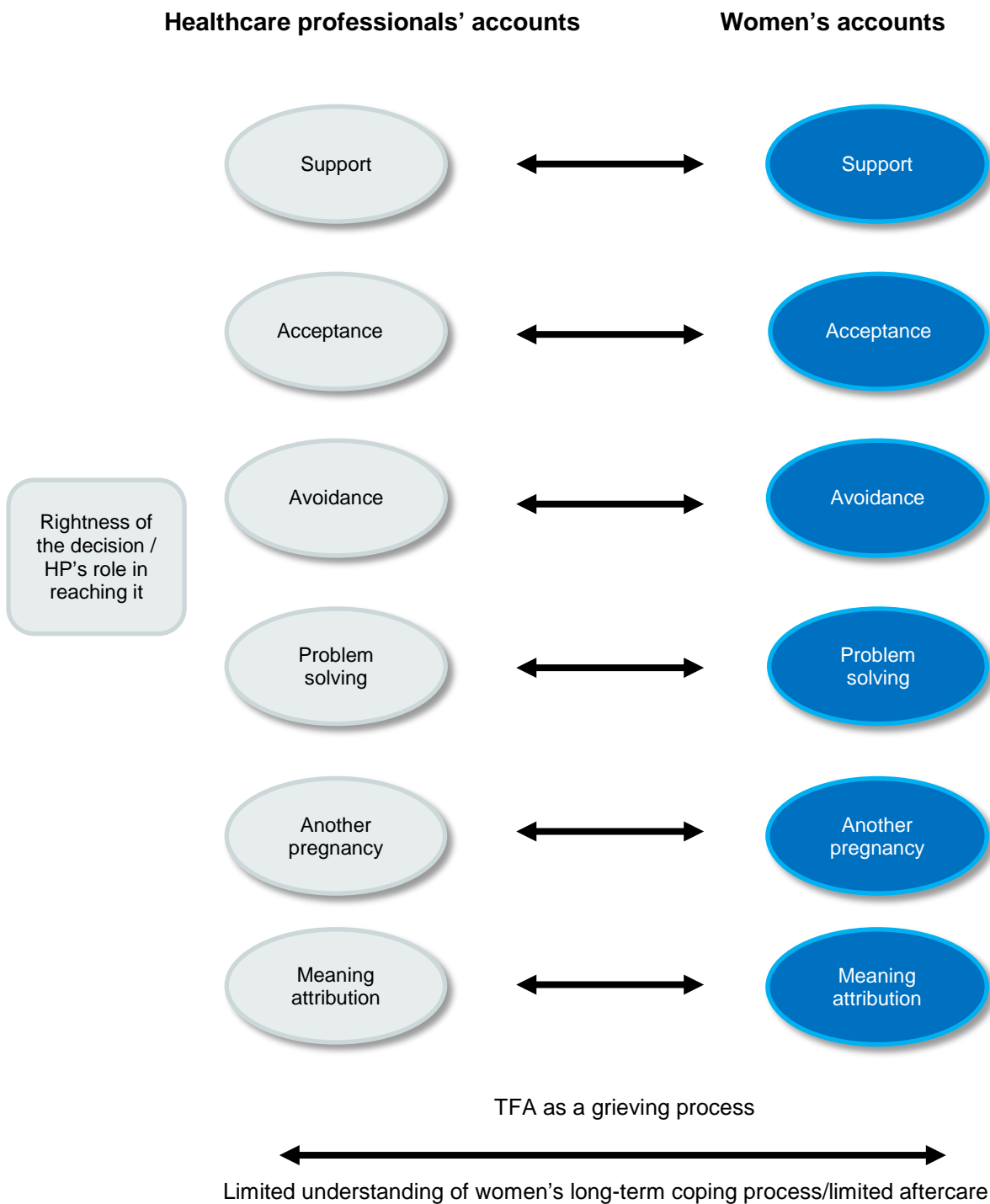
6.3.3 Comparison between health professionals' and women's accounts

A comparative analysis between the health professionals' and the women's accounts on women's coping with TFA identified more commonalities than differences between the two datasets. An overview of the main commonalities and differences between the themes identified in the health professionals' and women's accounts is displayed in Figure 6.1.

Both groups of participants (health professionals and women) viewed the experience of coping with TFA as a unique grieving process, which can be complex and lengthy. Health professionals also acknowledged limitations to their understanding of women's longer-term coping with TFA, and considered the aftercare offered to women as limited and inconsistent. This view echoes women's experience of limited aftercare. The findings also indicate that regarding the coping strategies used by women when undergoing TFA, the health professionals' perceptions were mostly congruent with women's accounts. Both groups of participants considered 'support' as an essential coping strategy, whether 'support' is sourced from the woman's partner, friends and relatives, or from professionals. Both groups also acknowledged that some women draw emotional support from their religious beliefs.

Similarly, both health professionals and women considered 'acceptance' as one of women's key coping strategies. The analysis also indicates that midwives were generally more informed on this strategy than consultants, which may reflect differing clinical roles. 'Acknowledging the baby,' in particular, was seen as an important coping strategy. Naming the baby, taking pictures, obtaining a memory box, having a funeral and celebrating important milestones were reported in both health professionals' and women's accounts.

Figure 6.1. Main commonalities and differences between the themes identified in the health professionals' and women's accounts.



'Problem solving' was another theme present in both datasets. Gathering information, preparing for the procedure and framing it as a medical intervention were mentioned by both groups of participants. 'Avoidance' was also reported in both sets of accounts as an important coping strategy for women. Similarly to the women's data, the theme of 'avoidance' in the professionals' data was the least homogeneous. It comprised coping strategies such as 'self-distraction,' and more avoidant behaviours such as 'going into autopilot' or 'avoiding information' altogether. Finally, both groups considered 'another pregnancy' to play a significant role in women's coping process and to be indicative of women's readiness to move on, despite being also a time of heightened anxiety.

The comparative analysis also revealed several differences between the health professionals' and women's accounts. Health professionals strongly emphasised the importance for women to reach 'the right decision' in helping them cope with the termination. The emphasis on the rightness of the decision was less evident in the women's data. Health professionals also highlighted their role in helping women make a decision and generally saw their primary role as information providers. This was particularly true of the consultants, which is consistent with their clinical responsibilities in diagnosing the abnormality and counselling women on the management of their pregnancy. When comparing these findings to the women's accounts, women appeared more receptive to the health professionals' role as provider of emotional support rather than of information. Providing emotional support to women was mainly imparted to the midwives, because they often had a longer-term involvement with the women.

Women also emphasised the use of counselling and support organisations as coping strategies to a greater extent than the professionals did. Similarly, reciprocating support as a coping strategy was also more prevalent in women's than health professionals' accounts. This is consistent with the profile of women participants in Study 2a (chapter 4), who were all recruited from the ARC support organisation.

Despite 'another pregnancy' being mentioned as an important coping strategy by both groups of participants, health professionals' perspectives on this strategy could differ

from the women's. One professional, in particular, was keen to point to the possible risks of entering another pregnancy without having come to terms with the loss of the baby. Health professionals also remarked on the difficulty in reassuring women during a subsequent pregnancy, a point which was not mentioned in the women's accounts. Finally, although 'meaning attribution' was represented in the professionals' data, it was far less prominent than in the women's accounts. Similarly the theme 'looking to the future', identified in the women's data, which encompassed the positives of the decision to terminate, putting the experience to good use and deriving personal growth, was not represented in the health professionals' accounts.

6.4 Discussion

This study sought to examine health professionals' perceptions of women's coping with TFA and compare these to women's accounts of their own coping processes (Study 2a, chapter 4). The inductive analysis identified four themes relating to professionals' reflexions and assumptions about coping with TFA and their role in supporting women. These included: 'the nature of coping with TFA,' 'the idiosyncrasies of women's coping,' 'helping women cope' and 'the limitations to health professionals' understanding of women's long-term coping.' In addition, health professionals' perceptions of women's coping covered six areas, which were also present in women's accounts: 'support,' 'acceptance,' 'problem solving,' 'avoidance,' 'another pregnancy' and 'meaning attribution.' These findings suggest a high level of congruence between the women's and health professionals' perspectives on women's coping with TFA. There were, however, some discrepancies between accounts, which related mainly to health professionals' general reflexions on the process of coping with TFA and their role in supporting women. Only minor differences in coping strategies *per se* were identified. The findings also indicate a lack of insights into the way women coped long-term, although midwives appeared more knowledgeable than consultants on this point. The findings of the study are discussed in the subsequent sections alongside the study's

limitations. The study's implications in terms of theory, practice and further research are discussed in chapter 8.

6.4.1 Health professionals' assumptions regarding women's coping with TFA

In their general reflexions about coping with TFA, health professionals made several assumptions about what may influence women's coping (e.g. personality or termination-related variables), which, in turn, may have affected their perceptions of women's coping. In particular, health professionals regarded personality, coping styles, women's environment and termination-related variables (e.g. severity of the fetal condition or gestational age) as important factors in the way women cope with TFA. There were, however, some variations about the way health professionals thought these factors may impact upon women's coping. For example, whilst some believed that coping with a late termination may be more difficult than coping with an early termination, others did not. Collectively these findings suggest that health professionals may bring their personal values, biases and professional experience in their assessment of women's circumstances and coping processes. This supports existing evidence indicating that a degree of subjectivity is involved in the counselling and clinical management of procedures deemed morally controversial (e.g. Brown et al., 2014; Curlin et al., 2007; also see chapter 1, section 1.1.5). This subjectivity may conflict with the non-directive clinical approach recommended by the RCOG (2010) and, may, more generally, impact upon the care provided to women. If health professionals believe that it is easier to cope with terminating a pregnancy affected by an abnormality incompatible with life than one that is compatible with life, they may not offer the same level of care to both groups of women. Further research would be needed to establish to what extent health professionals' perceptions of women's coping with TFA influence the care they provide to women.

6.4.2 Congruence between health professionals and women

The congruence between the health professionals' and women's accounts adds credence to the findings on women's coping strategies when undergoing TFA. Collectively both sets of

findings underline the importance of 'support,' 'acceptance,' 'avoidance,' 'problem solving,' 'another pregnancy' and 'meaning attribution' as significant coping strategies used by women when dealing with TFA. These findings indicate that women use a range of coping strategies that are mostly considered to be adaptive (see chapter 4, section 4.4 and chapter 5, section 5.4.1). The findings of the present study also suggest that health professionals have a valid understanding of what coping with TFA may involve for women. This has significant clinical implications as understanding the patients' experience may assist health professionals in delivering person-centred care, which may promote better health outcomes for women. This is particularly relevant as evidence suggests that women's experience of healthcare may influence the way they adjust to TFA (Asplin et al., 2014; Fisher & Lafarge, 2015; McCoyd, 2009a; Statham et al., 2001; Statham, 2002). It is also pertinent within the context of clinical concordance and shared decision making which has been shown to improve patients' health outcomes (De las Cuevas, Rivero-Santana, Perestelo-Pérez, Pérez-Ramos, & Serrano-Aguilar, 2012; Joosten et al., 2008). This issue is discussed in more detail in chapter 8 (section 8.4.1.4).

6.4.3 Women's need for health professionals' emotional support

Although health professionals in this study mentioned providing emotional support to women as one of their key responsibilities, many viewed their role primarily as information providers. This position was shared by most health professionals including the midwives, despite the fact that midwives were often more involved in supporting women throughout the termination process. Providing information was considered essential in assisting women reach the 'right decision'. This, somewhat, contrasted with women's accounts, which emphasised the importance of receiving emotional support from health professionals.

The discrepancy between health professionals' and women's accounts may reflect some of the health professionals' difficulty in providing emotional support to women. Kelley and Trinidad (2012) conducted a study into patients' and health professionals' experiences of stillbirth, which indicates that some health professionals view the informative and

supportive roles as conflicting with each other. Furthermore, research suggests that some professionals may struggle with their own moral dilemmas in the context of TFA (Garel et al., 2002; 2007 and see chapter 1, sections 1.1.4.2.2, 1.1.5 and 1.2.3.3.1) and this may hinder their ability to support women.

This discrepancy may also reflect women's expectations regarding the care they may receive. It is possible that women consider reaching the 'right decision' as a fundamental element in their coping process and thus, regard information provision as a basic component of their care. Consequently, they may not make mention of such information when it is provided. By contrast, women may be less certain about the level of emotional support they can expect to receive from health professionals. They may feel particularly grateful when this support is provided and more prone to comment on it. Women's perceptions of emotional support from health professionals may also relate to how much they perceive health professionals understand their situation. A study by Geller and colleagues (2010) indicated that women's dissatisfaction with care following stillbirth resulted from a perceived incongruence between health professionals and themselves regarding the significance of the event.

Whether this discrepancy is accounted for by health professionals' attitudes or women's expectations regarding the care they may receive, the importance for women to reach a decision they feel comfortable is essential to their psychological adjustment following TFA. This was evidenced in Study 2b (chapter 5), with women who were uncomfortable with their decision to terminate displaying higher levels of grief compared to those who were comfortable with it.

6.4.4 The need for aftercare

The findings also revealed a lack of insights into the way women coped long-term with TFA, although midwives appeared more knowledgeable than consultants on this point. In particular, coping strategies such as 'looking to the future,' which included deriving personal growth, putting the experience to good use and looking for the positives of the situation were

not mentioned by health professionals. This may reflect health professionals' limited long-term involvement with the women. This is consistent with a perceived lack of aftercare reported in the women's accounts in study 2a (chapter 4) and also evidenced in the meta-ethnography (Study 1, chapter 2). A lack of aftercare has also been documented in studies about perinatal loss in general (Gold, Dalton, & Schwenk, 2007), miscarriage (Gellers et al., 2010) and stillbirth (Kelley & Trinidad, 2012). This has important clinical implications for women's long-term health outcomes.

6.4.5 Limitations of the study

The study has several limitations. The fieldwork was mostly conducted in two hospitals in England and therefore, the findings may not be transferrable to other fetal medicine centres. In particular, the hospital in which the majority of interviews were conducted (Site 1) is one of the main fetal medicine referral centres in the UK. Thus, it is likely that the staff's level of expertise and the profile of the cases they manage differ from other fetal medicine centres in the country. It is also possible that health professionals working in smaller units and managing cases that do not require referral to tertiary units, may be involved in women's care for longer periods of time. Consequently, they may have more in-depth knowledge and understanding of women's long-term coping with TFA.

The sample was self-selected, which raises the potential for bias. Health professionals who agreed to participate in the study may be more attuned to women's experience than those who did not. Participants in Site 2 were pre-selected by one of the lead consultants. This may constitute another source of bias. The fact that the topic guide included a section on the practice of prenatal diagnosis prior to the section on women's coping strategies, may have primed participants to reflect on their professional activity. This may have resulted in more prominence being given to health professionals' role in helping women reach the right decision than if the topic guide had exclusively focused on women's experience. Finally, these interviews were conducted as part of a larger international research project, which involved observations of clinical consultations (see chapter 3,

section 3.3.2.1 for more detail). Most of the professionals who participated in the interviews were also observed by the researcher during clinical consultations to investigate their practice of prenatal diagnosis. Therefore, a degree of social desirability bias in the observations and interviews cannot be excluded.

6.5 Conclusions and implications for the thesis

This study indicates that health professionals make several assumptions about the way women may cope with TFA. Nonetheless, there was a high level of congruence between health professionals' perceptions of women's coping and women's accounts of their own coping processes when dealing with TFA. The study also identified several discrepancies, which mainly centred on the role of health professionals as providers of information and/or emotional support. The findings also indicate a lack of insights from health professionals into the way women coped long-term with TFA. These findings have a number of practical implications for theory, practice and further research, which are discussed in detail in chapter 8.

The study findings have several implications for the research reported in this thesis and its development. The congruence between the health professionals' and women's accounts adds credence to the findings on women's coping strategies already reported in this thesis (Study 2a, chapter 4 and Study 2b, chapter 5). Collectively these findings emphasise the significance of 'support,' 'acceptance,' 'avoidance,' 'problem solving,' 'meaning attribution' and 'another pregnancy' as coping strategies used by women when dealing with TFA.

The findings also have an important implication for the development of the research. Health professionals did not mention personal growth as a coping process nor an outcome of the experience of TFA. However, this theme is present in the three studies focusing on women's experience and reported in this thesis (Studies 1, 2a and 2b, chapters 2, 4 and 5). It is, therefore, essential to investigate this concept further because it is an important aspect

of women's experience, but which is largely overlooked by professionals. This supports the rationale for investigating the concept of posttraumatic growth in the context of TFA, which is the subject of the next chapter. The next chapter (chapter 7) describes a quantitative study, which aims to measure posttraumatic growth in the context of TFA and examine its relationship with the coping strategies used by women and their levels of perinatal grief.

Chapter 7 - Posttraumatic growth following termination of pregnancy for fetal abnormality: The role of coping strategies and perinatal grief

This chapter describes the research's fourth empirical study (Study 4), which examines the relationship between the coping strategies women use when dealing with TFA, their levels of perinatal grief and posttraumatic growth. Whilst the focus of the study is on the experience of posttraumatic growth following TFA and the way coping strategies and perinatal grief relate to this construct, this study also has a confirmatory purpose in investigating, for a second time, women's coping strategies and their level of perinatal grief. The study also contains a longitudinal element through the comparison of the scores on coping strategies and perinatal grief of 62 participants who participated in both quantitative studies (Study 2b, chapter 5 and Study 4 presented in this chapter). The chapter outlines the methodology used in the study (discussed in more detail in chapter 3). It also provides a measure of the variables (coping, perinatal grief and posttraumatic growth) and assesses their relationship with each other. A discussion of the findings and an evaluation of the study's limitations are provided at the end of the chapter.

7.1 Introduction

The findings from Studies 1 (chapter 2), 2a (chapter 4) and 2b (chapter 5) indicate that some women experience positive growth following TFA. This supports existing evidence suggesting that trauma survivors may experience growth as a result of their experience (Joseph, 2011; Tedeschi & Calhoun, 2004). The concept of posttraumatic growth has been documented in various contexts (Helgeson et al., 2006) including natural disasters (Lowe, Manove, & Rhodes, 2013), interpersonal violence (Cobb, Tedeschi, Calhoun, & Cann, 2006; Laufer, & Solomon, 2006; Peltzer, 2000), health-related trauma (Barskova & Oesterreich, 2009; Hefferon et al., 2009) and bereavement (Calhoun et al., 2010; Englekemeyer & Marwit, 2008; Riley et al., 2007; Taku et al., 2015). Its relevance to perinatal loss is,

however, in its infancy (Black & Wright, 2012; Thomadaki, 2012). Only one study has examined posttraumatic growth in the context of TFA (Black & Sandelowski, 2010) but this study also included women who had continued with their pregnancy. Nonetheless this study, suggests that women do experience positive changes following perinatal loss, in particular in their relationship to others. The objective of this study is twofold. Firstly, it aims to examine the levels of posttraumatic growth following TFA. Secondly, it aims to investigate the relationship between women's coping strategies, their levels of perinatal grief and posttraumatic growth. More specifically, the study aims to ascertain whether coping strategies and/or levels of grief can predict posttraumatic growth, and which coping strategies (if any) may facilitate growth.

7.2 Methods

7.2.1 Summary of the methodology

The methodological elements of this study (Study 4) have been described in chapter 3, section 3.2. Participants were women members of ARC. All were over 18 years old and had undergone TFA. Participants were recruited through the ARC's email network and online forum membership. Participants who had participated in Study 2b and agreed to take part in further research, were also re-contacted via email. Data were collected online using SurveyMonkey between February and May 2014. Using the power calculation tool G*Power, the required sample size was estimated at 127. This procedure is described in more detail in chapter 3 (section 3.2.1.5). Once the minimum sample size required was reached, and after it became evident that no more questionnaires had been completed over a period of 14 days, the survey was closed.

Participants were asked to complete the Brief COPE (Carver, 1997), the Short Perinatal Grief Scale ([Short PGS], Potvin et al., 1989) and the Posttraumatic Growth Inventory [PTGI], Tedeschi & Calhoun, 1996). In addition, the questionnaire gathered information related to the terminated pregnancy (e.g. time elapsed since TFA), women's

obstetric history (e.g. number of pregnancies) and demographic profile (e.g. age). Women who had participated in Study 2b were not asked questions related to the terminated pregnancy again. This information was added by the researcher at the analysis stage (see chapter 3, section 3.2.2.2). The questionnaire and scales have been described in detail in chapter 3, sections 3.2.2.3 and 3.2.2.4.

7.2.2 Statistical data analysis

7.2.2.1 Statistical data analysis strategy

The statistical analysis for this study closely followed the analysis conducted on the data for Study 2b (chapter 5). The data analysis comprised seven steps. Data were verified for outliers and missing values. The subscales were then computed and their internal reliability examined. The data were subsequently examined to determine whether they were normally distributed or not. These steps are described in sections 7.2.2.2 to 7.2.2.5.

Descriptive and inferential statistics were then used to analyse the data. Women's use of coping strategies, levels of perinatal grief and of posttraumatic growth were compared across groups based on demographic and termination-related variables. Group differences were analysed using *t* tests and analyses of variance (ANOVA), followed by *post hoc* tests using the Bonferroni correction. Correlations and multiple regression analyses were also conducted to investigate the relationship between coping strategies, perinatal grief and posttraumatic growth. Variables exhibiting significant correlations with the posttraumatic growth variables were included in the regression analyses. A multiple hierarchical regression was run for each of the posttraumatic growth scales ('relating to others,' 'new possibilities,' 'personal strengths,' 'spiritual change' and 'PTGI overall') individually. As the main focus of analysis, coping strategies were entered first and other variables second according to the principle of research relevance (see chapter 3, section 3.2.4.2; Cohen et al., 2003). The Brief COPE and the Short PGS subscales were used as predictors and the PTGI measures as outcomes. These analyses are described in sections 7.3.2 to 7.3.6. For all tests, *p*-values < 0.05 were considered statistically significant. Effect sizes were calculated using an online

tool from the University of Colorado (n.d.). They were reported using the correlation coefficient r and the classification recommended by Cohen (1988): $r = .10$ (small effect), $r = .30$ (medium effect), $r = .50$ (large effect). Effect sizes for ANOVA were reported using the ω^2 statistic and the classification recommended by Field (2013): $\omega^2 = 0.01$ (small effect), $\omega^2 = 0.06$ (medium) and $\omega^2 = 0.14$ (large effect).

7.2.2.2 Data verification

Data were analysed using SPSS (version 22, SPSS Inc, Chicago). There were no missing data for any of the key variables (Brief COPE, Short PGS or PTGI variables). Data were verified for outliers through visual examination of the box plots and by calculating z-scores. This procedure has been described in chapter 5 section 5.2.2.2. z-scores that fall outside the -3.29/3.29 range are generally considered to be outliers (Field, 2009; Tabachnick & Fidell, 2007). Using this criterion, seven outliers were identified in the data, three for 'denial', three for 'substance use', and one each for 'behavioural disengagement' and 'active grief.' The outlying values for these subscales were 'high', which showed that these strategies were used to a greater extent by these participants compared to the overall sample. All outlying values were within the range of scores available, and originated from different participants. Similarly to the data verification conducted in Study 2b (chapter 5), the winsorising technique (i.e. of converting the outlier score to the next highest or lowest score in the distribution [Tabachnick & Fidell, 2007]) was tested to see whether it would reduce the impact of outliers on the data. This did not result in any significant changes in the mean scores for these variables. Therefore, as in Study 2b, the original scores were kept in the data.

7.2.2.3 Scoring variables and computing the subscales

Data were scored and the subscales computed for the Brief COPE and the Short PGS subscales following the guidelines issued by their authors (Carver, 1997; Potvin et al., 1989), and described in chapter 5 (section 5.2.2.3). Data scoring and computing of subscales for the PTGI were conducted in accordance with Tedeschi and Calhoun's (1996)

recommendations. No reverse coding was involved and the scores for each subscale were simply added up. Higher scores indicate greater growth. The PTGI comprises an overall scale, the 'PTGI overall' and five subscales. The subscale 'relating to others' is scored between 0 and 35, 'new possibilities' between 0 and 25, 'personal strength' between 0 and 20, 'spiritual change' between 0 and 10 and 'appreciation of life' between 0 and 15.

7.2.2.4 Subscale reliability

The subscales of the three scales displayed satisfactory levels of internal reliability with Cronbach's alpha values for the Brief COPE between 0.55 for 'self-distraction' and 0.93 for 'substance use.' Cronbach's alpha values ranged from 0.88 for 'despair' to 0.96 for 'total PGS' for the Short PGS subscale and from 0.77 for 'appreciation of life' to 0.92 for 'PTGI overall.' The Cronbach's alpha values are shown in Table 7.4 (p.287) for the Brief COPE, Table 7.17 (p.303) for the Short PGS and Table 7.22 (p.313) for the PTGI.

7.2.2.5 Data distribution

The distribution of scores was assessed by visually examining histograms, calculating z-scores and by running the Shapiro-Wilk test on the variables. These analyses revealed that the scores were not normally distributed except for the 'total PGS' and the 'PTGI overall' subscales. The results of the Shapiro-Wilk test are displayed in Table 7.1. The histograms illustrating the data distribution are displayed in Appendix XI. The violation of distribution normality raised several questions such as whether to transform the data and use non-parametric or parametric tests. These questions have been discussed in depth in chapter 5 (section 5.2.2.5.). A similar approach to the statistical analysis utilised in Study 2b was used in this study. Parametric tests, which are known to be robust to violation of normality (*t* tests [Vickers, 2005], ANOVA [Schmider et al., 2010] and Pearson's correlations [Field, 2009; Havlivek & Peterson, 1977]) were used without transforming the data.

Table 7.1. Distribution of scores for the Brief COPE, the Short PGS and the PTGI based on the Shapiro-Wilk test

Variables	Statistic	df	p-value
Brief COPE			
Self-distraction	0.947	161	$p < 0.001$
Active coping	0.937	161	$p < 0.001$
Denial	0.720	161	$p < 0.001$
Substance use	0.617	161	$p < 0.001$
Emotional support	0.927	161	$p < 0.001$
Instrumental support	0.930	161	$p < 0.001$
Behavioural disengagement	0.718	161	$p < 0.001$
Venting	0.938	161	$p < 0.001$
Positive reframing	0.915	161	$p < 0.001$
Planning	0.944	161	$p < 0.001$
Acceptance	0.896	161	$p < 0.001$
Religion	0.723	161	$p < 0.001$
Self-blame	0.920	161	$p < 0.001$
Short PGS			
Active grief	0.978	161	$p = 0.011$
Difficulty coping	0.976	161	$p = 0.006$
Despair	0.983	161	$p = 0.045$
Total PGS	0.990	161	$p = 0.335$
PTGI			
Relating to others	0.972	161	$p = 0.002$
New possibilities	0.959	161	$p < 0.001$
Personal strength	0.977	161	$p = 0.010$
Spiritual change	0.786	161	$p < 0.001$
Appreciation for life	0.971	161	$p = 0.002$
PTGI overall	0.990	161	$p = 0.286$

7.3 Results

7.3.1 Participants' profile

Altogether, 178 participants agreed to participate in the study. Of those, 16 (8.90%) did not complete the survey in full. One record was identified as a duplicate and removed from the dataset. Thus, the total number of completed questionnaires for this study is 161.

As indicated in chapter 5, section 5.3.1, it is not possible to calculate an exact response rate given that ARC has no information about the profile of its email or forum members (see chapter 5, section 5.3.1). Of the 161 participants, 62 (38.5%) had already taken part in Study 2b (chapter 5), the remainder of the sample was recruited from the ARC's email network and online forum. Participants in this study were aged between 20 and 47 years old ($M = 35.5$, $SD = 5.3$), the majority ($n = 112$, 69.6%) were educated at university level. All participants were married or in a relationship, and almost all ($n = 144$, 89.4%) were White British. For 69 participants (43.1%), this was their first pregnancy. Pregnancies were terminated between 11 and 34 weeks of gestation ($M = 18.1$, $SD = 4.7$), with the majority terminated before 24 weeks of gestation ($n = 142$, 88.2%). Most terminations were medical ($n = 132$, 82.0%). For 59 participants (36.6%), the termination had occurred over 24 months prior to study participation. In that respect, the sample differed from the one used in Study 2b (chapter 5) in which over half the participants ($n = 88$, 53.0%) had terminated their pregnancy up to six months prior to study participation. This difference can be accounted for by the fact that 62 participants (38.5%) had already taken part in Study 2b, almost two years earlier. Similarly, more participants in this study had had children since the termination ($n = 85$, 53.5%) compared to Study 2b ($n = 53$, 31.9%). Participants' demographic and obstetric profiles are shown in Tables 7.2 and 7.3.

Table 7.2. Participants' demographic profile

Variables	N/n	%	Mean	SD	Range
Age (years)	161		35.5	5.3	20-47
Education					
No qualification	1	0.6			
GCSE	17	10.6			
A levels	31	19.3			
Graduate	64	39.8			
Postgraduate	48	29.8			
Socioeconomic status ³					
A	56	34.8			
B	64	39.8			
C1	26	16.1			
C2	11	6.8			
Prefer not to answer	4	2.5			
Ethnicity					
White British	144	89.4			
Other White background	14	8.7			
Other	3	1.8			
Marital status – Married/living together	161	100			
Religious status					
No religion	75	46.6			
Christian	74	46.0			
Other	7	4.2			
Prefer not to answer	5	3.1			

³ For more information about the social grade definitions system (ABC1), refer to footnote on p.187

Table 7.3. Participants' obstetric profile

<i>Variables</i>	<i>N/n</i>	<i>%</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>
Time elapsed since TFA					
Up to 6 months	47	29.2			
7-12 months	31	19.3			
13-24 months	24	14.9			
24 months+	59	36.6			
Gestational age at TFA (weeks)	161		18.1	4.7	11-34
Method of detection					
Routine check	150	93.2			
Directed search	9	5.6			
Don't know	2	1.2			
Method of termination					
Medical	132	82.0			
Surgical	27	16.8			
Don't know	1	0.6			
Prefer not to answer	1	0.6			
Abnormality prognosis					
Incompatible with life	62	38.8			
Compatible with life	78	48.8			
Not sure	19	11.9			
Prefer not to answer	1	0.6			
Would make the same decision again					
Yes	122	76.3			
No	9	5.6			
Don't know	28	17.5			
Prefer not to answer	1	0.6			
Children at time of TFA – Yes	80	49.7			
First pregnancy – Yes	69	43.1			
First TFA – Yes	152	95.0			
Children since TFA - Yes/pregnant	85	52.8			

7.3.2 Women's use of coping strategies

Coping strategies were first examined descriptively at an overall level. Group differences were also investigated in relation to demographic and termination-related variables.

7.3.2.1 General use of coping strategies

The mean use of the coping strategies was examined through descriptive statistics. The highest usage was recorded for 'acceptance' ($M = 6.23$), 'emotional support' ($M = 5.55$), 'active coping' ($M = 5.35$) and 'planning' ($M = 5.09$). For these coping strategies, the mean score was above the midpoint value of 5. In comparison, the strategies 'behavioural disengagement' ($M = 2.70$), 'substance use' ($M = 2.72$), 'denial' ($M = 3.01$) and 'religion' ($M = 3.14$) recorded the lowest usage. The results are displayed in Table 7.4.

Table 7.4. Mean scores, standard deviations and Cronbach's values for the Brief COPE

<i>Variables</i>	<i>Mean</i>	<i>SD</i>	<i>Cronbach's value</i>
Brief COPE (N = 161)			
Self-distraction	4.84	1.67	0.55
Active coping	5.35	1.74	0.68
Denial	3.01	1.49	0.77
Substance use	2.72	1.30	0.93
Emotional support	5.55	1.77	0.83
Instrumental support	4.77	1.86	0.84
Behavioural disengagement	2.70	0.98	0.57
Venting	4.47	1.52	0.56
Positive reframing	4.34	1.80	0.71
Planning	5.09	1.71	0.74
Acceptance	6.23	1.53	0.80
Religion	3.14	1.63	0.81
Self-blame	4.78	1.96	0.82

Values above the scale's midpoint (> 5) are highlighted in bold

7.3.2.2 Group differences in women's use of coping strategies

Differences in the use of coping strategies were assessed according to demographic and termination-related variables. Demographic variables included: age, marital status, ethnicity, level of education, socioeconomic status and religion. Variables related to the terminated pregnancy comprised: time elapsed since the termination, number of pregnancies, number of living children at the time of TFA, gestational age at TFA, method of abnormality detection, abnormality prognosis, method of termination, women's reproductive history post-TFA, and how women felt about their decision to terminate. These analyses were conducted using the same grouping variables as those utilised to analyse the data in Study 2b and described in chapter 5 sections 5.3.2.2.1 and 5.3.2.2.2. Group differences were investigated using unrelated *t* tests, except for the 'time elapsed since TFA' variable for which a one way ANOVA was conducted. Results pertaining to group differences in the use of coping strategies are detailed in the following sections (7.3.2.2.1 and 7.3.2.2.2). Variables for which results are statistically significant are marked by asterisks in the tables (* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$).

7.3.2.2.1 Differences in the use of coping strategies by demographic variables

Demographic variables comprised age, marital status, ethnicity, level of education, socioeconomic status and religion. The sample almost exclusively comprised White British, married women or women living in a partnership (89.4% and 100% respectively). Consequently, the analysis based on these variables was unlikely to differ from the analysis based on the whole sample (presented in section 7.3.2.1). Therefore, group differences according to these variables were not assessed.

Age

The age variable was examined using the two-category grouping described in chapter 5 (section 5.3.2.2.1): up to 34 years old ($n = 67$) and over 35 years old ($n = 94$). The results

indicated significant differences between age groups, with women in the younger age group making higher use of 'self-distraction' ($M = 5.34$, $SD = 1.52$ vs. $M = 4.48$, $SD = 1.68$, $t(159) = 3.35$, $p < 0.01$) compared to women in the older age group. Women in the younger age group also relied to a greater extent on 'positive reframing' ($M = 4.81$, $SD = 1.98$ vs. $M = 4.00$, $SD = 1.59$, $t(159) = 2.76$, $p < 0.01$) and 'self-blame' ($M = 5.19$, $SD = 1.92$ vs. $M = 4.48$, $SD = 1.94$, $t(159) = 2.32$, $p < 0.05$). Effect sizes were small to medium ($r = 0.26$, $r = 0.22$, $r = 0.18$ respectively). The results are shown in Table 7.5.

Table 7.5. Differences in the use of coping strategies by age

Variables	Up to 34 years old	Over 35 years old	t-value	p-value
Coping strategies	<i>n</i> = 67 (41.61%)	<i>n</i> = 94 (58.39%)		
Self-distraction	5.34 ($SD = 1.52$)	4.48 ($SD = 1.68$)	3.349	$p = 0.001^{**}$
Active coping	5.52 ($SD = 1.55$)	5.23 ($SD = 1.86$)	1.036	$p = 0.302$
Denial ^a	3.19 ($SD = 1.73$)	2.88 ($SD = 1.29$)	1.249	$p = 0.214$
Substance use	2.63 ($SD = 1.22$)	2.79 ($SD = 1.36$)	-.771	$p = 0.442$
Emotional support	5.78 ($SD = 1.72$)	5.39 ($SD = 1.80$)	1.354	$p = 0.178$
Instrumental support	4.85 ($SD = 1.84$)	4.71 ($SD = 1.89$)	.462	$p = 0.645$
Behaviour. disengagement	2.64 ($SD = 0.87$)	2.74 ($SD = 1.06$)	-.655	$p = 0.513$
Venting ^a	4.55 ($SD = 1.28$)	4.40 ($SD = 1.68$)	.633	$p = 0.527$
Positive reframing ^a	4.81 ($SD = 1.98$)	4.00 ($SD = 1.59$)	2.761	$p = 0.007^{**}$
Planning	5.25 ($SD = 1.64$)	4.98 ($SD = 1.76$)	1.006	$p = 0.316$
Acceptance	6.10 ($SD = 1.50$)	6.33 ($SD = 1.55$)	-.920	$p = 0.359$
Religion	3.28 ($SD = 1.78$)	3.03 ($SD = 1.52$)	.963	$p = 0.337$
Self-blame	5.19 ($SD = 1.92$)	4.48 ($SD = 1.94$)	2.319	$p = 0.022^*$

^a Equality of variance not assumed; * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Level of education

The variable 'level of education' was examined using the two-category grouping: secondary education ($n = 48$) and higher education ($n = 112$). The analysis revealed significant differences in usage of 'behavioural disengagement' and 'self-blame'. Women who had received secondary education reported higher usage of these strategies than women who

had received higher education ($M = 3.04$, $SD = 1.13$ vs. $M = 2.54$, $SD = 0.85$, $t(158) = 2.79$, $p < 0.01$ and $M = 5.23$, $SD = 2.07$ vs. $M = 4.55$, $SD = 1.86$, $t(158) = 2.03$, $p < 0.05$ respectively). Differences were of a small to medium magnitude ($r = 0.24$ and $r = 0.17$ respectively). The results are displayed in Table 7.6.

Table 7.6. Differences in the use of coping strategies by level of education

Variables	Secondary education	Higher education	t-value	p-value
Coping strategies	$n = 48$ (30.00%)^b	$n = 112$ (70.00%)^b		
Self-distraction	4.63 ($SD = 1.70$)	4.95 ($SD = 1.65$)	-1.120	$p = 0.264$
Active coping	5.06 ($SD = 1.74$)	5.48 ($SD = 1.74$)	-1.397	$p = 0.164$
Denial ^a	3.31 ($SD = 1.70$)	2.86 ($SD = 1.35$)	1.645	$p = 0.104$
Substance use	2.83 ($SD = 1.36$)	2.64 ($SD = 1.24$)	.863	$p = 0.389$
Emotional support	5.38 ($SD = 1.92$)	5.61 ($SD = 1.70$)	-.761	$p = 0.448$
Instrumental support	4.63 ($SD = 1.89$)	4.82 ($SD = 1.87$)	-.608	$p = 0.544$
Behav. disengagement ^a	3.04 ($SD = 1.13$)	2.54 ($SD = 0.85$)	2.786	$p = 0.007^{**}$
Venting	4.29 ($SD = 1.47$)	4.54 ($SD = 1.55$)	-.925	$p = 0.357$
Positive reframing	4.31 ($SD = 1.84$)	4.35 ($SD = 1.80$)	-.114	$p = 0.909$
Planning	4.71 ($SD = 1.54$)	5.24 ($SD = 1.76$)	-1.821	$p = 0.071$
Acceptance ^a	6.17 ($SD = 1.80$)	6.28 ($SD = 1.41$)	-.377	$p = 0.707$
Religion	3.15 ($SD = 1.57$)	3.11 ($SD = 1.65$)	.138	$p = 0.891$
Self-blame	5.23 ($SD = 2.07$)	4.55 ($SD = 1.86$)	2.033	$p = 0.044^*$

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category ($n = 160$); * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Socioeconomic status

Differences in coping strategies according to socioeconomic status were assessed using the two-category grouping AB ($n = 120$) and C1C2⁴ ($n = 37$). Women in the AB group ($M = 2.58$, $SD = 0.88$) made lower use of 'behavioural disengagement' compared to women in the C1C2 group ($M = 2.97$, $SD = 1.17$), $t(155) = -2.16$, $p < 0.05$. The effect size, however, was small ($r = 0.09$). The results are shown in Table 7.7.

⁴ None of the participants fell into the D and E categories

Table 7.7. Differences in the use of coping strategies by socioeconomic status

Variables	AB	C1C2	t-value	p-value
Coping strategies	<i>n</i> = 120 (76.43%)^b	<i>n</i> = 37 (23.57%)^b		
Self-distraction	4.79 (<i>SD</i> = 1.58)	5.08 (<i>SD</i> = 1.92)	-.926	<i>p</i> = 0.356
Active coping	5.46 (<i>SD</i> = 1.73)	4.95 (<i>SD</i> = 1.78)	1.565	<i>p</i> = 0.120
Denial ^a	2.89 (<i>SD</i> = 1.32)	3.35 (<i>SD</i> = 1.89)	-1.380	<i>p</i> = 0.174
Substance use	2.65 (<i>SD</i> = 1.29)	2.84 (<i>SD</i> = 1.26)	-.777	<i>p</i> = 0.438
Emotional support	5.55 (<i>SD</i> = 1.72)	5.46 (<i>SD</i> = 1.92)	.272	<i>p</i> = 0.786
Instrumental support	4.76 (<i>SD</i> = 1.79)	4.62 (<i>SD</i> = 2.05)	.392	<i>p</i> = 0.695
Behaviour. disengagement	2.58 (<i>SD</i> = 0.88)	2.97 (<i>SD</i> = 1.17)	-2.164	<i>p</i> = 0.032*
Venting	4.53 (<i>SD</i> = 1.51)	4.16 (<i>SD</i> = 1.57)	1.294	<i>p</i> = 0.198
Positive reframing ^a	4.42 (<i>SD</i> = 1.89)	4.16 (<i>SD</i> = 1.52)	.839	<i>p</i> = 0.404
Planning	5.08 (<i>SD</i> = 1.77)	5.03 (<i>SD</i> = 1.59)	.173	<i>p</i> = 0.863
Acceptance	6.30 (<i>SD</i> = 1.55)	6.11 (<i>SD</i> = 1.54)	.660	<i>p</i> = 0.510
Religion	3.08 (<i>SD</i> = 1.54)	3.32 (<i>SD</i> = 1.90)	-.785	<i>p</i> = 0.434
Self-blame	4.64 (<i>SD</i> = 1.90)	5.19 (<i>SD</i> = 2.09)	-1.498	<i>p</i> = 0.136

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category (*n* = 157); * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

Religious status

The use of coping strategies was also examined based on women's religious status. The questionnaire included nine categories of answer, but most fell within the 'no religion' and 'Christian' categories. The data were, therefore, recoded in two categories: 'no religion' (*n* = 75) and 'religion' (*n* = 81). The analysis indicated a significant difference in the use of 'religious' coping, with women in the no-religion group making lower use of this strategy than women in the religion group (*M* = 2.40, *SD* = 0.81 vs. *M* = 3.78, *SD* = 1.90, *t*(154) = -5.96, *p* < 0.001, with a medium to large effect size, *r* = 0.43). Results are displayed in Table 7.8.

Table 7.8. Differences in the use of coping strategies by religious status

Variables	No religion	Religion	t-value	p-value
Coping strategies	<i>n</i> = 75 (48.08%)^b	<i>n</i> = 81 (51.92%)^b		
Self-distraction	4.73 (<i>SD</i> = 1.74)	4.88 (<i>SD</i> = 1.60)	-.535	<i>p</i> = 0.593
Active coping	5.32 (<i>SD</i> = 1.74)	5.35 (<i>SD</i> = 1.74)	-.092	<i>p</i> = 0.927
Denial	3.01 (<i>SD</i> = 1.56)	3.04 (<i>SD</i> = 1.46)	-.098	<i>p</i> = 0.922
Substance use	2.83 (<i>SD</i> = 1.38)	2.63 (<i>SD</i> = 1.25)	.936	<i>p</i> = 0.351
Emotional support	5.41 (<i>SD</i> = 1.61)	5.65 (<i>SD</i> = 1.91)	-.850	<i>p</i> = 0.397
Instrumental support ^a	4.71 (<i>SD</i> = 1.72)	4.83 (<i>SD</i> = 2.00)	-.403	<i>p</i> = 0.687
Behaviour. disengagement	2.65 (<i>SD</i> = 0.92)	2.75 (<i>SD</i> = 1.06)	-.626	<i>p</i> = 0.532
Venting	4.35 (<i>SD</i> = 1.54)	4.57 (<i>SD</i> = 1.51)	-.907	<i>p</i> = 0.366
Positive reframing	4.12 (<i>SD</i> = 1.75)	4.57 (<i>SD</i> = 1.86)	-1.548	<i>p</i> = 0.124
Planning	4.92 (<i>SD</i> = 1.72)	5.21 (<i>SD</i> = 1.71)	-1.055	<i>p</i> = 0.293
Acceptance	6.48 (<i>SD</i> = 1.27)	6.04 (<i>SD</i> = 1.72)	1.840	<i>p</i> = 0.068
Religion ^a	2.40 (<i>SD</i> = 0.81)	3.78 (<i>SD</i> = 1.90)	-5.962	<i>p</i> < 0.001 ^{***}
Self-blame	4.88 (<i>SD</i> = 2.03)	4.68 (<i>SD</i> = 1.94)	.632	<i>p</i> = 0.528

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category (*n* = 156); * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

7.3.2.2.2 Differences in the use of coping strategies by termination-related variables

Similarly to the demographic variables of ethnicity and marital status, the sample almost exclusively comprised women for whom the fetal abnormality had been detected through a routine check (93.2%). Hence, the analysis of the coping strategies based on this variable was likely to follow the same pattern as the analysis based on the whole sample (presented in section 7.3.2.1). Therefore, group differences were not examined for this variable. The analysis was run for the following termination-related variables: time elapsed since TFA, number of pregnancies, number of living children at the time of TFA, gestational age at TFA, abnormality prognosis, method of termination, women's reproductive history post-TFA, and how women felt about their decision to terminate.

Time elapsed since TFA

An unrelated one-way ANOVA was run to assess the main effect of time elapsed since TFA on the use of coping strategies. The analysis revealed a main effect of time elapsed on the use of 'instrumental support' $F(3,157) = 5.37$ $p < 0.01$, 'acceptance' $F(3,157) = 6.09$, $p < 0.01$ and 'self-blame' $F(3,157) = 7.10$, $p < 0.001$, all with a medium effect size ($\omega^2 = 0.08$, $\omega^2 = 0.09$ and $\omega^2 = 0.10$). *Post hoc* tests with the Bonferroni correction established that women who had a termination up to six months prior to study participation made greater use of 'instrumental support' compared to those who had had their termination over 24 months prior to study participation ($M = 5.00$, $SD = 1.84$ vs. $M = 4.05$, $SD = 1.81$, $p < 0.05$). They also made greater use of 'self-blame' compared to women who had had a termination 13-24 months and over 24 months prior to partaking in the study ($M = 5.49$, $SD = 1.85$ vs. $M = 5.08$, $SD = 1.41$ $p < 0.05$ and vs. $M = 3.92$, $SD = 1.94$ $p < 0.05$ respectively). By contrast, they relied to a lesser extent on 'acceptance' than women in the 13-24 or over 24 months categories ($M = 5.53$, $SD = 1.44$ vs. $M = 6.54$, $SD = 1.38$ $p < 0.05$ and vs. $M = 6.71$, $SD = 1.59$ $p < 0.05$ respectively). The results are displayed in Table 7.9.

Despite exhibiting significant group differences, homogeneity of variance could not be established for 'denial' and 'emotional support,' therefore, Kruskal-Wallis tests were used to analyse these variables. The analyses indicated that the use of 'denial' was significantly affected by time elapsed since TFA, $H(3) = 13.31$, $p = 0.004$. Pairwise comparisons with adjusted p -values showed significant differences in the use of 'denial' between women whose termination had occurred most recently (up to six months) compared to those whose termination had occurred over 24 months prior to study participation ($p = 0.005$, with a medium effect size, $r = 0.32$). Comparisons between other groups were not significant ($p > 0.05$). The use of 'emotional support' was also significantly affected by time elapsed since TFA $H(3) = 8.50$, $p = 0.037$. However, pairwise comparisons did not reveal any significant differences between groups (all p -values > 0.05).

Table 7.9. Differences in the use of coping strategies by time elapsed since TFA

Variables	Up to 6 months	7-12 months	13-24 months	24 + months
Coping strategies	<i>n</i> = 47 (29.19%)	<i>n</i> = 31 (19.25%)	<i>n</i> = 24 (14.91%)	<i>n</i> = 59 (36.65%)
Self-distraction	5.30 (<i>SD</i> = 1.64)	4.81 (<i>SD</i> = 1.51)	4.83 (<i>SD</i> = 1.49)	4.49 (<i>SD</i> = 1.78)
Active coping	5.11 (<i>SD</i> = 1.70)	5.52 (<i>SD</i> = 1.50)	5.58 (<i>SD</i> = 1.61)	5.37 (<i>SD</i> = 1.95)
Denial ^{ab}	3.45 (<i>SD</i> = 1.70)	3.32 (<i>SD</i> = 1.64)	2.96 (<i>SD</i> = 1.49)	2.53 (<i>SD</i> = 1.04)**
Substance use ^a	2.98 (<i>SD</i> = 1.61)	2.77 (<i>SD</i> = 1.20)	2.75 (<i>SD</i> = 1.07)	2.47 (<i>SD</i> = 1.13)
Emotional support ^{ab}	5.94 (<i>SD</i> = 1.49)	5.87 (<i>SD</i> = 1.77)	5.83 (<i>SD</i> = 1.37)	4.97 (<i>SD</i> = 1.99)
Instrumental support	5.00 (<i>SD</i> = 1.84)	5.26 (<i>SD</i> = 1.77)	5.46 (<i>SD</i> = 1.67)	4.05 (<i>SD</i> = 1.81)*
Behav. disengag.	2.87 (<i>SD</i> = 0.88)	2.65 (<i>SD</i> = 0.95)	2.54 (<i>SD</i> = 0.78)	2.66 (<i>SD</i> = 1.14)
Venting	4.66 (<i>SD</i> = 1.39)	4.61 (<i>SD</i> = 1.26)	4.75 (<i>SD</i> = 1.65)	4.12 (<i>SD</i> = 1.67)
Positive reframing	4.00 (<i>SD</i> = 1.68)	4.35 (<i>SD</i> = 1.84)	4.67 (<i>SD</i> = 1.95)	4.46 (<i>SD</i> = 1.81)
Planning	5.13 (<i>SD</i> = 1.61)	5.32 (<i>SD</i> = 1.56)	5.71 (<i>SD</i> = 1.49)	4.69 (<i>SD</i> = 1.88)
Acceptance	5.53 (<i>SD</i> = 1.44)	6.16 (<i>SD</i> = 1.29)	6.54 (<i>SD</i> = 1.38)*	6.71 (<i>SD</i> = 1.59)*
Religion	3.15 (<i>SD</i> = 1.44)	3.13 (<i>SD</i> = 1.69)	3.08 (<i>SD</i> = 1.53)	3.15 (<i>SD</i> = 1.82)
Self-blame	5.49 (<i>SD</i> = 1.85)	5.10 (<i>SD</i> = 1.97)	5.08 (<i>SD</i> = 1.41)*	3.92 (<i>SD</i> = 1.94)*

Groups were compared against the group whose loss was most recent (up to six months);

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$; ^a Equality of variance not assumed; ^b Kruskal-Wallis test with pairwise comparison

First pregnancy

Group differences according to whether this was a woman's first pregnancy or not, were examined using the two-category grouping: 'first pregnancy' ($n = 69$) and 'not first pregnancy' ($n = 91$). The results showed significant differences for several strategies.

Compared to women for whom it was not the first pregnancy, those for whom it was the first pregnancy made greater use of 'active coping' ($M = 5.77$, $SD = 1.68$ vs. $M = 5.03$, $SD = 1.73$, $t(158) = 2.69$, $p < 0.01$), 'emotional support' ($M = 5.94$, $SD = 1.71$ vs. $M = 5.23$, $SD = 1.76$, $t(158) = 2.57$, $p < 0.05$) and 'instrumental support' ($M = 5.14$, $SD = 1.87$ vs. $M = 4.47$, $SD = 1.83$, $t(158) = 2.28$, $p < 0.05$). Group differences were of a small to medium magnitude ($r = 0.21$, $r = 0.20$ and $r = 0.18$ respectively). Results are shown in Table 7.10.

Table 7.10. Differences in the use of coping strategies by whether this was a first pregnancy

Variables	First pregnancy	Not first pregnancy	t-value	p-value
Coping strategies	<i>n</i> = 69 (43.13%)^b	<i>n</i> = 91 (56.88%)^b		
Self-distraction ^a	4.99 (<i>SD</i> = 1.49)	4.73 (<i>SD</i> = 1.80)	1.001	<i>p</i> = 0.318
Active coping	5.77 (<i>SD</i> = 1.68)	5.03 (<i>SD</i> = 1.73)	2.690	<i>p</i> = 0.008**
Denial	2.84 (<i>SD</i> = 1.39)	3.14 (<i>SD</i> = 1.56)	-1.272	<i>p</i> = 0.205
Substance use	2.68 (<i>SD</i> = 1.41)	2.76 (<i>SD</i> = 1.22)	-.370	<i>p</i> = 0.712
Emotional support	5.94 (<i>SD</i> = 1.71)	5.23 (<i>SD</i> = 1.76)	2.567	<i>p</i> = 0.011*
Instrumental support	5.14 (<i>SD</i> = 1.87)	4.47 (<i>SD</i> = 1.83)	2.284	<i>p</i> = 0.024*
Behaviour. disengagement	2.55 (<i>SD</i> = 0.90)	2.82 (<i>SD</i> = 1.03)	-1.757	<i>p</i> = 0.081
Venting	4.61 (<i>SD</i> = 1.56)	4.37 (<i>SD</i> = 1.50)	.965	<i>p</i> = 0.336
Positive reframing	4.62 (<i>SD</i> = 1.79)	4.10 (<i>SD</i> = 1.78)	1.838	<i>p</i> = 0.068
Planning	5.28 (<i>SD</i> = 1.71)	4.96 (<i>SD</i> = 1.71)	1.168	<i>p</i> = 0.245
Acceptance	6.49 (<i>SD</i> = 1.42)	6.04 (<i>SD</i> = 1.60)	1.845	<i>p</i> = 0.067
Religion	3.12 (<i>SD</i> = 1.76)	3.12 (<i>SD</i> = 1.52)	-.019	<i>p</i> = 0.985
Self-blame	4.86 (<i>SD</i> = 1.89)	4.73 (<i>SD</i> = 2.02)	.414	<i>p</i> = 0.680

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category (*n* = 160); * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

Children at the time of TFA

Similar results were observed in relation to whether women had children at the time of TFA (*n* = 80) or not (*n* = 81). Compared to women who had children at the time of TFA, those who were childless recorded higher usage of: 'active coping' (*M* = 5.73, *SD* = 1.64 vs. *M* = 4.98, *SD* = 1.77, *t*(159) = 2.80, *p* < 0.01), 'emotional support' (*M* = 5.86, *SD* = 1.68 vs. *M* = 5.24, *SD* = 1.82, *t*(159) = 2.27, *p* < 0.05) and 'instrumental support' (*M* = 5.12, *SD* = 1.78 vs. *M* = 4.41, *SD* = 1.89, *t*(159) = 2.46, *p* < 0.05). They also made greater use of 'positive reframing' (*M* = 4.62, *SD* = 1.79 vs. *M* = 4.05, *SD* = 1.78, *t*(159) = 2.02, *p* < 0.05). All group differences were small to medium in size (*r* = 0.21, *r* = 0.17, *r* = 0.19 and *r* = 0.16 respectively). Results are displayed in Table 7.11.

Table 7.11. Differences in the use of coping strategies by whether women had children at the time of TFA

Variables	No children	Children	t-value	p-value
Coping strategies	<i>n</i> = 81 (50.31%)	<i>n</i> = 80 (49.69%)		
Self-distraction ^a	5.02 (<i>SD</i> = 1.50)	4.65 (<i>SD</i> = 1.81)	1.430	<i>p</i> = 0.155
Active coping	5.73 (<i>SD</i> = 1.64)	4.98 (<i>SD</i> = 1.77)	2.804	<i>p</i> = 0.006**
Denial	2.96 (<i>SD</i> = 1.50)	3.06 (<i>SD</i> = 1.48)	-.423	<i>p</i> = 0.673
Substance use	2.65 (<i>SD</i> = 1.38)	2.79 (<i>SD</i> = 1.22)	-.649	<i>p</i> = 0.517
Emotional support	5.86 (<i>SD</i> = 1.68)	5.24 (<i>SD</i> = 1.82)	2.274	<i>p</i> = 0.024*
Instrumental support	5.12 (<i>SD</i> = 1.78)	4.41 (<i>SD</i> = 1.89)	2.456	<i>p</i> = 0.015*
Behaviour. disengagement	2.60 (<i>SD</i> = 0.92)	2.80 (<i>SD</i> = 1.04)	-1.265	<i>p</i> = 0.208
Venting	4.58 (<i>SD</i> = 1.56)	4.35 (<i>SD</i> = 1.49)	.958	<i>p</i> = 0.340
Positive reframing	4.62 (<i>SD</i> = 1.79)	4.05 (<i>SD</i> = 1.78)	2.020	<i>p</i> = 0.045*
Planning	5.15 (<i>SD</i> = 1.73)	5.04 (<i>SD</i> = 1.70)	.410	<i>p</i> = 0.683
Acceptance	6.46 (<i>SD</i> = 1.47)	6.01 (<i>SD</i> = 1.57)	1.855	<i>p</i> = 0.065
Religion	3.05 (<i>SD</i> = 1.70)	3.23 (<i>SD</i> = 1.57)	-.681	<i>p</i> = 0.497
Self-blame	4.79 (<i>SD</i> = 1.90)	4.76 (<i>SD</i> = 2.03)	.089	<i>p</i> = 0.929

^a Equality of variance not assumed; * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

Gestational age

Group differences were noted for gestational age based on the two-category grouping: 'up to 20 weeks' (*n* = 95) and 'above 20 weeks' (*n* = 66). Women who terminated their pregnancy at a gestational age below 20 weeks made lower use of 'emotional support' than women whose gestational age at TFA was above 20 weeks (*M* = 5.26, *SD* = 1.84 vs. *M* = 5.97, *SD* = 1.59, *t*(159) = -2.53, *p* < 0.05 with a small to medium effect size: *r* = 0.20). Results are displayed in Table 7.12.

Table 7.12. Differences in the use of coping strategies by gestational age

Variables	Up to 20 weeks	20 weeks +	t-value	p-value
Coping strategies	n = 95 (59.01%)	n = 66 (40.99%)		
Self-distraction	4.78 (SD = 1.71)	4.92 (SD = 1.61)	-.543	$p = 0.588$
Active coping	5.31 (SD = 1.87)	5.42 (SD = 1.54)	-.425	$p = 0.671$
Denial	3.03 (SD = 1.55)	2.98 (SD = 1.41)	.195	$p = 0.845$
Substance use	2.79 (SD = 1.28)	2.62 (SD = 1.33)	.807	$p = 0.421$
Emotional support	5.26 (SD = 1.84)	5.97 (SD = 1.59)	-2.531	$p = 0.012^*$
Instrumental support	4.55 (SD = 1.80)	5.09 (SD = 1.92)	-1.832	$p = 0.069$
Behaviour. disengagement	2.73 (SD = 0.95)	2.67 (SD = 1.03)	.379	$p = 0.705$
Venting	4.39 (SD = 1.52)	4.58 (SD = 1.53)	-.761	$p = 0.448$
Positive reframing	4.21 (SD = 1.79)	4.52 (SD = 1.81)	-1.057	$p = 0.292$
Planning	5.06 (SD = 1.72)	5.14 (SD = 1.71)	-.266	$p = 0.790$
Acceptance	6.12 (SD = 1.54)	6.41 (SD = 1.52)	-1.197	$p = 0.233$
Religion ^a	3.00 (SD = 1.34)	3.33 (SD = 1.98)	-1.192	$p = 0.236$
Self-blame	4.80 (SD = 2.03)	4.74 (SD = 1.86)	.183	$p = 0.855$

^a Equality of variance not assumed; * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Abnormality prognosis

Significant group differences were also observed in relation to whether the abnormality prognosis was incompatible ($n = 62$) or compatible with life ($n = 78$). When compared to women whose abnormality prognosis was compatible with life, those who had an abnormality prognosis incompatible with life made greater use of 'self-distraction' ($M = 5.15$, $SD = 1.67$ vs. $M = 4.55$, $SD = 1.53$, $t(138) = 2.19$, $p < 0.05$) and 'instrumental support' ($M = 5.18$, $SD = 1.99$ vs. $M = 4.54$, $SD = 1.79$, $t(138) = 2.00$, $p < 0.05$). Both differences were of a small magnitude ($r = 0.18$ and $r = 0.17$ respectively). Results are shown in Table 7.13.

Table 7.13. Differences in the use of coping strategies by abnormality prognosis

Variables	Incompatible	Compatible	t-value	p-value
Coping strategies	<i>n</i> = 62 (44.29%)^b	<i>n</i> = 78 (55.71%)		
Self-distraction	5.15 (<i>SD</i> = 1.67)	4.55 (<i>SD</i> = 1.53)	2.189	<i>p</i> = 0.030*
Active coping	5.40 (<i>SD</i> = 1.88)	5.35 (<i>SD</i> = 1.65)	.191	<i>p</i> = 0.849
Denial	3.11 (<i>SD</i> = 1.55)	2.96 (<i>SD</i> = 1.46)	.593	<i>p</i> = 0.554
Substance use ^a	2.94 (<i>SD</i> = 1.56)	2.65 (<i>SD</i> = 1.13)	1.197	<i>p</i> = 0.234
Emotional support	5.66 (<i>SD</i> = 1.88)	5.51 (<i>SD</i> = 1.79)	.477	<i>p</i> = 0.634
Instrumental support	5.18 (<i>SD</i> = 1.99)	4.54 (<i>SD</i> = 1.79)	2.000	<i>p</i> = 0.047*
Behaviour. disengagement	2.76 (<i>SD</i> = 0.95)	2.76 (<i>SD</i> = 1.05)	.010	<i>p</i> = 0.992
Venting	4.50 (<i>SD</i> = 1.62)	4.42 (<i>SD</i> = 1.39)	.302	<i>p</i> = 0.763
Positive reframing	4.44 (<i>SD</i> = 1.75)	4.36 (<i>SD</i> = 1.92)	.243	<i>p</i> = 0.808
Planning	5.06 (<i>SD</i> = 1.76)	5.23 (<i>SD</i> = 1.66)	-.573	<i>p</i> = 0.568
Acceptance	6.16 (<i>SD</i> = 1.56)	6.31 (<i>SD</i> = 1.55)	-.554	<i>p</i> = 0.581
Religion ^a	3.44 (<i>SD</i> = 1.74)	3.00 (<i>SD</i> = 1.47)	1.573	<i>p</i> = 0.118
Self-blame	4.89 (<i>SD</i> = 1.94)	4.58 (<i>SD</i> = 1.98)	.929	<i>p</i> = 0.354

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category (*n* = 140); * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

Method of termination

The analysis also indicated group differences based on the method of termination: medical (*n* = 132) and surgical (*n* = 27). Women who had a medical termination made higher use of 'religion' than those who had a surgical termination (*M* = 3.27, *SD* = 1.74 vs. *M* = 2.56, *SD* = 0.85, *t*(157) = 3.19, *p* < 0.01 with a small to medium effect size *r* = 0.25). Results are displayed in Table 7.14.

Table 7.14. Differences in the use of coping strategies by method of termination

Variables	Medical	Surgical	t-value	p-value
Coping strategies	<i>n</i> = 132 (83.02%)^b	<i>n</i> = 27 (16.98%)^b		
Self-distraction	4.85 (<i>SD</i> = 1.61)	4.96 (<i>SD</i> = 1.89)	-.327	<i>p</i> = 0.744
Active coping ^a	5.45 (<i>SD</i> = 1.64)	5.07 (<i>SD</i> = 2.13)	.860	<i>p</i> = 0.396
Denial	3.04 (<i>SD</i> = 1.52)	2.81 (<i>SD</i> = 1.24)	.715	<i>p</i> = 0.476
Substance use	2.71 (<i>SD</i> = 1.35)	2.81 (<i>SD</i> = 1.08)	-.371	<i>p</i> = 0.711
Emotional support	5.70 (<i>SD</i> = 1.76)	5.04 (<i>SD</i> = 1.63)	1.793	<i>p</i> = 0.075
Instrumental support	4.83 (<i>SD</i> = 1.87)	4.56 (<i>SD</i> = 1.85)	.705	<i>p</i> = 0.482
Behaviour. disengagement	2.68 (<i>SD</i> = 0.98)	2.78 (<i>SD</i> = 0.97)	-.463	<i>p</i> = 0.644
Venting	4.45 (<i>SD</i> = 1.50)	4.59 (<i>SD</i> = 1.67)	-.450	<i>p</i> = 0.654
Positive reframing	4.47 (<i>SD</i> = 1.80)	3.78 (<i>SD</i> = 1.74)	1.833	<i>p</i> = 0.069
Planning	5.16 (<i>SD</i> = 1.66)	4.96 (<i>SD</i> = 1.87)	.547	<i>p</i> = 0.585
Acceptance	6.28 (<i>SD</i> = 1.54)	5.93 (<i>SD</i> = 1.49)	1.095	<i>p</i> = 0.275
Religion ^a	3.27 (<i>SD</i> = 1.74)	2.56 (<i>SD</i> = 0.85)	3.190	<i>p</i> = 0.002**
Self-blame	4.83 (<i>SD</i> = 1.97)	4.44 (<i>SD</i> = 1.83)	.946	<i>p</i> = 0.346

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category (*n* = 159); * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

Children following TFA

Group differences according to whether women had children/were pregnant following TFA (*n* = 85) or not (*n* = 74) were significant for several coping strategies. Compared to women who had had children/were pregnant following TFA, those who did not have children relied to a greater extent on 'self-distraction' (*M* = 5.18, *SD* = 1.68 vs. *M* = 4.55, *SD* = 1.62, *t*(157) = 2.37, *p* < 0.05), 'substance use' (*M* = 2.95, *SD* = 1.43 vs. *M* = 2.47, *SD* = 1.00, *t*(157) = 2.40, *p* < 0.05), 'emotional support' (*M* = 5.86, *SD* = 1.57 vs. *M* = 5.27, *SD* = 1.89, *t*(157) = 2.17, *p* < 0.05), 'planning' (*M* = 5.50, *SD* = 1.73 vs. *M* = 4.72, *SD* = 1.62, *t*(157) = 2.94, *p* < 0.01), and self-blame' (*M* = 5.23, *SD* = 1.82 vs. *M* = 4.34, *SD* = 1.97, *t*(157) = 2.93, *p* < 0.01). By contrast, their usage of 'acceptance' was significantly lower than women who had had children/were pregnant following TFA (*M* = 5.80, *SD* = 1.36 vs. *M* = 6.67, *SD* = 1.54, *t*(157) = -3.76, *p* < 0.001). All group differences were of small to medium magnitude (*r* = 0.19, *r* =

0.19, $r = 0.17$, $r = 0.23$, $r = 0.23$ and $r = 0.29$ respectively). The results for 'positive reframing' approached significance in the same direction than 'acceptance' ($M = 4.05$, $SD = 1.75$ vs. $M = 4.60$, $SD = 1.81$, $t(157) = -1.92$, $p = 0.056$). Results are shown in Table 7.15.

Table 7.15. Differences in the use of coping strategies by whether women had children following TFA

Variables	No children	Children	t-value	p-value
Coping strategies	$n = 74$ (46.54%)^b	$n = 85$ (53.46%)		
Self-distraction	5.18 ($SD = 1.68$)	4.55 ($SD = 1.62$)	2.373	$p = 0.019^*$
Active coping	5.32 ($SD = 1.62$)	5.39 ($SD = 1.86$)	-.229	$p = 0.819$
Denial	3.20 ($SD = 1.54$)	2.84 ($SD = 1.44$)	1.553	$p = 0.122$
Substance use ^a	2.95 ($SD = 1.43$)	2.47 ($SD = 1.00$)	2.396	$p = 0.018^*$
Emotional support ^a	5.86 ($SD = 1.57$)	5.27 ($SD = 1.89$)	2.166	$p = 0.032^*$
Instrumental support	4.97 ($SD = 1.78$)	4.55 ($SD = 1.91$)	1.426	$p = 0.156$
Behaviour. disengagement	2.77 ($SD = 0.91$)	2.65 ($SD = 1.04$)	.786	$p = 0.433$
Venting ^a	4.57 ($SD = 1.36$)	4.38 ($SD = 1.68$)	.794	$p = 0.428$
Positive reframing	4.05 ($SD = 1.75$)	4.60 ($SD = 1.81$)	-1.924	$p = 0.056$
Planning	5.50 ($SD = 1.73$)	4.72 ($SD = 1.62$)	2.940	$p = 0.004^{**}$
Acceptance	5.80 ($SD = 1.36$)	6.67 ($SD = 1.54$)	-3.762	$p < 0.001^{***}$
Religion	3.27 ($SD = 1.67$)	3.01 ($SD = 1.62$)	.990	$p = 0.324$
Self-blame	5.23 ($SD = 1.82$)	4.34 ($SD = 1.97$)	2.933	$p = 0.004^{**}$

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category ($n = 159$); * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Feeling about the decision to terminate

A similar analysis was run on whether women were 'comfortable' ($n = 122$) or 'uncomfortable' ($n = 37$) with their decision to terminate their pregnancy. Women comfortable with their decision (i.e. would make the same decision) made greater use of 'acceptance' than women uncomfortable (i.e. would not make the same decision/unsure) with their decision ($M = 6.40$, $SD = 1.49$ vs. $M = 5.73$, $SD = 1.50$, $t(157) = 2.40$, $p < 0.05$). They also made less use of 'behavioural disengagement' ($M = 2.56$, $SD = 0.85$ vs. $M = 3.11$, $SD =$

1.22, $t(157) = -2.56, p < 0.05$), 'religion' ($M = 2.93, SD = 1.43$ vs. $M = 3.73, SD = 2.01, t(157) = -2.24, p < 0.05$) and 'self-blame' ($M = 4.36, SD = 1.83$ vs. $M = 6.00, SD = 1.80, t(157) = -4.80, p < 0.001$). Effect sizes were of a small to medium magnitude, except for 'self-blame' for which the difference was larger ($r = 0.22, r = 0.25, r = 0.22$ and $r = 0.41$ respectively). Results are shown in Table 7.16.

Table 7.16. Differences in the use of coping strategies by feeling about the decision

Variables	Comfortable	Uncomfortable	t-value	p-value
Coping strategies	$n = 122 (76.73\%)^b$	$n = 37 (23.27\%)^b$		
Self-distraction	4.83 ($SD = 1.67$)	4.78 ($SD = 1.62$)	.141	$p = 0.888$
Active coping	5.36 ($SD = 1.76$)	5.30 ($SD = 1.73$)	.193	$p = 0.847$
Denial ^a	2.88 ($SD = 1.33$)	3.30 ($SD = 1.75$)	-1.351	$p = 0.183$
Substance use	2.64 ($SD = 1.25$)	2.97 ($SD = 1.44$)	-1.368	$p = 0.173$
Emotional support	5.52 ($SD = 1.77$)	5.70 ($SD = 1.79$)	-.535	$p = 0.593$
Instrumental support	4.74 ($SD = 1.81$)	4.89 ($SD = 2.01$)	-.442	$p = 0.659$
Behaviour. disengagement ^{*a}	2.56 ($SD = 0.85$)	3.11 ($SD = 1.22$)	-2.563	$p = 0.014^*$
Venting	4.35 ($SD = 1.49$)	4.68 ($SD = 1.51$)	-1.154	$p = 0.250$
Positive reframing	4.48 ($SD = 1.83$)	3.97 ($SD = 1.64$)	1.495	$p = 0.137$
Planning	5.16 ($SD = 1.76$)	4.84 ($SD = 1.57$)	1.011	$p = 0.314$
Acceptance [*]	6.40 ($SD = 1.49$)	5.73 ($SD = 1.50$)	2.403	$p = 0.017^*$
Religion ^{*a}	2.93 ($SD = 1.43$)	3.73 ($SD = 2.01$)	-2.242	$p = 0.030^*$
Self-blame [*]	4.36 ($SD = 1.83$)	6.00 ($SD = 1.80$)	-4.799	$p < 0.001^{***}$

^a Equality of variance not assumed; ^b Percentages based on participants who could be classified in either category ($n = 159$); * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

7.3.2.2.3 Summary of the results pertaining to women's use of coping strategies and comparison with Study 2b

The results pertaining to women's use of coping strategies are largely consistent with those of Study 2b (chapter 5), adding credence to the initial findings. Women used mainly strategies considered to be adaptive (Aldao & Nolen-Hoeksema, 2012; Carver, 1997; Lazarus & Folkman, 2004; Moskowitz et al., 2009) to cope with TFA. These included

'acceptance,' 'emotional support,' 'active coping' and 'planning,' which is comparable to Study 2b. However, participants in this study made lower use of 'self-distraction' and 'instrumental support' compared to those in Study 2b (chapter 5).

Group differences were noted according to demographic variables, although most differences were of small to medium magnitude. Younger women were more likely to use 'self-distraction,' 'positive reframing' and 'self-blame' than older women. Women who had received secondary education were more likely to engage in 'behavioural disengagement' and 'self-blame' than those who had received higher education. Women of lower socioeconomic status also engaged in 'behavioural disengagement' to a greater extent than those of higher socioeconomic status, although this difference was very small. Participants who stated that they had a religion also relied to a greater extent on 'religious' coping than women who stated they did not have a religion.

Group differences according to termination-related variables were also observed, although again, most of these differences were of a small to medium size. Women who had terminated their pregnancy most recently (up to six months prior to study participation) made greater use of 'instrumental support' than those whose termination had occurred over 24 months prior, which is comparable to the results of Study 2b. Women whose loss had occurred more recently also displayed higher level of 'denial' and 'self-blame' and lower levels of 'acceptance,' suggesting that 'acceptance' develops over time whilst the reliance on strategies generally considered to be maladaptive decreases. The absence of children at the time of TFA was associated with greater use of 'active coping,' 'emotional support,' 'instrumental support' and 'positive reframing,' whilst not having had children/being pregnant following TFA was related to higher levels of 'self-distraction,' 'substance use,' 'emotional support,' 'planning' and 'self-blame,' as well as lower levels of 'acceptance'.

There was a small difference regarding the use of religious coping by termination method, with women who had a medical termination making higher use of this strategy than women who had a surgical termination. Women whose gestational age at TFA was over 20 weeks made greater use of 'emotional support' than those whose gestational age was lower.

Women for whom the abnormality's prognosis was incompatible with life relied on 'self-distraction' and 'instrumental support' to a greater extent than those for whom the prognosis was compatible with life. Finally, women comfortable with their decision to terminate the pregnancy relied to a greater extent on 'acceptance' and a lesser extent on 'self-blame' than women who were uncomfortable with their decision. They also displayed lower use of 'behavioural disengagement' and 'religion'. This is, in part, consistent with the results of Study 2b.

7.3.3 Women's levels of perinatal grief

Similarly to the coping strategies, women's levels of perinatal grief were examined descriptively at the overall level. Group differences based on demographic and termination-related variables were also investigated.

7.3.3.1 General levels of perinatal grief

The mean scores for the three grief subscales decreased progressively indicating incremental levels of pathological grief. The mean score for 'active grief' ($M = 37.70$) was above the midpoint, whereas the mean scores for 'difficulty coping' ($M = 29.27$), 'despair' ($M = 28.14$) and 'total PGS' ($M = 95.11$) were below the midpoint. Mean scores for the grief variables are shown in Table 7.17.

Table 7.17. Mean scores, standard deviations and Cronbach's values for the Short PGS

<i>Variables</i>	<i>Mean</i>	<i>SD</i>	<i>Cronbach's values</i>
Short PGS (N = 161)			
Active grief (11-55)	37.70	9.48	0.90
Difficulty coping (11-55)	29.27	10.50	0.92
Despair (11-55)	28.14	9.34	0.88
Total PGS (33-165)	95.11	27.65	0.96

Values above the scales' midpoints are highlighted in bold; active grief, difficulty coping and despair: > 33 and total PGS: > 99

7.3.3.2 Group differences in women's levels of grief

Similarly to the coping strategies, women's levels of perinatal grief were examined for differences according to demographic and termination-related variables.

7.3.3.2.1 Differences in levels of perinatal grief by demographic variables

Differences in levels of perinatal grief were examined according to age, level of education, socioeconomic status and religion, using unrelated *t* tests. Significant differences were found for 'active grief' according to the age variable. Women in the younger group (up to 34 years old) displayed significantly higher levels of 'active grief' than women in the older group ($M = 39.54$, $SD = 8.49$ vs. $M = 36.38$, $SD = 9.96$, $t(159) = 2.10$, $p < 0.05$). However, this difference was very small in size ($r = 0.02$). Significant group differences were also identified for 'despair' based on women's level of education. Women who had received secondary education exhibited higher levels of 'despair' than those who had received higher education ($M = 30.29$, $SD = 9.54$ vs. $M = 27.02$, $SD = 8.91$, $t(158) = 2.09$, $p < 0.05$ with a small effect size $r = 0.17$). Group differences for the other demographic variables (socioeconomic status and religion) were not statistically significant. Results are shown in Table 7.18.

Table 7.18. Differences in levels of perinatal grief by demographic variables

Variables	Categories		t-value	p-value
Age	Up to 34 years old	35 years and above		
Short PGS	n = 67 (41.61%)	n = 94 (58.39%)		
Active grief	39.54 (SD = 8.49)	36.38 (SD = 9.96)	2.104	p = 0.037*
Difficulty coping	30.91 (SD = 10.73)	28.11 (SD = 10.22)	1.680	p = 0.095
Despair	29.16 (SD = 9.75)	27.41 (SD = 9.03)	1.172	p = 0.243
Total PGS	99.61 (SD = 27.68)	91.90 (SD = 27.32)	1.755	p = 0.081
Level of education	Secondary education	Higher education		
Short PGS	n = 48 (30.00%)^b	n = 112 (70.00%)^b		
Active grief	39.17 (SD = 9.73)	36.91 (SD = 9.23)	1.394	p = 0.165
Difficulty coping	30.85 (SD = 10.13)	28.40 (SD = 10.45)	1.373	p = 0.172
Despair	30.29 (SD = 9.54)	27.02 (SD = 8.91)	2.085	p = 0.039*
Total PGS	100.31 (SD = 28.16)	92.33 (SD = 26.68)	1.705	p = 0.090
Socioeconomic status	AB	C1C2		
Short PGS	n = 120 (76.43%)^b	n = 37 (23.57%)^b		
Active grief	37.01 (SD = 9.03)	38.97 (SD = 10.51)	-1.112	p = 0.268
Difficulty coping	28.86 (SD = 10.32)	29.30 (SD = 10.72)	-.224	p = 0.823
Despair	27.53 (SD = 9.15)	28.97 (SD = 9.33)	-.838	p = 0.403
Total PGS	93.39 (SD = 26.80)	97.24 (SD = 28.84)	-.751	p = 0.454
Religious status	No religion	Religion		
Short PGS	n = 75 (48.08%)^b	n = 81 (51.92%)^b		
Active grief	37.44 (SD = 10.27)	37.80 (SD = 8.87)	-.236	p = 0.813
Difficulty coping	29.57 (SD = 10.83)	29.11 (SD = 10.46)	.271	p = 0.787
Despair	27.89 (SD = 9.37)	28.30 (SD = 9.60)	-.265	p = 0.791
Total PGS	94.91 (SD = 28.70)	95.21 (SD = 27.45)	-.067	p = 0.946

^b Percentages based on participants who could be classified in either category: level of education (n = 160), socioeconomic status (n = 157) and religious status (n = 156); * p < 0.05, ** p < 0.01, *** p < 0.001

7.3.3.2.2 Differences in levels of perinatal grief by termination-related variables

Differences in levels of perinatal grief were assessed according to termination-related variables. Significant differences in levels of perinatal grief were observed for time elapsed since termination, whether women had children following TFA and feeling about the decision

to terminate. These results are displayed in Table 7.19. Analyses based on other termination-related variables (number of pregnancies, whether women at children at the time of TFA, gestational age, abnormality prognosis and termination method) were not statistically significant. These are displayed in Table 7.20.

Time elapsed since TFA

Women's levels of grief were analysed according to time elapsed since the termination using a one-way unrelated ANOVA. The analysis indicated a main effect of time elapsed on all grief variables: 'active grief' $F(3,157) = 21.79$ $p < 0.001$, 'difficulty coping' $F(3,157) = 16.11$ $p < 0.001$, 'despair' $F(3,157) = 11.15$ $p < 0.001$ and 'total PGS' $F(3,157) = 18.51$, $p < 0.001$, all with large effect sizes ($\omega^2 = 0.28$, $\omega^2 = 0.22$, $\omega^2 = 0.16$, $\omega^2 = 0.25$). *Post hoc* tests with the Bonferroni correction revealed that women who had terminated their pregnancy up to six months prior to study participation displayed significantly higher levels of grief on all grief variables, compared to women who had terminated their pregnancy 13-24 months or over 24 months prior to taking part in the study.

Children following TFA

Grief levels were compared according to whether women had had children/were pregnant following the termination or not. Women who had not had children following TFA displayed significantly higher levels of grief on all grief variables, compared to women who had had children/were pregnant. These differences were all significant at the $p < 0.001$ level. Effect sizes were of medium to large magnitude ($r = 0.46$, $r = 0.43$, $r = 0.36$ and $r = 0.44$ respectively).

Feeling about the decision to terminate

Group differences were noted in relation to women's feeling about their decision to terminate. Women who were 'uncomfortable' with their decision scored significantly higher on all grief variables than those 'comfortable' with their decision. All differences were

significant at the $p < 0.001$ level or below. Effect sizes were of medium to large magnitude ($r = 0.40$, $r = 0.36$, $r = 0.47$ and $r = 0.43$ respectively).

Table 7.19. Differences in levels of perinatal grief by time elapsed since TFA, whether women had children following TFA and feeling about the decision

Variables	Categories			
Time since TFA	Up to 6 months	7-12 months	13-24 months	24+
Short PGS⁺	<i>n</i> = 47 (29.19%)	<i>n</i> = 31 (19.25%)	<i>n</i> = 24 (14.91%)	<i>n</i> = 59 (36.65%)
Active grief	43.85 (<i>SD</i> = 6.64)	40.35 (<i>SD</i> = 8.27)	37.29 (<i>SD</i> = 5.85)*	31.56 (<i>SD</i> = 9.54)*
Difficulty coping	35.21 (<i>SD</i> = 8.63)	32.26 (<i>SD</i> = 10.53)	28.83 (<i>SD</i> = 8.36)*	23.15 (<i>SD</i> = 9.40)*
Despair	33.04 (<i>SD</i> = 8.56)	30.13 (<i>SD</i> = 9.61)	26.92 (<i>SD</i> = 7.11)*	23.69 (<i>SD</i> = 8.52)*
Total PGS	112.11 (<i>SD</i> = 21.72)	102.74 (<i>SD</i> = 27.14)	93.04 (<i>SD</i> = 18.74)*	78.41 (<i>SD</i> = 25.75)*
Children post-TFA	No children	Children	<i>t</i>-value	<i>p</i>-value
Short PGS	<i>n</i> = 74 (46.54%)^b	<i>n</i> = 85 (53.46%)^b		
Active grief ^a	42.31 (<i>SD</i> = 6.87)	33.55 (<i>SD</i> = 9.58)	6.682	$p < 0.001^{***}$
Difficulty coping	33.97 (<i>SD</i> = 9.27)	24.98 (<i>SD</i> = 9.58)	5.996	$p < 0.001^{***}$
Despair	31.74 (<i>SD</i> = 8.75)	24.96 (<i>SD</i> = 8.83)	4.847	$p < 0.001^{***}$
Total PGS	108.03 (<i>SD</i> = 22.94)	83.49 (<i>SD</i> = 26.45)	6.203	$p < 0.001^{***}$
Feeling about decision	Comfortable	Uncomfortable	<i>t</i>-value	
Short PGS	<i>n</i> = 122 (76.73%)^b	<i>n</i> = 37 (23.27%)^b		
Active grief	35.88 (<i>SD</i> = 9.33)	43.32 (<i>SD</i> = 7.35)	-4.450	$p < 0.001^{***}$
Difficulty coping	27.26 (<i>SD</i> = 9.63)	35.03 (<i>SD</i> = 10.66)	-4.188	$p < 0.001^{***}$
Despair	25.96 (<i>SD</i> = 8.76)	34.59 (<i>SD</i> = 7.49)	-5.423	$p < 0.001^{***}$
Total PGS	89.10 (<i>SD</i> = 26.01)	112.95 (<i>SD</i> = 23.72)	-4.982	$p < 0.001^{***}$

⁺ Group comparisons were run against the group whose loss was most recent (up to 6 months), * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$; ^a Equality of variance not assumed,

^b Percentages based on participants who could be classified in either category: children post-TFA and feeling about the decision ($n = 159$)

Other termination-related variables

Analyses were also carried out in relation to the number of pregnancies (first vs. not first), whether women had children at the time of TFA (Yes vs. No), gestational age (up to 20 weeks vs. over 20 weeks), abnormality prognosis (incompatible vs. compatible with life) and termination method (medical vs. surgical). These analyses did not show any significant differences in grief levels. Results for these variables are displayed in Table 7.20.

Table 7.20. Differences in levels of perinatal grief by other termination-related variables

Variables	Categories		t-value	p-value
First Pregnancy	Yes	No		
Short PGS	n = 69 (43.13%)^b	n = 91 (56.88%)^b		
Active grief	38.23 (SD = 8.75)	37.21 (SD = 10.04)	.674	p = 0.501
Difficulty coping	28.42 (SD = 10.76)	29.96 (SD = 10.35)	-.914	p = 0.362
Despair	27.94 (SD = 8.91)	28.32 (SD = 9.75)	-.251	p = 0.802
Total PGS	94.59 (SD = 26.84)	95.48 (SD = 28.53)	-.200	p = 0.842
Children at TFA	No children	Children		
Short PGS	n = 81 (50.31 %)	n = 80 (49.69%)		
Active grief	38.09 (SD = 9.07)	37.30 (SD = 9.91)	.525	p = 0.600
Difficulty coping	28.59 (SD = 10.82)	29.96 (SD = 10.18)	-.827	p = 0.409
Despair	28.06 (SD = 8.72)	28.23 (SD = 9.99)	-.111	p = 0.912
Total PGS	94.74 (SD = 26.94)	95.49 (SD = 28.51)	-.171	p = 0.865
Gestational age	Up to 20 weeks	Over 20 weeks		
Short PGS	n = 95 (59.01%)	n = 66 (40.99%)		
Active grief	38.00 (SD = 9.80)	37.26 (SD = 9.05)	.488	p = 0.626
Difficulty coping	29.75 (SD = 10.52)	28.59 (SD = 10.51)	.686	p = 0.493
Despair	28.99 (SD = 9.14)	26.92 (SD = 9.56)	1.383	p = 0.169
Total PGS	96.74 (SD = 27.82)	92.77 (SD = 27.43)	.894	p = 0.373

Table 7.20. Differences in levels of perinatal grief by other termination-related variables (continued)

Variables	Categories		t-value	p-value
Abnormality prognosis	Incompatible with life	Compatible with life		
Short PGS	<i>n</i> = 62 (44.29%)^b	<i>n</i> = 78 (55.71%)^b		
Active grief	38.68 (<i>SD</i> = 8.80)	37.86 (<i>SD</i> = 9.52)	.522	<i>p</i> = 0.602
Difficulty coping	29.84 (<i>SD</i> = 10.02)	28.78 (<i>SD</i> = 11.16)	.582	<i>p</i> = 0.562
Despair	28.39 (<i>SD</i> = 9.20)	28.15 (<i>SD</i> = 9.74)	.144	<i>p</i> = 0.886
Total PGS	96.90 (<i>SD</i> = 26.41)	94.79 (<i>SD</i> = 28.79)	.446	<i>p</i> = 0.656
Termination method	Medical	Surgical		
Short PGS	<i>n</i> = 132 (83.02%)^b	<i>n</i> = 27 (16.98%)^b		
Active grief	37.67 (<i>SD</i> = 9.17)	37.37 (<i>SD</i> = 10.94)	.152	<i>p</i> = 0.880
Difficulty coping	28.77 (<i>SD</i> = 10.48)	31.56 (<i>SD</i> = 10.18)	-1.263	<i>p</i> = 0.208
Despair	27.77 (<i>SD</i> = 9.28)	29.52 (<i>SD</i> = 9.44)	-.888	<i>p</i> = 0.376
Total PGS	94.22 (<i>SD</i> = 27.25)	98.44 (<i>SD</i> = 29.02)	-.726	<i>p</i> = 0.469

^b Percentages based on participants who could be classified in either category: first pregnancy (*n* = 160) abnormality prognosis (*n* = 140), and termination method (*n* = 159)

7.3.3.2.3 Summary of the results pertaining to women's levels of perinatal grief and comparison with Study 2b

The mean scores for the three Short PGS subscales, which reflect incremental levels of pathological grief, decreased progressively. This is consistent with Study 2b.

Levels of grief in this study were lower than those observed in Study 2b ('active grief': *M* = 37.70 vs. 41.53 in Study 2b; 'difficulty coping': *M* = 28.27 vs. 33.11 in Study 2b; 'despair': *M* = 28.14 vs. 29.49 in Study 2b; 'total PGS': *M* = 95.11 vs. 104.14 in Study 2b). The greatest difference was for 'total PGS' (mean difference: -9.03) whilst the smallest was for 'despair' (mean difference: -1.35). Scores for two grief subscales ('active grief' and 'total PGS') were above the midpoint in Study 2b, compared to only one ('active grief') in this study. The differences in sample profiles between the two studies may account for these differences (e.g. larger proportion of women who had a recent termination in Study 2b compared to

Study 4), particularly given that grief levels were found to decrease over time in both Studies 2b and 4.

Despite being lower than in Study 2b, women's levels of grief were still higher than those recorded in other studies using the Short PGS (Hunfeld et al., 1994; Nazaré et al., 2013, 2014). They were also above the threshold for 'complicated grief' as defined by Toedter et al (2001) of 34 for 'active grief,' 30 for 'difficulty coping,' 27 for 'despair' and 91 for 'general grief' indicated 'complicated grief.' In this study, 65.8% ($n = 106$) of the women scored above 34 for 'active grief,' 44.7% ($n = 72$) above 30 for 'difficulty coping,' 52.2% ($n = 84$) above 27 for 'despair' and 55.3% ($n = 89$) above 91 for 'total PGS.' This confirms the impact of TFA on women's psychological adjustment, initially observed in Study 2b. The long-time effect of the TFA is further explored in the longitudinal analysis (section 7.3.4).

Few group differences in grief levels were noted in relation to demographic variables. Younger women displayed higher levels of 'active grief' than older women, which is comparable to Study 2b. Levels of 'despair' were also higher among women who had received secondary education compared to higher education. However, these differences were of a small magnitude. Group differences were noted according to termination-related variables. Analyses conducted on the grief variables according to the time elapsed since TFA, indicate that grief levels decrease as time elapsed since TFA increases. Higher levels of grief were noted among women who had not had children since TFA/ were not pregnant (all grief variables) and were uncomfortable with their decision to terminate (all grief variables), which is consistent with the results of Study 2b. Collectively, these results indicate that women's personal and familial circumstances may influence levels of grief to a greater extent than factors purely related to the terminated pregnancy (e.g. gestational age), which is in keeping with the results of Study 2b.

7.3.4 Longitudinal analysis

Data were analysed to assess the potential effect of time on the use of coping strategies and perinatal grief. The analysis focused on a group of participants ($n = 62$) who participated in both quantitative studies Study 2b (time 1) and Study 4 (time 2). The time elapsed between the two studies ranged between 18 and 36 months. Mean scores for the coping strategies and perinatal grief scales were run for each time period. Paired samples t tests were carried out to ascertain whether there were any differences in the use of coping strategies and level of grief over time. The results show that usage of coping strategies decreased over time except for 'positive reframing' and 'acceptance,' for which usage increased significantly. The coping strategies for which usage decreased the most comprised: 'emotional' and 'instrumental support,' 'venting,' 'planning' and 'self-blame' (all $p < 0.01$). The levels of perinatal grief also decreased significantly over time to levels which, according to the definition by Toedter et al. (2001), are no longer pathological. Whilst these results are encouraging, a significant proportion of women still display levels compatible with 'complicated grief,' with 41.9% ($n = 26$) of women scoring above 34 for 'active grief,' 25.8% ($n = 16$) above 30 for 'difficulty coping,' 37.1% ($n = 23$) above 27 for 'despair' and 33.9% ($n = 21$) above 91 for 'total PGS.' Therefore, although the levels of perinatal grief decreased overall, a significant subset of the sample still displayed levels defined as pathological.

Furthermore, in this group of participants ($n = 62$), just under a third (29%, $n = 18$) had terminated their pregnancy at least a year prior to participating in Study 2b (time 1). Consequently, at the time of rating their levels of perinatal grief for Study 4 (time 2), a minimum of 32 months would have elapsed since their termination. It is possible that the actual time between the termination and the completion of Study 4 (time 2) may be higher than 36 months. Given that the evidence reported in this thesis and elsewhere (Kersting et al., 2007; 2009; Korenromp et al., 2009) indicates that levels of grief decrease over time, it is not surprising that the levels of grief for this particular group at time 2 are lower than at time 1 (Study 2b). The results for the longitudinal analysis are displayed in Table 7.21.

Table 7.21. Differences in the use of coping strategies and levels of perinatal grief over time

Variables	Study 2b	Study 4	t-value	p-value
Coping strategies	n = 62	n = 62		
Self-distraction	5.29 (SD = 1.83)	4.73 (SD = 1.80)	2.345	$p = 0.022^*$
Active coping	5.61 (SD = 1.74)	5.52 (SD = 1.96)	0.342	$p = 0.734$
Denial	3.04 (SD = 1.08)	2.65 (SD = 1.10)	2.398	$p = 0.020^*$
Substance use	2.82 (SD = 1.47)	2.58 (SD = 1.17)	1.260	$p = 0.212$
Emotional support	5.85 (SD = 1.74)	4.98 (SD = 1.95)	3.603	$p = 0.001^{**}$
Instrumental support	5.19 (SD = 1.76)	4.21 (SD = 1.93)	3.835	$p < 0.001^{***}$
Behaviour disengagement	2.95 (SD = 1.23)	2.65 (SD = 1.12)	1.575	$p = 0.120$
Venting	5.03 (SD = 1.82)	4.24 (SD = 1.74)	2.924	$p = 0.005^{**}$
Positive reframing	3.94 (SD = 1.92)	4.47 (SD = 1.76)	-2.073	$p = 0.042^*$
Planning	5.73 (SD = 1.80)	4.82 (SD = 1.87)	3.199	$p = 0.002^{**}$
Acceptance	6.00 (SD = 1.58)	6.77 (SD = 1.54)	-3.483	$p = 0.001^{**}$
Religion	2.97 (SD = 1.44)	3.00 (SD = 1.66)	-0.173	$p = 0.863$
Self-blame	4.843 (SD = 1.78)	4.13 (SD = 1.93)	2.713	$p = 0.009^{**}$
Short PGS				
Active grief	41.53 (SD = 8.04)	32.74 (SD = 9.75)	8.573	$p < 0.001^{***}$
Difficulty coping	33.55 (SD = 8.58)	23.61 (SD = 9.52)	8.196	$p < 0.001^{***}$
Despair	29.68 (SD = 8.57)	24.10 (SD = 8.64)	6.648	$p < 0.001^{***}$
Total PGS	104.76 (SD = 22.67)	80.18 (SD = 26.24)	8.738	$p < 0.001^{***}$

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

7.3.5 Women's levels of posttraumatic growth

Similarly to other variables, women's levels of posttraumatic growth were examined descriptively at the overall level and in relation to demographic and termination-related variables.

7.3.5.1 General levels of posttraumatic growth

The mean scores for 'relating to others' ($M = 17.55$), 'personal strengths' ($M = 10.92$) and 'appreciation of life' ($M = 7.80$) were on a par or just above the scales' midpoints, whereas

the mean scores for 'new possibilities' ($M = 8.46$), 'spiritual change' ($M = 1.88$) and 'PTGI overall' ($M = 46.61$) were below the midpoints. These results suggest that women's levels of posttraumatic growth were moderate overall and varied across PTGI dimensions. These results are shown in Table 7.22.

Table 7.22. Mean scores, standard deviations and Cronbach's values for the PTGI

<i>Variables</i>	<i>Mean</i>	<i>SD</i>	<i>Cronbach's values</i>
PTGI (N = 161)			
Relating to others (0-35)	17.55	7.66	0.84
New possibilities (0-25)	8.46	5.73	0.83
Personal strengths (0-20)	10.92	4.53	0.78
Spiritual change (0-10)	1.88	2.39	0.74
Appreciation of life (0-15)	7.80	3.99	0.77
PTGI overall (0-105)	46.61	19.58	0.92

Values above the scales' midpoints are highlighted in bold; relating to others: > 17.5, new possibilities: > 12.5, personal strength: > 10, spiritual change: > 5, appreciation of life: > 7.5 and PTGI overall: > 52.5

On average, participants reported 16 of the 21 changes ($M = 16.1$, $SD = 4.53$), decreasing to 10 ($M = 9.8$, $SD = 5.49$) when only including changes experienced at a moderate, strong or very strong degree. The changes most frequently reported included: 'I have discovered that I am stronger than I thought I was' (77.6%), 'I changed my priorities about what is important in life' (73.3%), 'I know better that I can handle difficulties' (72.7%) and 'I have more compassion for others' (72.1%). By contrast, 'I have a stronger religious faith' (13.0%), 'New opportunities are available which wouldn't have been otherwise' (16.8%) and 'I have a better understanding of spiritual matters' (19.9%) were least reported. Results are shown in Table 7.23.

Table 7.23. PTGI - Changes experienced to a moderate, strong and very strong degree

PTGI items	n	%
I discovered that I am stronger than I thought	125	77.64
I changed my priorities about what is important in life	118	73.29
I know better that I can handle difficulties	117	72.67
I have more compassion for others	116	72.05
I put more effort into my relationships	88	54.66
I more clearly see that I can count on people in times of trouble	88	54.66
I have a greater sense of closeness with others	86	53.42
I am more willing to express my emotions	84	52.17
I have a greater appreciation for the value of my own life	81	50.31
I learned a great deal about how wonderful people are	81	50.31
I am more likely to try to change things which need changing	78	48.45
I better accept needing others	76	47.20
I have a greater feeling of self-reliance	70	43.48
I can better appreciate each day	70	43.48
I am better able to accept the way things work out	64	39.75
I established a new path for my life	59	36.65
I am able to do better things with my life	52	32.30
I developed new interests	50	31.06
I have a better understanding of spiritual matters	32	19.88
New opportunities are available which wouldn't have been otherwise	27	16.77
I have a stronger religious faith	21	13.04

(Total sample, $N = 161$)

7.3.5.2 Group differences in women's levels of posttraumatic growth

7.3.5.2.1 Differences in levels of posttraumatic growth by demographic variables

Posttraumatic growth levels were examined for differences based on age, level of education, socioeconomic status and religious status. The same groupings as those used to analyse women's coping strategies and levels of perinatal grief were utilised. Women in the 'no religion' group had lower levels of 'spiritual change' than those in the 'religion' category ($M = 0.84$, $SD = 1.39$ vs. $M = 2.74$, $SD = 2.74$ $t(154) = -5.52$, $p < 0.001$, with a medium to large effect size $r = 0.40$). Group difference for 'appreciation of life' according to education level

approached significance. Women educated at the secondary level displayed higher levels of 'appreciation of life' than those who had received higher education ($M = 8.73$, $SD = 3.68$ vs. $M = 7.41$, $SD = 4.09$ $p = 0.056$). Differences based on other demographic variables were not significant ($p > 0.05$). The results are displayed in Table 7.24.

Table 7.24. Differences in posttraumatic growth levels by demographic variables

Variables	Categories		t-value	p-value
Age	Up to 34 years old	35 years and above		
PTGI	$n = 67$ (41.61%)	$n = 94$ (58.39%)		
Relating to others	18.31 ($SD = 7.63$)	17.01 ($SD = 7.68$)	1.064	$p = 0.289$
New possibilities	8.70 ($SD = 6.03$)	8.29 ($SD = 5.53$)	.451	$p = 0.652$
Personal strengths	11.10 ($SD = 4.18$)	10.79 ($SD = 4.79$)	.436	$p = 0.663$
Spiritual change	1.97 ($SD = 2.58$)	1.82 ($SD = 2.26$)	.394	$p = 0.694$
Appreciation of life	8.06 ($SD = 3.68$)	7.61 ($SD = 4.22$)	.709	$p = 0.479$
PTGI overall	48.15 ($SD = 18.86$)	45.51 ($SD = 20.10$)	.842	$p = 0.401$
Level of education	Secondary education	Higher education		
PTGI	$n = 48$ (30.00%)^b	$n = 112$ (70.00%)^b		
Relating to others	18.38 ($SD = 7.97$)	17.20 ($SD = 7.57$)	.888	$p = 0.376$
New possibilities	8.71 ($SD = 5.79$)	8.35 ($SD = 5.75$)	.362	$p = 0.718$
Personal strengths	11.94 ($SD = 4.68$)	10.53 ($SD = 4.42$)	1.817	$p = 0.071$
Spiritual change	1.79 ($SD = 2.26$)	1.90 ($SD = 2.46$)	-.266	$p = 0.791$
Appreciation of life	8.73 ($SD = 3.68$)	7.41 ($SD = 4.09$)	1.925	$p = 0.056$
PTGI overall	49.54 ($SD = 19.39$)	45.38 ($SD = 19.70$)	1.229	$p = 0.221$
Socioeconomic status	AB	C1C2		
PTGI	$n = 120$ (76.43%)^b	$n = 37$ (23.57%)^b		
Relating to others	17.29 ($SD = 7.49$)	18.35 ($SD = 7.96$)	-.741	$p = 0.460$
New possibilities	8.31 ($SD = 5.79$)	9.00 ($SD = 5.46$)	-.644	$p = 0.521$
Personal strengths	10.62 ($SD = 4.46$)	12.03 ($SD = 4.55$)	-1.673	$p = 0.096$
Spiritual change ^a	1.77 ($SD = 2.33$)	2.24 ($SD = 2.62$)	-1.055	$p = 0.293$
Appreciation of life	7.68 ($SD = 4.05$)	8.24 ($SD = 3.82$)	-.756	$p = 0.451$
PTGI overall	45.66 ($SD = 19.22$)	49.86 ($SD = 19.77$)	-1.156	$p = 0.249$

Table 7.24. Differences in posttraumatic growth levels by demographic variables (continued)

<i>Variables</i>	<i>Categories</i>		<i>t-value</i>	<i>p-value</i>
Religious status	No religion	Religion		
PTGI	<i>n</i> = 75 (48.08%)^b	<i>n</i> = 81 (51.92%)^b		
Relating to others	16.81 (<i>SD</i> = 7.59)	17.89 (<i>SD</i> = 7.71)	-.877	<i>p</i> = 0.382
New possibilities	7.88 (<i>SD</i> = 5.77)	8.74 (<i>SD</i> = 5.71)	-.936	<i>p</i> = 0.351
Personal strengths	10.72 (<i>SD</i> = 4.42)	10.90 (<i>SD</i> = 4.55)	-.252	<i>p</i> = 0.802
Spiritual change ^a	0.84 (<i>SD</i> = 1.39)	2.74 (<i>SD</i> = 2.74)	-5.523	<i>p</i> < 0.001***
Appreciation of life	7.41 (<i>SD</i> = 4.09)	7.94 (<i>SD</i> = 3.91)	-.819	<i>p</i> = 0.414
PTGI overall	43.67 (<i>SD</i> = 18.50)	48.21 (<i>SD</i> = 20.06)	-1.467	<i>p</i> = 0.144

^a Equality of variance not assumed, ^b Percentages based on participants who could be classified in either category: level of education (*n* = 160), socioeconomic status (*n* = 157), religious status (*n* = 156); * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

7.3.5.2.2 Differences in levels of posttraumatic growth by termination-related variables

Differences in levels of posttraumatic growth were assessed according to termination-related variables. Significant differences were identified for only one variable: feeling about the decision to terminate. The results for this variable are displayed in Table 7.25. Group differences in levels of posttraumatic growth based on other termination-related variables were not statistically significant (*p* > 0.05). The results for these variables are shown in Table 7.26.

Feeling about the decision to terminate

Women 'comfortable' with their decision exhibited significantly lower levels of 'spiritual change' than women uncomfortable with their decision (*M* = 1.62, *SD* = 2.25 vs. *M* = 2.59, *SD* = 2.50 *t*(157) = -2.24, *p* < 0.05, with a small to medium effect size *r* = 0.20).

Table 7.25. Differences in levels of posttraumatic growth by feeling about the decision

Variables	Comfortable with decision	Uncomfortable with decision	t-value	p-value
PTGI	<i>n</i> = 122 (76.73%)^b	<i>n</i> = 37 (23.27%)^b		
Relating to others	17.53 (<i>SD</i> = 7.75)	17.86 (<i>SD</i> = 7.59)	-.229	<i>p</i> = 0.819
New possibilities	8.39 (<i>SD</i> = 5.74)	8.78 (<i>SD</i> = 5.87)	-.368	<i>p</i> = 0.713
Personal strengths	11.17 (<i>SD</i> = 4.40)	10.30 (<i>SD</i> = 4.99)	1.027	<i>p</i> = 0.306
Spiritual change	1.62 (<i>SD</i> = 2.25)	2.59 (<i>SD</i> = 2.50)	-2.244	<i>p</i> = 0.026*
Appreciation of life	7.98 (<i>SD</i> = 4.06)	7.51 (<i>SD</i> = 3.64)	.620	<i>p</i> = 0.536
PTGI overall	46.69 (<i>SD</i> = 19.55)	47.05 (<i>SD</i> = 20.22)	-.099	<i>p</i> = 0.921

^a Equality of variance not assumed, ^b Percentages based on participants who could be classified in either category (*n* = 159); * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001

Other termination-related variables

Analyses were carried out by time elapsed since TFA (up to six months, 7-12, 13-24 or more than 24 months prior to study participation), number of pregnancies (first vs. not first), whether women at children at the time of TFA (Yes vs. No), gestational age (up to 20 weeks vs. over 20 weeks), abnormality prognosis (incompatible vs. compatible with life) termination method (medical vs. surgical) and whether they had children/were pregnant following TFA (Yes vs. No). These analyses did not show any significant group differences in grief levels (all *p*-values > 0.05). However, group differences approached significance for 'personal strengths' and 'PTGI overall' in relation to the method of termination, with women who had a medical termination reporting greater growth in these domains compared to those who had a surgical termination (*M* = 11.15, *SD* = 4.39 vs. *M* = 9.33, *SD* = 4.88, *p* = 0.056 and *M* = 47.80, *SD* = 18.74 vs. *M* = 39.78, *SD* = 22.48, *p* = 0.052 respectively). Results are shown in Table 7.26

Table 7.26. Differences in levels of posttraumatic growth by other termination-related variables

Variables	Categories			
Time since TFA	< 6 months	6-12 months	13-24 months	24+
PTGI	n = 47 (29.19%)	n = 31 (19.25%)	n = 24 (14.91%)	n = 59 (36.65%)
Relating to others	18.87 (SD = 7.23)	17.42 (SD = 8.54)	18.63 (SD = 7.43)	16.14 (SD = 7.55)
New possibilities	7.83 (SD = 5.89)	7.97 (SD = 5.75)	10.54 (SD = 5.34)	8.37 (SD = 5.68)
Personal strengths	9.94 (SD = 4.26)	11.19 (SD = 4.79)	11.88 (SD = 4.32)	11.17 (SD = 4.67)
Spiritual change	2.15 (SD = 2.47)	1.32 (SD = 2.12)	2.00 (SD = 2.47)	1.92 (SD = 2.45)
Appreciation of life	7.26 (SD = 3.86)	7.45 (SD = 4.26)	8.79 (SD = 3.32)	8.00 (SD = 4.20)
PTGI overall	46.04 (SD=19.17)	45.35 (SD = 20.50)	51.83 (SD = 17.91)	45.59 (SD = 20.20)
First Pregnancy	Yes	No	t-value	p-value
PTGI	n = 69 (43.13%)^b	n = 91 (56.88%)^b		
Relating to others	18.65 (SD = 7.35)	16.60 (SD = 7.78)	1.689	p = 0.093
New possibilities	8.55 (SD = 5.69)	8.27 (SD = 5.71)	.303	p = 0.762
Personal strengths	10.75 (SD = 4.64)	10.99 (SD = 4.47)	-.325	p = 0.746
Spiritual change	1.64 (SD = 2.36)	2.02 (SD = 2.39)	-1.012	p = 0.313
Appreciation of life	7.70 (SD = 4.17)	7.84 (SD = 3.89)	-.218	p = 0.828
PTGI overall	47.29 (SD=19.78)	45.73 (SD = 19.30)	.503	p = 0.616
Children at TFA	No children	Children		
PTGI	n = 81 (50.31 %)	n = 80 (49.69%)		
Relating to others	18.10 (SD = 7.68)	17.00 (SD = 7.66)	.909	p = 0.365
New possibilities	8.88 (SD = 5.91)	8.04 (SD = 5.55)	.929	p = 0.354
Personal strengths	10.59 (SD = 4.57)	11.25 (SD = 4.51)	-.919	p = 0.359
Spiritual change	1.64 (SD = 2.31)	2.13 (SD = 2.46)	-1.283	p = 0.201
Appreciation of life	7.58 (SD = 4.25)	8.01 (SD = 3.73)	-.685	p = 0.494
PTGI overall	46.79 (SD=20.26)	46.43 (SD = 18.98)	.118	p = 0.906
Gestational age	Up to 20 weeks	Over 20 weeks		
PTGI	n = 95 (59.01%)	n = 66 (40.99%)		
Relating to others	16.95 (SD = 8.09)	18.42 (SD = 6.97)	-1.205	p = 0.230
New possibilities	8.45 (SD = 6.09)	8.47 (SD = 5.21)	-.019	p = 0.985
Personal strengths	10.88 (SD = 4.60)	10.97 (SD = 4.48)	-.117	p = 0.907
Spiritual change ^a	1.68 (SD = 2.08)	2.17 (SD = 2.77)	-1.198	p = 0.233
Appreciation of life	7.56 (SD = 4.20)	8.14 (SD = 3.67)	-.903	p = 0.368
PTGI overall	45.53 (SD = 20.88)	48.17 (SD = 17.57)	-.841	p = 0.402

Table 7.26. Differences in levels of posttraumatic growth by other termination-related variables (continued)

<i>Variables</i>	<i>Categories</i>		<i>t-value</i>	<i>p-value</i>
Abnormality prognosis	Incompatible with life	Compatible with life		
PTGI	<i>n</i> = 62 (44.29%)^b	<i>n</i> = 78 (55.71%)^b		
Relating to others	17.68 (<i>SD</i> = 7.88)	17.82 (<i>SD</i> = 7.76)	-.108	<i>p</i> = 0.914
New possibilities	9.31 (<i>SD</i> = 5.80)	8.06 (<i>SD</i> = 5.85)	1.253	<i>p</i> = 0.212
Personal strengths	11.00 (<i>SD</i> = 4.65)	10.96 (<i>SD</i> = 4.72)	.048	<i>p</i> = 0.962
Spiritual change	2.23 (<i>SD</i> = 2.56)	1.64 (<i>SD</i> = 2.16)	1.468	<i>p</i> = 0.144
Appreciation of life	8.35 (<i>SD</i> = 3.91)	7.51 (<i>SD</i> = 4.03)	1.245	<i>p</i> = 0.215
PTGI overall	48.56 (<i>SD</i> = 20.40)	46.00 (<i>SD</i> = 19.86)	.750	<i>p</i> = 0.455
Termination method	Medical	Surgical		
PTGI	<i>n</i> = 132 (83.02%)^b	<i>n</i> = 27 (16.98%)^b		
Relating to others	18.04 (<i>SD</i> = 7.45)	15.19 (<i>SD</i> = 8.49)	1.769	<i>p</i> = 0.079
New possibilities	8.55 (<i>SD</i> = 5.61)	7.78 (<i>SD</i> = 6.30)	.640	<i>p</i> = 0.523
Personal strengths	11.15 (<i>SD</i> = 4.39)	9.33 (<i>SD</i> = 4.88)	1.925	<i>p</i> = 0.056
Spiritual change	1.99 (<i>SD</i> = 2.48)	1.19 (<i>SD</i> = 1.84)	1.602	<i>p</i> = 0.111
Appreciation of life ^a	8.07 (<i>SD</i> = 3.76)	6.30 (<i>SD</i> = 4.82)	1.802	<i>p</i> = 0.081
PTGI overall	47.80 (<i>SD</i> = 18.74)	39.78 (<i>SD</i> = 22.48)	1.958	<i>p</i> = 0.052
Children post-TFA	No children	Children		
PTGI	<i>n</i> = 74 (46.54%)^b	<i>n</i> = 85 (53.46%)^b		
Relating to others	18.24 (<i>SD</i> = 7.72)	16.81 (<i>SD</i> = 7.62)	1.174	<i>p</i> = 0.242
New possibilities	8.18 (<i>SD</i> = 6.00)	8.60 (<i>SD</i> = 5.53)	-.464	<i>p</i> = 0.643
Personal strengths	10.77 (<i>SD</i> = 4.57)	11.05 (<i>SD</i> = 4.57)	-.381	<i>p</i> = 0.704
Spiritual change	2.09 (<i>SD</i> = 2.49)	1.68 (<i>SD</i> = 2.29)	1.085	<i>p</i> = 0.280
Appreciation of life	7.49 (<i>SD</i> = 4.09)	8.05 (<i>SD</i> = 3.95)	-.878	<i>p</i> = 0.382
PTGI overall	46.77 (<i>SD</i> = 20.32)	46.19 (<i>SD</i> = 19.15)	.186	<i>p</i> = 0.853

^a Equality of variance not assumed, ^b Percentages based on participants who could be classified in either category: first pregnancy and abnormality prognosis (*n* = 160), children post-TFA and termination method (*n* = 159)

The relationship between posttraumatic growth and time elapsed since TFA was also assessed by comparing the levels of growth between participants who had taken part in both Studies 2b and 4 ($n = 62$) and whose termination was less recent, and those who had only participated in Study 4. Although the results show that women who participated in both studies exhibited higher levels of growth in the areas of 'new possibilities,' 'personal strengths' and 'appreciation of life' than those who only took part in Study 4, these differences were not statistically significant (see Appendix XII).

7.3.5.2.3 Summary of the results pertaining to women's levels of posttraumatic growth

The study findings indicate that women reported growth on some dimensions more than others. However, the levels of posttraumatic growth were generally moderate, with three out of the six variables on or marginally above the midpoint: 'relating to others,' 'personal strengths' and 'appreciation of life.' Other variables' mean scores were below the midpoints, with the scores for 'spiritual change' being the lowest. On average, women reported having experienced ten of the 21 changes to a moderate, strong or very strong degree. The changes most frequently mentioned focused on discovering new strengths, setting new life priorities and having more compassion for others. Only a few group differences were observed, and all related to 'spiritual change.' Differences in 'spiritual change' were noted according to religious status, with higher levels noted among women who stated having a religion compared to those who stated they had no religion. Lower levels of 'spiritual change' were also observed among women comfortable with their decision to terminate compared to women uncomfortable with their decision. These differences were of small to large magnitude (for religious status). These results suggest that neither women's demographic or obstetric profile, nor termination-related variables had any real significant impact upon whether women experienced posttraumatic growth following TFA.

7.3.6 Relationship between coping strategies, perinatal grief and posttraumatic growth

Analyses were run to examine the relationship between women's use of coping strategies, their levels of perinatal grief and posttraumatic growth. The aim of these analyses was to ascertain whether coping and/or grief variables predicted women's levels of posttraumatic growth.

7.3.6.1 Correlations between variables

Pearson's correlations indicated that scores on the posttraumatic growth subscales were inter-correlated, ranging from $r = 0.21, p < 0.01$ between 'spiritual change' and 'appreciation of life,' to $r = 0.88, p < 0.01$ between 'relating to others' and 'PTGI overall.' A similar pattern was observed for the grief variables (e.g. 'active grief' and 'difficulty coping' $r = 0.82, p < 0.01$) with the inter-correlation coefficients generally higher than for the posttraumatic growth variables. Coping strategies generally considered to be adaptive were also positively correlated with each other (e.g. 'positive reframing' and 'acceptance' $r = 0.38, p < 0.01$). Similarly, coping strategies generally considered to be maladaptive were generally correlated with each other (e.g. 'denial' and 'self-blame', $r = 0.48, p < 0.01$).

The results also identified clear patterns of relationships between the three sets of variables. Coping strategies considered to be adaptive were negatively correlated with grief (e.g. 'acceptance' and 'total PGS' $r = -0.54, p < 0.01$), but positively related to posttraumatic growth variables (e.g. 'positive reframing' and 'PTGI overall' $r = 0.46, p < 0.01$). By contrast, coping strategies considered to be maladaptive exhibited a positive relationship with grief (e.g. 'behavioural disengagement' and 'total PGS' $r = 0.44, p < 0.01$) but a negative one, although not significant, with posttraumatic growth variables (e.g. 'denial' and 'PTGI overall' $r = -0.06, p > 0.05$). These results indicate negative relationships between grief and posttraumatic growth (e.g. 'total PGS' and 'PTGI overall' $r = -0.24, p < 0.01$). The only exception was 'spiritual change' which was positively correlated with all four grief variables,

although not to a statistically significant level ($p > 0.05$). Results of the correlation analyses are displayed in Table 7.27.

Several coping strategies were significantly positively correlated with the posttraumatic growth variables. These included: 'active coping,' 'emotional support,' 'positive reframing' and 'acceptance,' which correlated with five posttraumatic growth variables (e.g. 'positive reframing' and 'PTGI overall' $r = 0.46, p < 0.01$); 'instrumental support,' which correlated with three posttraumatic growth variables; 'religion,' which correlated with two posttraumatic growth variables; and 'venting' which correlated with one growth variable. 'Self-blame' was the only coping strategy to be significantly negatively correlated with one growth measure ('personal strengths' $r = -0.16, p < 0.05$). All grief variables ('active grief,' 'difficulty coping,' 'despair' and 'total PGS') were significantly negatively correlated with the posttraumatic growth subscales (e.g. 'difficulty coping' and 'appreciation of life' $r = -0.32, p < 0.01$) except for 'relating to others' for which the negative correlations with grief were not statistically significant. Positive correlations were also observed between the grief variables and 'spiritual change,' but these were not significant.

Correlations were also run between posttraumatic growth, demographic and termination-related variables, mostly using point-biserial correlations that enable continuous and dichotomous variables to be correlated (Field, 2009, 2014). The analysis revealed significant positive correlations between religious status, feeling about the decision to terminate and 'spiritual change' with higher scores related to having a religion ($r_{pb} = 0.40, p < 0.01$) and being uncomfortable with the decision to terminate ($r_{pb} = 0.18, p < 0.05$). The results also show a significant negative correlation between method of termination and 'appreciation of life' with higher scores among women who had a medical termination ($r_{pb} = -0.17, p < 0.05$). Correlations on the other variables were not significant ($p > 0.05$). The results are displayed in Table 7.28.

Table 7.27. Correlations between the Brief COPE, the Short PGS and the PTGI

<i>Variables</i>	<i>Self-distract</i>	<i>Active cop.</i>	<i>Denial</i>	<i>Subs use</i>	<i>Emo sup</i>	<i>Instru sup</i>	<i>Behav diseng</i>	<i>Vent.</i>	<i>Posit. reframe</i>	<i>Plan</i>	<i>Accept</i>	<i>Relig.</i>	<i>Self-blame</i>
Active coping	.156*												
Denial	.215**	-.069											
Substance use	.080	.030	.186*										
Emotional. support	.206**	.398**	-.026	.059									
Instrumental. support	.185*	.326**	.019	.174*	.680**								
Behaviour. disengagement	.215**	-.125	.461**	.170*	-.099	-.062							
Venting	.266**	.302**	.256**	.249**	.348**	.385**	.324**						
Positive reframing	.064	.397**	-.097	-.173*	.279**	.247**	-.173*	.086					
Planning	.253**	.550**	-.013	.181*	.334**	.369**	-.009	.350**	.146				
Acceptance	-.083	.334**	-.289**	-.089	.138	.004	-.274**	.030	.382**	-.016			
Religion	.102	.099	.123	.018	.214**	.109	.209**	.268**	.074	.139	-.075		
Self-blame	.250**	.009	.478**	.197*	.054	.085	.457**	.347**	-.142	.135	-.339**	.162*	
Active grief	.244**	-.090	.392**	.145	.042	.117	.428**	.250**	-.286**	.110	-.496**	.159*	.615**
Difficulty coping	.210**	-.191*	.351**	.264**	-.009	.093	.458**	.239**	-.372**	.077	-.554**	.124	.600**
Despair	.245**	-.132	.445**	.224**	-.057	.056	.525**	.268**	-.312**	.079	-.475**	.204**	.683**
Total PGS	.246**	-.148	.418**	.226**	-.008	.095	.498**	.267**	-.345**	.094	-.541**	.170*	.670**
Relating to others	.009	.302**	-.033	.025	.396**	.313**	-.153	.102	.395**	.141	.167*	.153	-.075
New possibilities	.001	.261**	-.076	.002	.198*	.243**	-.089	.051	.435**	.079	.190*	.087	-.084
Personal strengths	.007	.275**	-.073	-.011	.178*	.071	-.135	.052	.375**	.037	.379**	.133	-.160*
Spiritual change	.047	.039	.090	-.091	.164*	.116	.126	.174*	.120	.044	-.069	.754**	.061
Appreciation of life	-.081	.200*	-.069	.035	.130	.093	-.089	-.011	.371**	-.059	.262**	.089	-.111
PTGI overall	-.006	.304**	-.055	.004	.301**	.243**	-.120	.086	.459**	.080	.254**	.227**	-.106

Table 7.27. Correlations between the Brief COPE, the Short PGS and the PTGI (continued)

<i>Variables</i>	<i>Active grief</i>	<i>Difficulty coping</i>	<i>Despair</i>	<i>Total PGS</i>	<i>Relating to others</i>	<i>New possibilities</i>	<i>Personal strength</i>	<i>Spiritual change</i>	<i>Life appreciation</i>
Difficulty coping	.821**								
Despair	.812**	.866**							
Total PGS	.929**	.954**	.945**						
Relating to others	-.068	-.149	-.111	-.117					
New possibilities	-.194*	-.277**	-.187*	-.235**	.634**				
Personal strengths	-.318**	-.376**	-.284**	-.348**	.612**	.546**			
Spiritual change	.114	.065	.149	.114	.296**	.263**	.295**		
Appreciation of life	-.208**	-.322**	-.214**	-.266**	.616**	.716**	.662**	.212**	
PTGI overall	-.186*	-.284**	-.189*	-.236**	.880**	.846**	.802**	.427**	.834**

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 7.28. Correlations between the PTGI and demographic, obstetric and termination-related variables

Variables	Relating to others	New possibilities	Personal strengths	Spiritual change	Life appreciation	PTG overall
Age	-.120	-.052	.048	.025	-.039	-.056
Education level†	-.070	-.029	-.143	.021	-.151	-.097
Socioeconomic status†	.059	.052	.133	.084	.061	.092
Religious status†	.071	.075	.020	.399**	.066	.117
Time since TFA	-.133	.060	.109	-.012	.092	.008
Gestational age†	.095	-.001	.009	.099	.071	.067
First pregnancy†	-.133	-.024	.026	.080	.017	-.040
Children at time of TFA†	-.072	-.073	.073	.101	.054	-.009
Children since TFA†	-.093	.037	.030	-.086	.070	-.015
Feeling about decision†	.018	.029	-.082	.176*	-.049	.008
Detection method†	-.079	-.058	-.079	-.148	-.136	-.112
Abnormality prognosis†	.009	-.106	-.004	-.124	-.105	-.064
Termination method†	-.140	-.051	-.152	-.127	-.167*	-.154

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$; † Point-biserial correlations

7.3.6.2 Predicting posttraumatic growth: regression analyses

7.3.6.2.1 Methodological elements

Multiple hierarchical regression analyses were run to ascertain whether coping strategies and/or grief predicted levels of posttraumatic growth (see chapter 3, section 3.2.4.2 for further details on the nature of the regression analyses conducted). Variables showing a significant correlation with the posttraumatic growth variables were used as predictors. Individual models were run for each posttraumatic growth measure. Despite the four grief variables being significantly correlated with all the posttraumatic growth subscales (except 'spiritual change'), the decision was made to only include the 'total PGS' measure as a predictor in the regression analyses. This decision was based on several factors.

Firstly, grief variables were highly correlated with each other, and particularly with 'total PGS' (e.g. 'total PGS' and 'difficulty coping' $r = 0.95, p < 0.01$). Thus, initial analyses which included the four grief variables exhibited high levels of multicollinearity, demonstrated by tolerance values being less than the recommended levels of 0.2 and Eigenvalues loading on multiple dimensions (Field, 2009, 2014). Multicollinearity has important implications as it affects the statistical robustness of the regression model (Tabachnick & Fidell, 2007). It creates a "shared variance between variables" and makes it more difficult to identify each predictor's exact contribution to the model (Hair et al., 2013, p.197). Secondly, the inclusion of the four grief variables resulted in a decrease in the model's predictive capability. For example, the regression model for 'personal strength' exhibited an F value of 8.00 when only the 'total PGS' measure was included, which decreased to 6.4 when all four grief variables were included. Thirdly, one aim of regression analysis is to use the minimum number of predictors with the highest predictive value (Tabachnick & Fidell, 2007). Given that 'total PGS' is a composite measure of perinatal grief that encompasses 'active grief,' 'difficulty coping' and 'despair,' it was considered the most appropriate measure of perinatal grief to use for these analyses.

The coping strategies were entered first and the grief variable ('total PGS') second. Given the low number of demographic and termination-related variables to be included in the

regression analyses, these were entered at the same time as the grief variable. The regression results are displayed in Table 7.29.

The results showed that 'positive reframing' was a positive, significant predictor of all the posttraumatic growth variables expect for 'spiritual change.' Other significant predictors of growth included 'emotional support' for 'relating to others,' 'religious coping' for 'spiritual change' and 'PTGI overall.' The grief subscale 'total PGS' had a significant negative predictive value on 'personal strengths.' The variance explained by the models amounted to 22.6% for 'relating to others,' 19.8% for 'new possibilities,' 20.8% for 'personal strengths,' 55.3% for 'spiritual change,' 15.3% for 'appreciation of life' and 26.3% for the 'PTGI overall.' The inclusion of the grief variable ('total PGS') as well as the demographic and termination-related measures, added little predictive value to the models, with the R^2 change ranging from 0.01 and 0.02. Furthermore, in some cases, the addition of these predictors contributed to a significant reduction of the F value (e.g. for 'spiritual change' $F(3,150) = 63.62, p < 0.001$ at step 1 and $F(3,150) = 38.89, p < 0.001$ at step 2). Thus, coping strategies were the main predictors of posttraumatic growth, with other variables contributing very little predictive capability to the models.

Table 7.29. Results of multiple regression analyses for the PTGI scales

<i>Variable</i>	<i>Relating to others</i>	<i>New possibilities</i>	<i>Personal strengths</i>	<i>Spiritual change</i>	<i>Life appreciation</i>	<i>PTG overall</i>
Step 1 - Coping predictors	β	β	β	β	β	β
Active coping	0.07	0.07	0.09	n/a	0.06	0.06
Emotional support	0.26*	-0.05	0.05	0.04	n/a	0.09
Instrumental support	0.04	0.16	n/a	n/a	n/a	0.06
Positive reframing	0.29***	0.37***	0.23**	n/a	0.31***	0.34***
Acceptance	-0.00	0.03	0.24**	n/a	0.12	0.10
Religion	n/a	n/a	n/a	0.75***	n/a	0.18*
Venting	n/a	n/a	n/a	-0.06	n/a	n/a
Self-blame	n/a	n/a	-0.05	n/a	n/a	n/a
<i>F</i> model	10.34***	8.47***	8.58***	63.62***	9.63***	10.15***
<i>R</i> ² on step 1	0.23	0.19	0.19	0.55	0.14	0.26
Step 2 - Other predictors						
Active coping		0.08	0.08	n/a	0.07	0.07
Emotional support		-0.05	0.06	0.04	n/a	0.09
Instrumental support		0.18	n/a	n/a	n/a	0.08
Positive reframing		0.34***	0.19*	n/a	0.27**	0.31***
Acceptance		-0.04	0.17	n/a	0.05	0.04
Religion		n/a	n/a	0.71***	n/a	0.20**
Venting		n/a	n/a	-0.06	n/a	n/a
Self-blame		n/a	0.07	n/a	n/a	n/a
Total PGS		-0.15	-0.22*	n/a	-0.13	-0.14
Feeling about TFA		n/a	n/a	0.02	n/a	n/a
Termination method		n/a	n/a	n/a	-0.11	n/a
Religious status		n/a	n/a	0.10	n/a	n/a
<i>F</i> model		7.60***	8.00***	38.89***	6.72***	9.16***
<i>R</i> ² on step 2		0.20	0.21	0.55	0.15	0.26
^a Change in <i>R</i> ²		0.01	0.02*	0.01	0.02	0.01

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$; ^a difference in R^2 on steps 1 and 2, and the significance of F change.

7.3.6.2.2 *Evaluating the regression models*

Several tests were used to evaluate the regression models. These have been described in detail in chapter 5, section 5.3.4.2.3. The first step was to check for residuals (or errors in the model) and influential cases to assess whether the models were a good fit for the data.

Residuals were examined using z-scores (residual values divided by their standard deviation) and all satisfied the criterion of 99.9% of scores falling between -3.29 and +3.29 (Field, 2014). Individual cases that could have unduly influenced the results were then examined using Cook's distance, leverage and DFBeta, as described in chapter 5 (section 5.3.4.2.3). It is recommended that Cook's distance scores should fall below 1 (Field, 2009). In this analysis, all scores fulfilled this criterion.

Leverage values were also used to identify potential influential cases and were calculated for each model based on the number of predictors (see chapter 5, section 5.3.4.2.3 for more detail). The leverage values used in this analysis were 0.11 for 'relating to others,' 'spiritual change' and 'appreciation of life;' 0.13 for 'new possibilities' and 'personal strengths,' and 0.15 for 'PTGI overall.' All values fell within the recommended range except for one value in the 'spiritual change' and one in the 'appreciation of life' models. Given that these values were not significantly above the maximum values (0.14 and 0.15 respectively instead of 0.11) and that the other diagnostic tests indicated that no individual cases had an undue influence on the data, the decision was made to keep these records in the data. Finally, cases were examined using DFBeta value. Field (2009) posits that scores greater than 1 exert a large influence on the model. DFBeta values for the regression models satisfied this criterion. Collectively, these tests indicate that the models were a good fit for the data as no individual case had an excessive influence on any of the regression models.

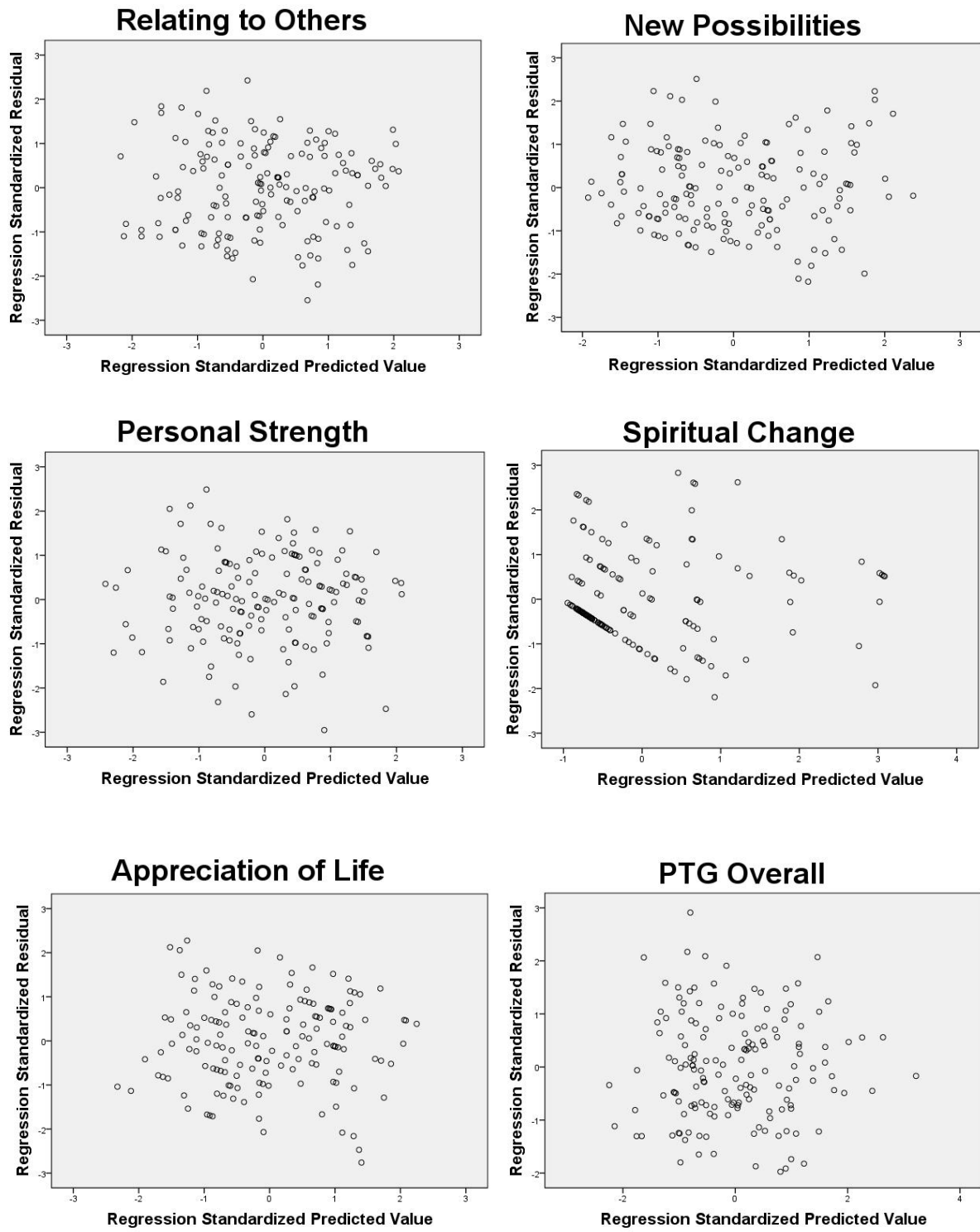
The second step in evaluating the regression models was to ascertain the generalisability of the models, by testing the statistical robustness of the regression analyses (Tabachnick & Fidell, 2007). First, the models were checked for multicollinearity, which indicates high inter-correlations between the predictor variables. As described in section 7.3.6.2.1, there was an indication of multicollinearity between the grief variables, which led to

the inclusion of the sole 'total PGS' measure in the analyses. The variance inflation factor (VIF) value is also generally used to assess multicollinearity, alongside the tolerance value (Hair et al., 2013). It is thought that VIF values should be lower than 10 and not "substantially" greater than 1 (Field, 2009, p.343). Tolerance values should be higher than 0.2 (Field, 2009; Hair et al., 2013). The VIF values in the models averaged 1.2 for 'spiritual change,' 1.4 for 'appreciation of life,' 1.6 for 'relating to others,' 'personal strengths' and 'PTGI overall' and 1.7 for 'new possibilities.' Tolerance values were all above 0.2. Collectively these measures indicate that there was no significant multicollinearity present in the regression models.

The models were also checked for independent errors, using the Durbin-Watson statistics, with values less than 1 and greater than 3 considered to be problematic (Field, 2009). The Durbin-Watson values were close to 2 (2.0 for 'relating to others' and 'new possibilities,' 2.1 for 'appreciation of life,' 2.2 for 'spiritual change' and 'PTGI overall' and 2.3 for 'personal strengths') suggesting that the residuals were not inter-correlated in any significant way.

Finally, the models were checked for linearity and homoscedasticity, as violations of these assumptions may weaken a model's statistical power and ability to generalise the results (Field, 2009; Tabachnick & Fidell, 2007). Linearity and homoscedasticity were assessed through the visual examination of the *ZRESID against *ZPRED scatterplot (Field, 2009; Osborne & Waters, 2002) and tested using the Breusch-Pagan test. The plots for the six regression models are displayed in Figure 7.1. Both visual examination and the Breusch-Pagan tests did not suggest heteroscedasticity on any of the variables except for 'spiritual change.'

Figure 7.1. Scatterplots illustrating the relationship between the standardised predicted values and the standardised residuals for each of the posttraumatic growth variables



Heteroscedasticity implies that the residuals (or errors in the model) have unequal variance (Field 2009), which may undermine the ability to generalise the models to different populations. The bootstrapping technique can be used when the assumption of homoscedasticity is violated (Field, 2014). Bootstrapping is considered a 'robust test' and consists of creating subsamples from the data set (often set at 1,000 samples) in order to estimate the sampling distribution. This technique enables a more conservative evaluation of the b coefficient, standard errors, p value and confidence intervals. However it does not alter the Beta (or standardised coefficients). The regression model for 'spiritual change' was re-run using this technique. Based on this analysis, the coping strategy 'religion' was still the only significant predictor of spiritual change. The results are displayed in Table 7.30.

Table 7.30. Linear model of predictors of spiritual change, with 95% corrected and accelerated confidence intervals. Confidence intervals and standard errors based on 1000 bootstrap

<i>Variable</i>	<i>b</i>	<i>Confidence</i>	<i>SE B</i>	β	<i>p-value</i>
Step 1 - Coping predictors					
Emotional support	0.06	-0.08, 0.20	0.08	0.04	$p = 0.483$
Religion	1.09	0.94, 1.27	0.09	0.75	$p = 0.004^{**}$
Venting	-0.10	-0.27, 0.11	0.10	-0.06	$p = 0.301$
Step 2 – Other predictors					
Emotional support	0.06	-0.09, 0.24	0.08	0.04	$p = 0.478$
Religion	1.02	0.82, 1.23	0.10	0.71	$p = 0.004^{**}$
Venting	-0.10	-0.28, 0.11	0.10	-0.06	$p = 0.347$
Feeling about TFA	0.11	-0.63, 0.86	0.36	0.02	$p = 0.728$
Religious status	0.46	-0.11, 0.95	0.27	0.10	$p = 0.116$

Normality of the residuals was assessed through visually examining histograms and normal P-P plots. These plots revealed a fairly normal distribution of the residuals both on the histograms and the P-P plots for all posttraumatic growth measures except for 'spiritual change'.

7.3.6.2.3 Summary of the results pertaining to the relationship between coping strategies, perinatal grief and posttraumatic growth

A positive relationship existed between several coping strategies and posttraumatic growth variables with significant emphasis on: 'active coping,' 'emotional support,' 'positive reframing,' 'acceptance,' 'instrumental support' and 'religion.' 'Self-blame' was the only coping strategy negatively related to growth. Grief variables displayed negative relationships with posttraumatic growth, which were statistically significant for most variables. The results of the multiple hierarchical regression analyses confirmed the relationship between coping strategies and posttraumatic growth. 'Positive reframing' was the most consistent predictor of posttraumatic growth for all subscales except for 'spiritual change.' 'Emotional support' was another coping strategy with positive predictive ability for 'relating to others', whilst the use of 'religion' as a coping strategy predicted 'spiritual change' and 'PTGI overall.' Grief (as measured by 'total PGS') was a significant negative predictor of 'personal strengths' with lower levels of grief predicting higher levels of 'personal strengths.'

The amount of variance explained by the regression models was moderate (between 15.3% for 'appreciation of life' and 55.3% for spiritual change'). These figures, alongside the statistically significant reports of analysis of variance in the models, nonetheless indicate that coping strategies, in particular, 'positive reframing' and the use of 'religion' predict posttraumatic growth. These figures also suggest that other variables, which were not measured in this study, may also account for this phenomenon. Grief, demographic and termination-related variables contributed little to explaining the variance in the models (between 1 and 2%).

7.4 Discussion

This study sought to measure women's levels of posttraumatic growth following TFA and examine the relationship between the coping strategies used by women, their levels of perinatal grief and posttraumatic growth. More specifically, the study aimed to ascertain

whether coping strategies and/or levels of grief could predict growth, and which coping strategies (if any) may facilitate this phenomenon. The study also served a confirmatory purpose in investigating, for a second time, women's use of coping strategies and their level of perinatal grief. The study also comprised a longitudinal element through the examination of the scores on coping and perinatal grief of a group of participants who participated in both quantitative studies (Study 2b, chapter 5 and Study 4). These findings are discussed in the subsequent sections. An evaluation of the study's limitations is also presented. More detailed evaluation of the study's implications in terms of theory, practice and further research is presented in chapter 8.

7.4.1 Women's use of coping strategies and their levels of perinatal grief

The findings of the study indicate that women relied to a greater extent on coping strategies generally considered to be adaptive rather than maladaptive to cope with TFA. This confirms the results of Study 2a (chapter 4) and Study 2b (chapter 5), adding credence to the initial findings. Similarly to Study 2b, the coping strategies 'acceptance,' 'emotional support,' 'active coping' and 'planning' displayed the highest usage. The scores for 'self-distraction,' 'emotional support,' 'instrumental support' and 'venting' were also higher than other coping strategies. When compared to Study 2b, the scores for these strategies were generally lower, except for 'acceptance,' which was higher in the present study. These differences may be due to the fact that women, in this study, had experienced their loss less recently than women in Study 2b (36.6 % had terminated their pregnancy over 24 months prior to study participation compared to 9% in Study 2b). Support for this hypothesis can be found in the relationship between 'time elapsed since TFA' and the use of 'support' and 'acceptance' in this study. Women whose termination occurred over 24 months prior to participation relied less on 'emotional' and 'instrumental support,' and more on 'acceptance' compared to women whose termination was more recent. This suggests that with the passing of time,

women seek less support and display higher levels of acceptance. This finding is also supported by the longitudinal analysis.

The levels of perinatal grief in this study were lower than in Study 2b. The differences in sample profiles between the two studies may account for these differences (i.e. the larger proportion of women who had a recent termination in Study 2b compared to Study 4), particularly given that grief levels were found to decrease over time in both Studies 2b and 4. This finding is consistent with the longitudinal analysis, which indicates that levels of grief decreased significantly over time, and is in keeping with existing evidence on TFA (Kersting et al., 2007, 2009; Korenromp et al., 2009). However, despite being lower than in Study 2b, women's levels of grief in this study were still higher than those recorded in other studies using the Short PGS (Hunfeld et al., 1994; Nazaré et al., 2013, 2014). This was also the case in the longitudinal analysis. Collectively, the results also indicate that a significant proportion of the participants in this study (between 52.2% and 65.8%) displayed pathological levels of grief. This was also observed in the longitudinal analysis with between 25.8% and 41.9% of the participants exhibiting levels compatible with complicated grief. These findings have implications with regards to the diagnosis of 'complicated grief' introduced in the *DSM-V* in 2013 (APA, 2013), briefly mentioned in chapter 5, section 5.4.2. This issue is discussed more fully in chapter 8 (section 8.4.2.1).

7.4.2 Women's levels of posttraumatic growth

Women reported some growth in the domains of 'relating to others', which is consistent with their engagement with a support group organisation such as ARC. Women also reported growth on the 'personal strengths' and 'appreciation of life' but scores on these subscales were just above the scales' midpoints. 'Spiritual change' was the domain for which the lowest level of growth was recorded. However, women who stated having a religion did report a significant change in this domain ('spiritual change'). Levels of posttraumatic growth in this study were generally lower than in other empirical investigations using the PTGI. PTGI scores have been shown to vary between 40.30 for the 'PTGI overall' scale among South

African survivors of violent crime (Peltzer, 2000) and 75.18 among US female students who had experienced a traumatic event (Tedeschi & Calhoun, 1996). More recent studies have shown the scores for 'PTGI overall' to vary between 59.3 and 73.1 among cancer survivors (Lelorain et al., 2010; Morris, & Shakespeare-Finch, 2011; Schroevers & Teo, 2008), and reaching 68.9 among Somali refugees (Kroo & Nagy, 2011). Following bereavement, 'PTGI overall' scores have ranged from 64.7 and 71.1 (Engelkemeyer & Marwit, 2008; Shakespeare-Finch & Amstrong, 2010). Thus, in comparison, the PTGI scores in this study were lower ('PTGI overall': $M = 46.6$). The moderate levels of growth observed in this study may, at first, appear somewhat surprising given that evidence suggests that self-disclosure within supportive environments may promote posttraumatic growth (Tedeschi & Calhoun, 2004). In this study, women were all active, to some degree, within the ARC's online forum and email network, since they were recruited using these channels. This would, theoretically, provide them with an opportunity to create narratives and make sense of their experience, and possibly identify positive changes as a result.

Several factors may account for the moderate levels of posttraumatic growth recorded in this study. Calhoun et al. (2010) posited that growth only occurs when an event triggers a fundamental re-appraisal of individuals' worldviews and beliefs systems. Thus, posttraumatic growth coexists with distress and results from the cognitive and emotional work that individuals have to undertake following the traumatic event. One explanation for the relatively moderate levels of posttraumatic growth in this study may be that women, in this sample, were particularly resilient and that the experience of TFA may not have shaken their worldviews to the extent that it would generate growth. However, the high levels of grief in the study challenges this interpretation. Another explanation may be found in the evidence suggesting that high levels of distress may hinder growth (Kleim & Ehlers, 2009). A study by Currier, Holland and Niemeyer (2012) suggested that posttraumatic growth follows a curvilinear relationship with distress, and that too little or too much distress may inhibit growth. Although the levels of grief in this study were lower than in Study 2b, they were higher than in other investigations using the short PGS scale (Hunfeld et al., 1994; Nazaré et

al., 2013, 2014) and above the threshold of 'normative' grief responses defined by Toedter et al. (2001). Thus, it is possible that women's high levels of grief may have restricted growth. The fact that the grief variables were negatively correlated with growth measures in this study supports this hypothesis. This interpretation would also be in keeping with the findings from the meta-ethnography described in chapter 2 and other empirical studies about TFA (Kersting et al., 2007, 2009; Korenromp et al., 2009; McCoyd, 2007) which indicate that women consider TFA as a highly traumatic event.

Women's relatively low levels of posttraumatic growth may also be accounted for by the nature of their loss. Although, growth following bereavement has been shown to be higher than following other types of trauma such as motor vehicle accident or sexual abuse (Shakespeare-Finch & Armstrong, 2010), several studies have suggested that some bereaved parents may struggle to make sense of their loss and identify any benefits from their experience (Keesee et al., 2008; Lichtenthal, Currier, Neimeyer & Keesee, 2010). The 'unnatural' characteristic of the loss in which a parent outlives his/her child may contribute to these difficulties (Keesee et al., 2008; Lichtenthal et al., 2010). The fact that, in the context of TFA, parents choose to end the pregnancy may make it harder for them to derive, or indeed report, any benefits following the termination. Evidence also suggests that unexpected and/or violent losses are generally more conducive to growth because they tend to shake individuals' worldviews more profoundly (Currier, Mallot, Martinez, Sandy, & Neimeyer, 2013). Therefore, the degree of anticipation and perceived control over a difficult event may influence the experience of growth in the aftermath.

Another factor impacting posttraumatic growth may be the time elapsed since the traumatic event; in this case, the termination. However, in this study, there was no evidence that time elapsed since the termination related to growth. It is difficult to ascertain to what extent this finding is consistent with existing evidence, because studies on posttraumatic growth vary significantly with regards to this criterion (Barskova & Osterreich, 2009). It is generally accepted, however, that because posttraumatic growth involves intense cognitive work (Cann et al., 2011; Tedeschi & Calhoun, 2004), it is not a quick process. The sample in

this study was evenly divided between women whose termination had occurred within a year of study participation (48.5%) and over a year (51.5%). Whilst a year may be too short for individuals to process their loss and identify any positive change, a longer timeframe should, theoretically, enable growth to occur. However, the analysis of the scores from the subgroup who completed both surveys ($n = 62$) shows that although they scored higher in the domains of 'new possibilities,' 'personal strengths' and 'appreciation of life' than the rest of the sample, these differences were not statistically significant.

Further research among a larger group of women who have terminated their pregnancy less recently, and using a range of timeframes may yield different results. The lack of relationship between time elapsed since TFA and posttraumatic growth may also simply reflect individual differences. Indeed, Tedeschi and Calhoun (2004) suggested that some individuals may report positive changes close to the event, whilst others may report them much later in life.

7.4.3 The relationship between coping strategies and posttraumatic growth

This study demonstrates that a relationship exists between the coping strategies used by women when dealing with TFA and their levels of posttraumatic growth. Several coping strategies were positively associated with posttraumatic growth ('active coping,' 'emotional support,' 'positive reframing,' 'acceptance,' 'instrumental support' and 'religious coping') and 'positive reframing' was found to be a significant predictor of growth. Collectively, these findings indicate that the use of coping strategies that are generally considered to be adaptive is associated with growth. These findings are consistent with some of the existing literature on posttraumatic growth (Barskova & Osterreich, 2009; Currier, et al., 2013; Joseph & Butler, 2010; Lelorain et al., 2010). Therefore, it may be helpful to promote these strategies to facilitate growth. Reliance upon religious coping was also an important coping strategy for some women and may be an additional resource they may choose to draw upon. This is consistent with research indicating that engaging in religious activities is associated with posttraumatic growth (Shaw, Joseph, & Linley, 2005). The relationship between coping

strategies and posttraumatic growth is also relevant in relation to the debate about whether posttraumatic growth is a coping process or the outcome of a traumatic event (Zoellner & Maercker, 2006). This issue is fully addressed in chapter 8 (section 8.4.1.3).

7.4.4 Limitations of the study

This study has several limitations. Some of these have been discussed in chapter 4 section 4.4.7 and chapter 5 section 5.4.5. As mentioned in chapter 5 (section 5.4.5), the mostly cross-sectional design of the present study prevented the identification of the directional causality between coping strategies and posttraumatic growth. A longitudinal design would be needed to address this limitation. The levels of variance explained by the regression models were generally moderate. This indicates that other variables, which were not included in the study, would account for some of the variance in posttraumatic growth. For example, adding a measure of perceived social support may have been helpful, as social support has been shown to buffer against stress and promote psychological adaptation (Cobb, 1976; Cohen & Wills, 1985). Other variables such as experience of other traumatic events may also contribute to explain the phenomenon of posttraumatic growth (Hegelson et al., 2006; Tedeschi & Calhoun, 2004).

In addition, there were several potential biases in this study. The sample mainly comprised White, well-educated participants and all were members of ARC. The latter issue has already been discussed in depth in chapter 3 (section 3.2.1), chapter 4 (section 4.4.7) and chapter 5 (section 5.4.5). It is unclear whether membership of a support organisation such as ARC would impact upon levels of posttraumatic growth. Although Tedeschi and Calhoun (2004) have suggested that disclosure within a supportive environment may facilitate growth, other factors such as the degree of engagement within that group, may have a bearing on the reported level of growth. It is also possible that women who feel the need to use a support organisation may be experiencing more distress and/or may be processing their loss more intensely than women who do not use a support organisation and thus, may struggle to identify any positive changes associated with their experience. By

contrast, women who do not feel the need to use support organisations may be more resilient individuals and thus, may be also experiencing relatively low levels of posttraumatic growth. Alternatively, they may already have processed their loss to a degree that enables them to grow from the experience. Further research among women who are not members of a support group may provide insights on this question.

Another bias relates to the use of self-reports and whether posttraumatic growth is a real or illusory experience. However, although Tedeschi and Calhoun (2004) have argued that growth following a traumatic event may be a real transformation, it remains to be determined whether, in the context of TFA, self-reports alone may be sufficient to measure growth. Finally, a social desirability bias cannot be excluded. The concept of feeling rules mentioned in chapter 4 (section 4.4.7), is highly relevant to posttraumatic growth. Feeling rules (Hochschild, 1983) are a set of beliefs about how people think they should behave in certain circumstances. In the context of TFA, given that women have chosen to terminate their pregnancy, they may be aware of the social stigma surrounding their decision. Consequently, some may find it difficult to report any benefits following the termination. Conversely, it has been suggested that the widespread appeal of Positive Psychology in Western societies may have led to exaggerated public perceptions that positive attitudes *per se* protect against adversity (Coyne & Tennen, 2010). This phenomenon has been referred to as 'saccharine terrorism' (Aspinwall & Tedeschi, 2010). Within that context, women may feel pressurised to report positive growth after a traumatic event. A qualitative investigation may provide insights into this issue.

Lastly, although this study suggests that religious coping is associated with the experience of spiritual change (albeit to a moderate level), it is important to remain cognisant of the Brief COPE's limitations in measuring such a complex concept (Pargament, Feuille, & Burdzy, 2011). Research conducted in the past 20 years into the relationship between religion and health has demonstrated that religious coping is a multi-faceted construct. It covers both religious and spiritual coping which are often used interchangeably (Hall, Meador, & Koenig, 2008), and encompasses strategies which may be categorised as

adaptive (e.g. seeking religious support, spiritual connection) and maladaptive (e.g. spiritual discontent, reappraisal of God's powers [Hall et al., 2008; Pargament et al., 1998]) coping mechanisms. The fact that one of the most frequently used measures of religious coping, the Brief RCOPE, contains 14 items covering five coping domains (finding meaning, gaining control, gaining comfort and closeness to God, gaining intimacy with others, and life transformation [Pargament et al., 2011]) illustrates the complexity of assessing this concept (Pargament et al., 2011). By contrast the Brief COPE only contains two statements on religious coping. Therefore, the study findings relating to the use of religious coping and its potential impact upon the experience of spiritual change need to be interpreted with caution. More research would be needed to identify exactly which types of religious coping may be associated with spiritual change in the context of TFA.

7.5 Conclusions and implications for the thesis

With regards to coping strategies and perinatal grief, this study's findings were in line with those of Study 2b. Women used generally adaptive coping strategies to cope with TFA and their levels of perinatal grief were high, albeit lower than in Study 2b. Collectively these two studies provide robust evidence into the question of how women coped with TFA and how this relates to their psychological adjustment.

This study also indicates that some women experience growth following TFA. Whilst the levels of posttraumatic growth were moderate, women exhibited growth in several domains: 'relating to others,' 'personal strengths' and 'appreciation of life.' In line with the findings of Studies 1 (chapter 2) and 2a (chapter 4), these results support the view that posttraumatic growth is a relevant psychological construct in the context of TFA. The study also suggests that the high levels of grief in this study may have inhibited the experience of growth. It is also possible that the moral complexity of TFA may have contributed to women finding it difficult to experience and/or report growth. The study also shows that the use of coping strategies that are generally considered to be adaptive is related to growth. This was

particularly the case with 'positive reframing.' These strategies were also related to lower levels of perinatal grief. Thus, there may be clear clinical benefits in promoting these strategies among women who have undergone TFA as it may not only reduce distress but also promote growth. The next chapter presents a general discussion of the findings of the studies (Studies 1, 2a, 2b and 3) that form this research programme, in terms of their implications for theory, practice and further research.

Chapter 8 - General discussion and conclusions

This chapter provides a summary of the findings from the studies presented in this thesis and underlines the research's contribution to knowledge. It also presents the implications of the research in terms of theory and practice. An evaluation of the research's limitations is presented as well as directions for future research. The chapter concludes with a proposal for the development and implementation of an online intervention to support women following TFA.

8.1 Introduction

The aim of the research was to examine women's experience of coping with TFA, particularly the coping strategies used by women and their relationship to psychological adjustment measured by perinatal grief and posttraumatic growth. Specifically, the research had four objectives: 1) to provide a synthesis of women's experiences of TFA; 2) to explore the coping strategies used by women when dealing with TFA and measure their relationship to women's levels of perinatal grief; 3) to explore health professionals' perceptions of women's coping with TFA to assess to what extent these perceptions are congruent with women's accounts; 4) to measure posttraumatic growth following TFA and examine the relationship between coping strategies, perinatal grief and posttraumatic growth.

To answer these diverse research objectives, a mixed methods approach was utilised. A systematic review and synthesis of the qualitative evidence pertaining to the experience of TFA was carried out. In addition, two qualitative and two quantitative empirical studies were conducted, three with women who had undergone TFA and one with the health professionals responsible for their care. The inclusion of health professionals in the research aimed to provide a comprehensive understanding of what coping with TFA may involve for women. The studies presented in this thesis have generated several important findings, some of which build on existing knowledge, whilst others provide novel insights into the

experience of coping with TFA. These findings and their implications are discussed in the subsequent sections.

8.2 Summary of the findings

The research shows that TFA is a traumatic event for women and that it may be akin to an existential crisis (chapter 2). The experience of TFA is one of life crisis. It shatters women's internal world, their sense of self and identity as mothers. It is characterised by ambivalence towards the decision to terminate, the unborn baby and what to disclose to others. Women are unprepared for the magnitude of the pain and the erratic nature of the recovery process (chapter 2). The research also indicates that TFA is a social as much as an individual experience, and that the way women experience it both reflects and shapes the political-legal-cultural environment within which TFAs are conducted (chapter 2). The absence of frames of reference due to the relative recency of this phenomenon, coupled with the stigma attached to pregnancy termination (whether for medical or non-medical reasons), leave many women feeling isolated, and their grief disenfranchised. This is exacerbated by a perceived deficit in aftercare (chapters 2 and 4), a view corroborated by health professionals' accounts (chapter 6).

The research also indicates that women mainly use coping strategies that are considered to be adaptive to deal with TFA, whether at the time of the procedure or afterwards (chapters 4, 5 and 7). These strategies include: 'support,' 'acceptance,' 'meaning attribution,' 'active coping' and 'planning.' Avoidant strategies considered to be more maladaptive such as 'self-distraction' and 'self-blame' are also used, but to a lesser extent (chapters 5 and 7). Yet despite using mainly adaptive coping strategies, women's level of grief are high, and the majority exhibit high levels of grief on measures considered to indicate pathology ('difficulty coping' and 'despair' [chapters 5 and 7]). The research also shows that several obstetric and termination-related variables are associated with grief. In particular, longer time elapsed since TFA, having children at the time of TFA, having had

children/being pregnant following TFA, and feeling comfortable with the decision to terminate all related to lower levels of grief (chapters 5 and 7).

The research also suggests that health professionals have an accurate understanding of what coping with TFA may involve for women (chapter 6). Health professionals understand the challenges women encounter and are generally cognisant of the coping strategies women use during and immediately after the termination. However, they also make several assumptions about what may influence women's coping with TFA (e.g. gestational age and the severity of the fetal abnormality), which may impact upon the care they provide. Furthermore, health professionals' understanding of women's long-term coping processes is limited. This highlights the lack of aftercare available to women, an issue raised in women's accounts (chapters 4). Health professionals also highlight the importance of the rightness of the decision as an essential element of the coping process, whilst women are more likely to comment on the emotional support provided by health professionals and emphasise the importance of meaning making (e.g. attributing meaning to the birth experience or experiencing personal growth following the termination [chapters 4 and 6]).

The research also reveals that despite being considered as a traumatic event, TFA also provides women with an opportunity for growth (chapters 2, 4 and 7). Some women, in this research, reported feeling stronger, having more empathy for others and a better appreciation of life following the termination. However, when measured quantitatively, the levels of posttraumatic growth were found to be moderate. It is possible that the high levels of grief reported in the studies contributed to restricting posttraumatic growth (chapter 7).

Finally, the research indicates that there is a strong relationship between the coping strategies used by women when dealing with TFA and their levels of perinatal grief (chapter 5 and 7). 'Acceptance' and 'positive reframing' were associated with lower levels of grief. By contrast, 'self-blame,' 'behavioural disengagement' and, to a smaller extent, 'planning,' 'venting' and 'religion' (as a coping strategy) related to higher levels of grief. A more modest relationship also exists between coping strategies and women's levels of posttraumatic

growth, with 'positive reframing' significantly related to all growth measures, and 'religious coping' linked to increases in 'spiritual change' (chapter 7). The research also highlights a weak and negative relationship between grief and growth measures and little predictive value of the grief variables on posttraumatic growth measures (chapter 7).

8.3 Contribution to knowledge

The research presented in this thesis supports the existing evidence suggesting that TFA is a traumatic event and that it impacts on women's psychological adjustment (Bryar, 2001; Fisher & Statham, 2009; Green & Statham, 2007; Iles & Garth, 1993; Kersting et al., 2005, 2007, 2009; Korenromp et al., 2005a, 2007a, 2009; McCoyd 2007; Mirlesse et al. 2011; Salvesen, et al., 1997; Statham et al., 2001). The research also supports the literature linking several obstetric factors to poorer psychological adjustment. In particular, the research is consistent with evidence suggesting that women whose termination was more recent (Statham et al., 2001; Statham, 2002), who were not comfortable with their decision (Korenromp et al., 2005a, 2007a; 2009), or did not have children following the termination (Statham et al., 2001) display higher levels of grief.

The research also significantly expands our understanding of TFA. The meta-ethnography represents the first systematic review and synthesis of the qualitative research on women's experiences of TFA. It complements the existing evidence which has been largely dominated by quantitative research and has focused on mental health outcomes of TFA. The review provides a more holistic representation of women's experiences. It also offers novel insights into the nature of the trauma experienced, the existential considerations women have to address, the challenges it poses to their sense of agency, the opportunity for growth, and the impact of the political-legal-cultural environment.

The research also furthers our understanding of coping and posttraumatic growth in the context of TFA. At the inception of the research programme, a review of the literature established that no empirical studies had investigated these constructs in the context of TFA.

The research presented in this thesis demonstrates that coping and posttraumatic growth are relevant constructs in the context of TFA. The research shows that coping is significantly related to women's psychological adjustment to TFA, although the direction of this relationship could not be established. Coping strategies considered to be adaptive related to lower levels of grief, and higher levels of posttraumatic growth. By contrast, strategies considered to be maladaptive were linked to elevated levels of grief. These findings are consistent with much of the coping literature suggesting that coping is linked to psychological adjustment and that some strategies promote better adaptation than others (Aldao & Nolen-Hoeksema, 2012; Carver et al., 1989; Carver & Connor-Smith, 2010; Glass et al., 2009; Harper et al., 2014a; Lazarus & Folkman, 1984; Moskowitz et al., 2009; Schnider et al., 2007).

The research also clearly indicates that psychological adjustment following TFA encompasses positive outcomes such as posttraumatic growth, particularly in the domains of 'personal strengths,' 'relating to others' and 'appreciation of life.' This finding supports the existing literature on posttraumatic growth, in particular, following bereavement and perinatal loss (Black & Sandelowoski, 2010; Calhoun et al., 2010; Engelkemeyer & Marwit, 2008; Tedeschi & Calhoun, 2004; Thomadaki, 2012). The research findings are also consistent with existing evidence linking coping and posttraumatic growth (Lichtenthal et al., 2010; Riley et al., 2007). However, it is the first time that this has been documented in the context of TFA.

The research also provides new insights into health professionals' perceptions of women's experience of coping with TFA and to what extent these perceptions are congruent with women's experiences. This comparison enables us to ascertain the levels of concordance between women and the health professionals responsible for their care, which has important implications for the care women receive.

This body of research also shows that the tools utilised to measure the constructs of coping, grief and posttraumatic growth are appropriate to use in the context of TFA. The three scales, the Brief COPE (Carver, 1997), the Short PGS (Potvin et al., 1989) and the

PTGI (Tedeschi & Calhoun, 1996) exhibited good reliability. The comparative analysis between the qualitative and quantitative investigations of women's coping strategies also suggests that the Brief COPE is a suitable tool to use in the context of TFA. However, the scale does not currently allow for the reciprocal nature of support to be measured. Given that this factor was important to women's coping, it may be beneficial to include it in further research in this area and arguably others (e.g. other types of perinatal loss). The research also highlighted the Brief COPE's limitations in measuring religious coping (see chapter 7, section 7.4.4). Yet, despite these caveats, the Brief COPE remains a suitable tool to assess coping in the context of TFA. As Carver himself posited, the Brief COPE is meant to "foster a wider examination of coping" (Carver, 1997, p.98). The tool's brevity and flexibility are designed to enable researchers to assess coping strategies in a quick and efficient way. Given that no research had been conducted on coping in the context of TFA, the use of the Brief COPE was therefore appropriate as a starting point.

Collectively, these findings provide novel insights into the experience of coping with TFA, which expand our understanding of this phenomenon, and thus, constitute an important contribution to knowledge. Since the inception of the research programme, several qualitative studies have been conducted into women's experiences of TFA, which is a testimony of the current level of interest in TFA (e.g. Asplin et al., 2014; Koponen et al., 2013). Similarly, Nazaré et al. (2013) investigated the relationship between the coping strategies used by both the women and their partners following TFA, and their levels of grief. This study largely corroborates the present research's findings highlighting the link between 'acceptance' and positive psychological outcome, and between 'self-blame' and more negative outcomes, as well as pointing to differences in grieving between partners. To our knowledge, to date, no other empirical studies have been conducted into posttraumatic growth following TFA or into health professionals' understanding of this phenomenon.

8.4 Implications of the research

These findings have several implications in terms of theory and practice which are discussed in the next sections.

8.4.1 Theory

The research has four main implications for theory. These are: the classification of coping strategies as adaptive or maladaptive, the relevance of bereavement theories to the experience of TFA, the question of whether PTG is a coping strategy or an outcome, and the importance of concordance and shared decision making between patients and health professionals.

8.4.1.1 Coping: moving away from the 'adaptive versus maladaptive' classification

The research shows that women's levels of grief were high despite using coping strategies considered to be adaptive. This finding leads us to question the validity of classifying coping strategies into distinct categories either as adaptive or maladaptive. The qualitative investigation of women's coping strategies (Study 2a, chapter 4) indicates that several strategies traditionally labelled as avoidant were used (e.g. 'avoidance' or 'self-distraction'). However, it is possible that these strategies may have served an adaptive function. Despite being possibly maladaptive in the long-term, these strategies may have contributed to protecting women from emotional distress in the short-term and enable them to develop longer-term strategies. In a similar way, it is possible that the use of 'self-blame,' which was high in this research, may have enabled women to regain a sense of control over their experience and counter-balance feelings of helplessness (Duncan & Cacciatore, 2015; also see section 8.4.2.5). It is also possible that 'self-blame' reflects characteristics unique to TFA. Indeed, it may be unsurprising that some women experience a degree of self-blame given that they, and their partners, have made the decision to terminate their pregnancy (Ferreira da Costa et al., 2005; Gammeltoft et al., 2008; Leichtentritt, 2011; McCoyd, 2010a).

In the context of TFA, 'self-blame' may reflect a feeling inherent to the nature of the loss rather than a coping strategy per se.

Furthermore, some strategies may be more difficult than others to classify as either maladaptive or adaptive. For instance, the Brief COPE coping strategy 'substance use and misuse' relates to the use of 'alcohol and other drugs' to relieve distress. Thus, it would appear relatively easy to classify this strategy as 'maladaptive' (providing that prescription drugs such as anti-depressants are excluded from this definition). Other strategies such as 'venting' may be more difficult to categorise. In the context of bereavement, 'venting' could be considered to be adaptive in that it encourages individuals to process their loss, and possibly impart meaning (Pennebaker, Zech, & Rimé, 2001). However, it is also associated with rumination, which is generally regarded as maladaptive (Aldao & Nolen-Hoeksema, 2012; Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008). 'Religion' is another strategy difficult to classify due to the contrasted evidence of its adaptive function (Ai, Hall, Pargament, & Tice, 2013; Ano & Vasconcelles, 2005). How adaptive 'religious coping' is may also depend on individuals' religious status. For example, in Study 4 (chapter 7), there was a strong relationship between 'having a religion' and the use of religious coping which, in turn, related to growth, particularly in the domain of 'spiritual change.' However, in this research, religious coping was also associated with higher levels of grief. Religious coping itself has been divided between positive (e.g. seeking religious support, spiritual connection) and negative religious coping (e.g. spiritual discontent, reappraisal of God's powers [Pargament et al., 1998]). Positive religious coping itself has been linked to positive psychological adjustment (Ano & Vasconcelles, 2005) and posttraumatic growth (Ai et al., 2013; Bosson, Kelley, & Jones, 2012).

The quantitative investigation into women's coping strategies and their relation to perinatal grief (Study 2b) also indicates that although women relied principally on coping strategies considered to be adaptive to cope with TFA, they also made use of maladaptive ones. In particular, the use of 'self-distraction,' which is usually linked to avoidance strategies, was high. This suggests that women use a range of strategies, whether adaptive

or maladaptive, and that the adoption of a particular strategy may be based, in part, on their needs in terms of emotion regulation. Consequently, it may be more helpful to conceptualise coping on a maladaptive-adaptive continuum rather than mutually exclusive discreet categories, which is contextual and dependent of women's emotional needs at the time.

In that respect, the research presented in this thesis supports the view proposed by Lazarus and Folkman's cognitive stress theory (1984), that coping is contextual and situation-dependent. This theory suggests that coping varies according to the type of stressor and the individual's situation and resources. Folkman and Moskowitz (2004) further posited that one of the first prerogatives of coping is to alleviate distress so that more instrumental forms of coping may be put into practice. In this context, 'self-distraction,' and 'behavioural disengagement' may fulfil the initial task of stabilising levels of distress. Folkman and Moskowitz (2004) also suggested that coping with events that are perceived to be controllable are related to greater use of active, instrumental problem-focused forms of coping. By contrast, events that are perceived as uncontrollable lead to higher reliance on active or passive emotion-focused forms of coping. In this research, women's reliance on 'active coping,' 'planning' and 'instrumental support,' coupled with high levels of 'self-blame' suggests that they regard TFA as being, to some extent, controllable. However, high levels of 'emotional support' seeking and 'self-distraction' point to a more contrasted picture. It is possible that given the complex nature of TFA, women may regard this event as both controllable and uncontrollable.

8.4.1.2 Coping with bereavement: the relevance of the dual process model of coping with grief, continuing bonds and finding meaning

The research shows that TFA is a unique form of bereavement. As such, it is important to consider this phenomenon within the framework of bereavement theories (see chapter 1, section 1.3.2.1). The research presented in this thesis supports several bereavement theories. In particular, the research highlights the relevance of the theory of continuing bonds (Klass, Silverman, & Nickman, 1996), the dual process model of coping with bereavement

(Stroebe & Schut, 1999) and 'finding meaning' as an interpretative representation of grief (Niemeyer, 2001). There was evidence, in this research, that continuing bonds with the baby were soothing for women. Many women acknowledged and remembered their baby, and engaged in rituals and token acts, which they reported as being helpful. This is compatible with Klass and colleagues' theory (1996) which posits that the purpose of grief is not to sever bonds with the deceased but to maintain and integrate them with others. Nevertheless, the high levels of perinatal grief observed in the quantitative investigation also raises the issue that although continuing bonds may be perceived as soothing, they may also maintain women in a state of longing, which may hinder psychological adjustment in the long-term (Stroebe, van der Houwen, & Stroebe, 2008).

The research also demonstrates the relevance of the dual process model of coping with bereavement (Stroebe & Schut, 1999) to the experience of TFA. This model proposes that individuals are faced with two types of stressors following bereavement: loss-related and recovery-related, and that they oscillate between two coping processes. The first coping process is loss-orientated and involves processing the loss, grief work and oscillation between relinquishing and continuing bonds (Stroebe & Schut, 1999). The second one is restoration-orientated and consists of attending to life changes, distraction from grief and working through new roles and identities. The coexistence of high levels of grief and active coping strategies in this research suggests that whilst women contemplated their loss (through remembering the baby and meaning making), they also engaged in restoration activities (through seeking instrumental support, self-distraction, returning to work, looking after existing children and planning another pregnancy). The range of emotions (from despair to growth, through to ambivalence) displayed by women, and of the strategies used to cope with TFA provide evidence of the idiosyncrasies and complexities of the experience of TFA. In the same way that coping should be considered as situation-dependent, bereavement does not follow a linear and prescribed path. This perspective is compatible with the pluralistic perspective on coping with bereavement proposed by the dual process model.

Women in this research also engaged in finding meaning. Among those who gave birth to their baby, several sought to impart meaning to the birth experience. In addition, some women were able to derive benefit from their experience in terms of 'relating to others,' 'personal strengths' and 'appreciation of life.' This is consistent with the bereavement model of finding meaning which posits that following bereavement, individuals need to engage in the task of reconstructing meaning in a way that is congruent with their situation and experience (Niemeyer, 2001; Keesee, et al., 2008).

The relevance of these bereavement theories has been acknowledged in the context of parental bereavement and perinatal loss (Harper, O'Connor and O'Carroll, 2014b; Keesee et al., 2008; Koopman, Wilson, Cacciatore, & Flenady 2013; Meij et al., 2008; Wilson, 2014). The dual process model of coping has also been shown to account for gender differences in coping with loss. Wilson (2014) suggested that women may be loss-orientated whereas men may be more restoration-orientated. This may explain some of the inter-personal tensions reported in the qualitative investigation of women's coping strategies (Study 2a, chapter 4) and noted in the meta-ethnography (Study 1, chapter 2). Gender differences in grieving in the context of TFA have already been reported in several studies (Lafarge & Fox, 2013a; Nazaré et al., 2012, 2013). Although couple congruence aspect was not a focus of the present research (see chapter 1, section 1.2.3.4), further research in this area would be beneficial because the levels of congruence in grieving between partners is likely to impact upon women's experience (Lafarge & Fox, 2013a; Nazaré et al., 2012, 2013).

8.4.1.3 The nature of posttraumatic growth: coping or outcome

This research indicates that there is a relationship between the coping strategies used by women when dealing with TFA and posttraumatic growth, with 'positive reframing' a significant predictor of all growth measures. This finding needs to be considered in relation to the debate about whether posttraumatic growth is a coping process or the outcome of a traumatic event (Tedeschi & Calhoun, 2004; Zoellner & Maercker, 2006). This debate is rooted in the cognitive adaptation theory (Taylor, 1983) which posits that individuals try to

deal with a trauma by searching for meaning, attempting to regain control over the situation and using self-enhancing cognitions designed to alleviate distress. In this instance growth is, therefore, depicted more as a coping process than an outcome. In line with this theory, it has been suggested that posttraumatic growth, particularly when reported soon after a traumatic event, may be the manifestation of self-enhancing biases designed to help individuals cope with the trauma rather than a reflection of more permanent, positive changes (Sumalla, Ochoa, & Blanco, 2009; Tallman, 2013; Zoellner & Maercker, 2006).

This leads to the question of whether posttraumatic growth is a reality or an illusion (Tallman, 2013), which is illustrated by the Janus-Face model proposed by Zoellner and Maercker (2006). This model suggests that there are two sides to growth: a constructive side, which involves positive transformations as proposed by Tedeschi and Calhoun (2004), and an illusory side, which is more deceptive and may amount to cognitive avoidance aimed at containing distress. Although the illusory component may serve as a short-term adaptive strategy in protecting individuals from distress, it may hinder long-term adjustment by preventing cognitive processing necessary for transformative growth.

However, Tedeschi and Calhoun (2004) argued that, in many cases, the growth reported by individuals appears to be verified in real life, and that growth is generally experienced as an outcome of trauma rather than a coping process. In support of this argument, a longitudinal study by Peterson and Seligman (2003) on character strengths which was started before the terrorist attacks in the United States in September 2001 indicated that individual scores on dimensions such as gratitude, hope, kindness, leadership, love, spirituality, and teamwork had increased following the terrorist attacks. Self-reports of posttraumatic growth have also been corroborated by assessments from significant others (Joseph, 2011; Shakespeare-Finch & Barrington, 2012). Collectively these studies suggest that when individuals report growth following a traumatic event, a real transformation is taking place. This is particularly true if the transformation translates into behavioural changes such as expressing more empathy towards others, or taking up new interests (Shakespeare-Finch & Barrington, 2012).

In this research, it remains to be ascertained whether the changes reported by women amount to a real transformation. However, the high levels of 'acceptance' coupled with the significant predictive value of 'positive reframing' on growth measures suggest that women engaged in high levels of cognitive processing, which may be conducive to long-lasting changes. Furthermore, the changes most frequently reported in this study focused on discovering new strengths and altering life priorities which also point to enduring transformation.

8.4.1.4 *Concordance and shared decision making*

The research indicates that health professionals caring for women who undergo TFA have a valid understanding of what coping with TFA may involve for women. They are also aware of the range of strategies women may use, in particular at the time of the procedure and immediately afterwards. These findings are relevant in the context of clinical concordance and shared decision making which have gained increasing prominence (Légaré, Ratté, Gravel, & Graham, 2008). Clinical concordance and shared decision making have been shown to improve patients' health outcomes (De las Cuevas et al., 2012; Joosten et al., 2008). Therefore, it is likely that health professionals' level of understanding of women's coping processes would impact upon the quality of the care they provide to women.

Shared decision making may be particularly important in the context of TFA as the decision to continue or end the pregnancy is irreversible and has important psychosocial consequences. Evidence also suggests that, in the context of perinatal or neonatal loss, parents rely to a greater extent upon health professionals than their close family and friends to make decisions (Williams, Munson, Zupancic, & Kirpalani, 2008), possibly because of health professionals' technical expertise, but also possibly in an attempt to share 'the burden of choice.' The research presented in this thesis demonstrates that women uncomfortable with their decision experience higher levels of psychological distress than those who report being comfortable with it. Thus, it is paramount that women reach a decision that is right for them. The health professionals who participated in this research were acutely aware of this

imperative. Accordingly, they viewed their role, first and foremost, as providing information to women to enable them to make an informed decision. This responsibility is in keeping with clinical guidelines (NICE, 2008). Most professionals also commented on the non-directive nature of their counselling, which is also consistent with clinical recommendations (RCOG, 2010). Some participants even spoke of a shared decision-making process with the parents. However, how truly non-directive information provision can be (Martin et al., 2015), and how compatible the concepts of shared decision making and non-directiveness may be (Elwyn, Gray, & Clarke, 2000) is debatable. It is also possible that some women may want some directive input from health professionals in their decision process.

To what extent health professionals are involved in the decision making process and how truly non-directive the information they provide is, in the context of TFA, remains to be ascertained. However, how well supported women feel throughout the process may be of more relevance than a more objective measure of shared decision making. In that respect, being cared for by professionals who have a good understanding of their experience should benefit women through the quality of the care they receive. Whilst in this research, health professionals had a good understanding of women's experiences in the short-term, they lacked a long-term perspective, which has implications for practice.

8.4.2 Implications for practice

Collectively, the studies presented in this thesis have several implications for practice. These include: identifying women vulnerable to poor psychological adjustment; providing a truly person-centred care; the relevance of support groups; the need for aftercare; promoting protective factors and addressing self-blame; and promoting legal frameworks and policies that create a supportive environment for women.

8.4.2.1 The need to identify women at risk of poor psychological adjustment

The research clearly indicates that there may be some value in identifying women vulnerable to poor psychological adjustment following TFA. Women exhibited high levels of grief with a

large proportion displaying levels fulfilling the criterion for complicated grief as defined by Toedter and colleagues (2001). This finding is clinically relevant given that complicated grief has been included in the *DSM–V* (APA, 2013). This inclusion has generated debate with some arguing that it is necessary to ensure that those suffering receive help (Boelen & Prigerson, 2013; Shear et al., 2011) whereas others raise issues of false-positive diagnosis and medicalisation of normal human emotions (Wakefield, 2012).

To fulfil the criteria for a diagnosis of complicated grief as defined in the *DSM–V* (APA, 2013), the bereavement must have occurred at least 12 months previously and must involve substantial symptoms of reactive distress or identity disruption since the loss, significant distress in social/occupational life or additional areas of functioning and a response out of proportion or inconsistent with cultural, religious or age-appropriate norms (Boelen & Prigerson, 2013; Stroebe et al., 2013). It is difficult to know to what extent the levels of grief recorded in this research match the definition of complicated grief as defined in the *DSM–V* (APA, 2013). Regardless, women in this research displayed high levels of distress. Although these were lower in the second quantitative study (Study 4), the levels were also still higher than in other studies using the Short PGS (Hunfeldt et al., 1994; Nazaré et al., 2013, 2014; Toedter et al., 2001). This was also despite the fact that a sizeable proportion of the sample comprised women whose loss had occurred at least 24 months prior to taking part in the study, and who displayed lower levels of distress (see chapter 7, section 7.3.4 for the longitudinal analysis).

The research also identifies several risk factors for grief symptomatology. Women whose loss was more recent, who did not have children at the time of TFA, who had not had children/were not pregnant following TFA and/or who felt uncomfortable with their decision to terminate were more likely to display elevated levels of grief. This is in line with the main quantitative studies looking at women's adaptation following TFA (Kersting et al. 2007, 2009; Kersting & Wagner, 2012; Korenromp et al., 2009). Although these factors are mostly outside the women's control, they are nonetheless useful parameters that could be used to identify women who are particularly vulnerable to psychological complications.

Identifying women at risk of poor psychological adjustment is obviously important to women's mental health and quality of life. It is also important because poor psychological adjustment is likely to impact upon women's relationships with their partners. For example, a study by Gold, Sen, and Hayward (2010) suggests that there is an increased risk of parental separation following a stillbirth. The few studies conducted on marital congruence in the context of TFA (Lafarge & Fox, 2013a; Nazaré et al., 2012, 2013; Suslack et al., 1995) show that although the experience of TFA may contribute to bringing partners together, it can also lead to interpersonal tensions as partners grieve differently. In this research, women reported feeling closer to their partners, particularly at the time of the termination, but they also reported difficulties in the aftermath of the termination (chapter 4).

Identifying women vulnerable to poor psychological outcome is also important in the context of subsequent pregnancies. Research suggests that women who have experienced pregnancy loss (due to fetal anomaly or not) display higher levels of anxiety and depression during subsequent pregnancy than those who have not (Blackmore et al., 2011; McCarthy et al., 2015). Women who conceive after TFA have reported that a new pregnancy triggered a "re-emergence of anguish" (Rillstone & Hutchinson, 2001). A recent study by McCarthy et al. (2015) based on 5,575 women also shows that alongside emotional difficulties, previous obstetric loss is related to altered behavioural responses to pregnancy, such as limiting or avoiding usual activities, particularly in the first trimester of the pregnancy. This study also indicates that symptomatology is higher among women who had multiple losses. This is an important finding. Indeed, given the prevalence of miscarriage (20% of all pregnancies [NHS b, n.d.]) and of termination of pregnancy (whether for medical or non-medical reasons: 21% [ONS, 2014e]), it is likely that women who undergo TFA may have experienced other losses in the past, and that this may have an impact upon their experience in subsequent pregnancies. Although this was not captured in the present research, further research is needed in this area.

This research also provides evidence that women regard another pregnancy as a bitter-sweet experience and a failure to conceive may be seen as punitive (Fernandez,

Harris, & Leschied, 2011; Maguire et al., 2015). This finding raises a question about the recommended time between the termination and a subsequent pregnancy. Findings from a study by Hughes et al. (1999) on psychological adjustment to stillbirth suggest that women should preferably wait 12 months following their loss to conceive again. This recommendation was also echoed in Badenhorst and Hughes' (2007) review of psychological aspects of perinatal loss. This has implications not only for the mother but also for the baby, because anxiety and distress during pregnancy can negatively affect pregnancy outcomes (e.g. pre-term birth; Hobel et al., 2008), and the wellbeing and development of the baby (Brouwers et al., 2001; Laplante et al., 2008). The length of time between a pregnancy loss and the next pregnancy may also have an impact upon the type of emotional relationship parents form with their next born, and on the type of parenting they may adopt in the future (Badenhorst & Hughes, 2007). A recent study into the impact of TFA on the relationship between a mother and her subsequent child (Alexandre et al., 2015) suggests that unresolved grief impacts negatively upon the mother-child relationship. Unresolved grief may also be associated with language disruptions in the child and a lack of engagement with his/her environment. Further research would be needed in this area.

8.4.2.2 *The need for a truly person-centred care*

In order to provide adequate care to women undergoing TFA, it is essential that health professionals recognise the complexity and idiosyncrasies of the TFA experience. This involves recognising its unique nature and the range of emotions it generates as well as the range of strategies women use to deal with it.

The research shows that women regard TFA as a unique form of bereavement, and that this is inconsistent with the clinical and societal paradigm of abortion when pregnancy is unwanted. TFA differs from other perinatal losses in that it is self-perpetrated, and from abortion for non-medical reasons in that the pregnancy is wanted. It also differs from other types of bereavement in that the loss is not socially sanctioned in the same way, with women feeling that their grief is disenfranchised. White-Van Mourik et al. (1992) argued that most

negative feelings inherent to TFA can be articulated around the loss of self-esteem: loss of biological self-esteem because of the pregnancy ending in a failure; loss of moral self-esteem caused by feelings of responsibility and sometimes guilt that accompanies the decision to end the pregnancy; and finally, loss of social self-esteem derived from a perceived inability to bring a disabled child into the world. Thus, it is essential that health professionals acknowledge the complexity of this phenomenon.

It is also important that health professionals recognise the range of emotions TFA generates. The research indicates that women can experience shock, loss of control, ambivalence, guilt and despair, but also a sense of strength, renewed empathy, and appreciation of life. The research also demonstrates that women use a range of coping strategies. This diversity underlines the complexity and idiosyncrasy of the experience of TFA. This is illustrated by women's attitude towards spending time with and/or holding the baby. This research shows that whilst some women found this helpful, others were more ambivalent. This finding supports existing evidence (Bennett et al., 2005; Geerinck-Vercammen & Kanhai, 2003; Gold et al., 2007; Hughes et al., 2002; Kelley & Trinidad, 2012; Kersting & Wagner, 2012; Koopmans et al., 2013; Sloan et al., 2008; Wilson, 2014) and the clinical guidelines that recommend taking the parents' lead in deciding what would be more appropriate to them (NICE, 2007, 2014).

These differences call for a truly person-centred care, where women's preferences can be accommodated. The research shows that health professionals made a series of assumptions about what factors may influence women's coping, but that they also were generally cognisant of the complexity and idiosyncrasies of the experience of coping with TFA for women. However, research also shows that women's preferences are not always accommodated, for example, in terms of the termination method or the clinical environment for the procedure (Fisher et al., 2015; Fisher & Lafarge, 2015). Furthermore, it remains to be ascertained whether health professionals would display comparable levels of understanding in other clinical environments, given that only three clinical sites (and one in particular) were represented in the research. Whether this level of understanding would also apply in

different cultures would also need to be investigated, as the meta-ethnography (chapter 2) points to cultural variations in the care provision and women's expectations of care (e.g. the Vietnamese and British studies study [Gammeltoft et al., 2008; Hunt et al., 2009]).

Importantly, this research alludes to the fact that women generally feel under-prepared for the termination and its emotional toll and that that they generally consider the aftercare to be deficient. This was evidenced in the studies reviewed in the meta-ethnography and the qualitative investigations of women's coping with TFA, both from women's and health professionals' perspectives (chapters 4 and 6).

8.4.2.3 The relevance of support groups

The research indicates that many women feel unprepared for the magnitude of the pain, the decision they have to make and the emotional fallout in the short- and longer-term. Women need to be supported throughout the process i.e. before, during and after the termination.

Given that TFA is a relatively new phenomenon, women (and, to some extent, health professionals) are unable to draw upon previous knowledge. Furthermore, technological developments in screening (e.g. non-invasive prenatal testing [Hill et al., 2014]) mean that women are faced with new options regarding their reproductive health, which in turn, raise questions which have yet to receive normative responses (Bryant, 2014; McCoyd, 2009b).

Given the low incidence of TFA in the population (2% of all pregnancy terminations [DH, 2015]), women are also unlikely to encounter someone in their vicinity who has experience of this phenomenon. To address the lack of experiential knowledge of TFA, health professionals should consider early referral to support groups, or other support organisations. These organisations may be able to address women's questions, and fill some of the gaps in the care health professionals provide, in particular, post termination. This would also provide women with the opportunity to reciprocate support, which was important to their coping process, and has also been highlighted in other studies on perinatal grief (Fernandez et al., 2011).

Research suggests that the use of a support group following perinatal loss may offer some benefits in terms of psycho-education and support (Koopmans et al., 2013). A study by Cacciatore (2007) into the use of a support group following stillbirth indicates that women who attended a support group had fewer posttraumatic symptoms than those who did not attend. Similarly, Suslack et al. (1995) examined the experience of parents using a support group following TFA, and found that they also valued this source of support. Online support groups have also been found to be beneficial to women who consider them as a valuable forum to share stories (Capitulo, 2004). Participation in online support group activities in general has been shown to buffer the impact of stress (Barak et al., 2008) and to be a source of empowerment (Bartlett & Coulson, 2011; van Uden-Kaan et al., 2008). However, some concerns have also been voiced about the lack of research into the possible damage such groups could inflict on individuals, such as exploitation or abuse (Stroebe et al., 2008) and excessive rumination has also been reported (Eysenbach et al., 2004; Malik & Coulson, 2008). Furthermore, engaging in internet activities may reduce social interaction, which, in turn, could reduce access to and the provision of social support (Koopman et al., 2013; Stroebe et al., 2008). However, a study by van der Houwen, Stroebe, Schut, Stroebe and van der Bout (2010) on the impact of online support group following bereavement has shown that online support was not a substitute for offline social support. The study also indicated that those who had stopped using online support groups exhibited better psychological adaptation than those who were still using it. However, given the cross-sectional design of the study, the direction of the relationship could not be determined (i.e. whether bereaved individuals stopped using the groups once they felt better or whether they felt better since they had stopped using the group). Stroebe et al. (2008) also suggested that some online groups may develop their own normative rules which may constrain individuals and potentially lead them to feeling isolated.

Whilst it is important to recognise the potential limitations of using online support groups and the need for further research in this area (Stroebe et al., 2008), the research in this thesis suggests that women derived important benefits from being part of a support

group. It provided them with emotional support, the opportunity to reciprocate support and, in some way, put their experience to good use. It also enabled them to compare their experience and, get a sense of where they were in the recovery process (see chapter 4). The large number of women in the group also represents a resource on a scale that cannot be replicated in normal social interactions. Therefore, the data presented in this thesis indicate that it would be beneficial to refer women to support groups, as this may fill some of the support gaps women experience post termination (see chapters 2 and 4).

8.4.2.4 *The need for aftercare*

Whilst the health professionals in this research were cognisant of women's need for support, they also admitted to having a limited understanding of how women cope with TFA in the long-term (chapter 6). This is in keeping with women's accounts, which indicate support is lacking post termination (chapter 4, also see chapter 2). The reliance on support groups may illustrate this. Which type of aftercare should be provided, by whom and for how long needs to be examined. A recent study into the support desired by women who undergo TFA indicates that, at the time of the termination, the majority of women have not anticipated what their support needs may be (Ramdaney, Hashmi, Monga, Carter, & Czerwinski, 2015). It is also unrealistic to expect health professionals who care for women at the time of termination to provide the entirety of the aftercare. This would not only necessitate significant additional resources but also the development and/or acquisition of specific skills through training. Furthermore, women may prefer to be cared for by professionals not associated with the termination to avoid painful memories (chapter 6). It is also possible that women may favour support that they can access as and when they need it. The research has shown that there are important milestones in women's grieving, such as the baby's due date or the first anniversary (chapter 4). Therefore, it is likely that women's need for support would increase at these particular times. Based on these considerations, an online tool providing information as well as psychological support may be suitable for women. This is particularly relevant given that some women have reported anonymity as an important factor in their

likelihood to seek support (Ramdaney et al., 2015). A more exhaustive discussion of what such a tool may consist of is provided in section 8.7.

8.4.2.5 Promoting protective factors whilst minimising self-blame

The research identifies several protective factors which may enhance women's psychological adjustment, including coping strategies such as 'acceptance' and 'positive reframing.' These strategies were relevant to both perinatal grief and posttraumatic growth (chapter 7). Therefore, it may be beneficial to promote such strategies through information provision or talking therapies. Interventions based on Cognitive Behavioural Therapy (CBT) may be particularly appropriate, and this type of intervention has been used extensively in the context of bereavement and complicated grief (Bennett, Ehrenreich-May, Litz, Boisseau, & Barlow, 2012; Boelen, 2006; Wagner, Knaevelsrud & Maercker, 2006). A meta-analysis by Wittouck, Van Autreve, De Jaegere, Portzky, and van Heeringen (2011) looking at CBT-based interventions in the context of complicated grief, revealed that treatment interventions were successful in decreasing symptoms of complicated grief. Similarly, CBT interventions in the context of miscarriage have been shown to be effective in alleviating distress (Sejourné, Callahan, & Chabrol, 2010). A study conducted by Kersting et al. (2013) to test the effectiveness of a web-based CBT intervention following perinatal loss has shown promising results in reducing women's levels of psychological distress. These interventions usually rely upon several CBT-based components, the main ones being exposure to the event and cognitive reappraisal. Acceptance and Commitment Therapy (ACT), which blends "acceptance and mindfulness strategies with commitment and behaviour change strategies" (British Association for Behavioural and Cognitive Psychotherapies, n.d.) may also be helpful in the context of TFA. ACT consists of embracing experiences, acknowledging the feelings and cognitions that accompany these and devising a course of action in accordance with the individual's values (Hayes, 2004). Both CBT and ACT may be relevant tools to assist in the development of protective factors and facilitate the experience of growth following TFA.

The research also shows that many women use 'self-blame' as a coping strategy, and that 'self-blame' is related to higher levels of grief and, to a smaller extent, lower levels of growth. 'Self-blame' was also more widely used as a coping strategy among women uncomfortable with their decision to terminate. Thus, the importance of reaching the 'right decision' needs to be acknowledged. The fact that the health professionals in this research were acutely aware of it is encouraging. Still, in this research approximately a quarter of women were uncomfortable with their decision (chapters 5 and 7).

The negative impact of self-blame to psychological adaptation following perinatal loss and TFA has been well-documented (Cacciatore, Frøen, & Killian, 2013; Jind, 2003; Nazaré et al., 2013, 2014; Thomadaki, 2012). Self-blame can be conceptualised as a cognitive appraisal or attribution (Duncan & Cacciatore, 2015). As such, cognitive behavioural techniques are likely to be effective in reducing its negative impact. However, evidence also suggests that, in some cases, self-blame may serve an adaptive function by counterbalancing feelings of helplessness (Duncan & Cacciatore, 2015; Shapiro, 1995; Thomadaki, 2012). Attributing blame to themselves enables individuals to retain a degree of control over a negative event. Janoff-Bullman (1979) proposed that there are two types of self-blame: behavioural self-blame, which can be modifiable and thus avoidable, and characterological self-blame, which is harder to modify and implies a degree of deservingness. In this context, behavioural self-blame may be more adaptive than characterological self-blame.

The protective nature of self-blame has been evidenced in Thomadaki's study (2012) about posttraumatic growth following perinatal loss. In this qualitative study, several women used self-blame as a coping strategy to foster a sense of controllability over their loss. Furthermore, a recent study by Maguire et al. (2015) into grief following second trimester terminations of pregnancy suggests that women feel responsible for the anomaly despite knowing they cannot control it. This implies that attributing the responsibility to themselves may provide women with a sense of control. This is comparable to the meta-ethnography's findings which also indicate that, in the absence of clear explanation about the cause of the abnormality, some women attribute it to themselves (chapter 2). It is, therefore, important

that health professionals address the issue of self-blame. However, in doing so, they need to be mindful to differentiate between a form of self-blame that enables women to retain a sense of agency and a form of self-blame that is excessive and potentially leading to feelings of guilt and shame (Duncan & Cacciatore, 2015).

8.4.2.6 Legal frameworks and policies

The research indicates that although TFA is an individual life event, women's experiences are strongly rooted in their legal-political-social environment. The abortion paradigm fails to capture the experience in a holistic way, and it both reflects and perpetuates inappropriate policies and care. The research highlights a need for policies that create a context within which women are unconstrained by legal restrictions and social norms in their decision making, and for these policies to translate into clinical care. The meta-ethnography (chapter 2) has indicated that, in some countries, the practice of TFA is constrained by laws and policies. This is the case in Brazil where, at the time the study included in the meta-ethnography was conducted (Ferreira da Costa et al., 2005), women whose fetal abnormality was incompatible with life had to request authorisation to terminate their pregnancy. Although this policy has since been relaxed to legalise termination in cases of anencephaly (Mirlesse & Ville, 2013), the law does not yet extend to other lethal congenital anomalies or anomalies carrying a severe risk of impairment. The Israeli study (Leichtentritt, 2011) also illustrates the importance of removing obstacles to accessing a procedure most women already find difficult to contemplate. Although the study indicates that most requests were granted, there were also cases where women had to request the authorisation from several medical ethics committee before being granted approval for termination. Finally, the studies conducted in the USA outlined the polarisation of the debate surrounding pregnancy termination for fetal abnormality and more general abortion which lead to stigmatisation (Bryar, 1997; McCoyd, 2007; Rillstone & Hutchinson, 2001). Although these observations are specific to the countries from which the reviewed studies originated, the implications are relevant globally.

The abortion law in England imposes fewer restrictions than in the countries mentioned above, and clinical guidelines advocate for a person-centred, supportive care (RCOG, 2010; NICE, 2007, 2014). However, there are still areas where, in practice, women's preferences may not be accommodated, for example, regarding the choice of termination method (Fisher et al., 2015). Despite surgical and medical terminations carrying similarly low complication rates (Bryant et al., 2011; Lyus et al., 2013) and neither method being linked to poorer psychological outcome (Burgoine et al., 2005), women favouring a surgical termination following a diagnosis of severe fetal abnormality are generally not accommodated when their gestation exceeds 15 weeks (Fisher et al., 2015; Lyus et al., 2013). There are also on-going debates in the UK about abortion legislation (see chapter 1, section 1.1.4.3); for example the various amendments to the abortion law proposed to the House of Parliament, and the parliamentary inquiry (2013) into the relationship and compatibility between the Abortion Act (1967) and the Equality Act (2010). These indicate that the context within which TFA is taking place is dynamic. It is important that this context remains focused on putting women's needs first.

8.5 Limitations of the research

The limitations of each study have been discussed in detail in the relevant chapters. This section provides a summary of the main limitations of the research as a whole and their implications. The research programme had five main limitations, comprising: the use of ARC as a sample pool, demographic biases, possible recall bias and *post hoc* rationalisation, social desirability bias and the researcher's own preconceptions relating to TFA.

The use of ARC as sample pool

Most of the empirical work was conducted using a support group organisation, ARC, as a sampling pool. The limitations relating to using this sampling strategy have been discussed in chapter 3 (section 3.2.1.2.2), chapter 4 (section 4.4.7), chapter 5 (section 5.4.5) and

chapter 7 (section 7.4.4). It is possible that membership of this support group may have led to some coping strategies being over-represented (e.g. emotional and instrumental support) in this group as women may regard membership of ARC as a coping strategy in itself. It is also possible that women who use ARC would differ significantly in terms of their level of grief and posttraumatic growth from women who do not use this organisation. Furthermore, although research suggests some psychological benefits in using online support groups, concerns have also been voiced about its propensity to lead to rumination (Barack et al., 2008; Eysenbach et al., 2004; Malik & Coulson, 2010). Therefore, it remains to be ascertained whether women in this research displayed levels of grief and posttraumatic growth typical or atypical of the wider population of women who have undergone TFA. However, given that ARC represents between 20 and 25% of women who have undergone TFA in the UK, their patterns of grief may represent normative responses. Even if they were not, the fact that these women represent a sizeable proportion of women undergoing TFA in the UK, emphasises the high relevance of these research findings.

Demographic bias

In this research, there was a bias towards White British women educated at university level. Although this may be representative of ARC membership, it may not represent the entire population of women who undergo TFA. Given that there is no demographic profile of women who undergo TFA, it is not possible to ascertain the extent of this bias (see chapter 3, section 3.2.1). A bias towards White, well-educated participants has also been observed in other studies about TFA (Korenromp et al., 2009; McCoyd, 2007; Statham et al., 2001), and was also reflected in the meta-ethnography. Most of the reviewed studies originated from high-income countries, in which participants were predominantly White, middle class, and well educated. In the USA, given that TFA is not covered by universal healthcare, this bias may be a valid reflection of the population undergoing TFA. Still, it may be argued that evidence on TFA is biased towards one particular group of women.

Recall and post hoc rationalisation

All the empirical studies in this research were retrospective. Thus, recall bias and *post hoc* rationalisation cannot be discounted. It is possible that women's accounts of the coping strategies used reflect the way they are currently coping with TFA. It is also possible that women may have rationalised their answers, particularly in light of the decision to terminate their pregnancy. Following TFA, women may experience a certain degree of cognitive dissonance (Festinger et al., 1956) and may be torn between their feelings and emotions and the decision to terminate a pregnancy, which, in most cases, is wanted. Therefore, women may construct for themselves a narrative that they find more acceptable and may respond in a way that is congruent with their narratives. Although the risk of bias is real, these types of biases are inherent to retrospective research designs. This risk had to be balanced with the demands of conducting a prospective or longitudinal study with their own methodological limitations. Given the sensitivity of TFA as a research topic, a retrospective approach was deemed the most practical.

Social desirability bias

In this research, women may have felt pressurised to experience and express their grief, and growth in a way that matches society's idea of motherhood (McCoyd, 2009b). As societies convey messages about loving a child from conception, women may feel inadequate if they are not overwhelmed by grief. The concept of disenfranchised grief is helpful in that it refers to the impossibility of expressing and thus legitimising the loss, and to the impossibility of expressing the incumbent drive to restore equilibrium and grow (Attig, 2004). Similarly, given the widespread appeal of Positive Psychology in the last 15 years (Seligman, 2011), some women may have felt pressurised to identify positive outcomes from their experience (Aspinwall & Tedeschi, 2010). Framing the experience of TFA in a pre-defined way may result in neither women's grief nor their healing process being socially sanctioned in a way that is helpful to them.

Researcher's own preconceptions

In line with the qualitative research's reflexive tradition, the role of the researcher in shaping and conducting the research also needs to be acknowledged. As a supporter of women's reproductive choices, a volunteer for ARC and a member of Public Health's Complex Obstetrics Clinical Reference Group, it is likely that the researcher's previous knowledge, beliefs and experience influenced the way the research was conducted and the data analysed and interpreted. To minimise the risk of bias, several steps were taken including: cross-validation of the data analysis of the qualitative evidence by the researcher's second supervisor; opportunity given to participants to comment on the research findings through the provision of a results summary at the end of each of the study; and presentation of the results at professional conferences to gain feedback from peers.

Finally, the study conducted with health professionals (Study 3) also has the potential for biases. Health professionals were also self-selected and they only represented three out of many clinical settings. In addition, these professionals were also observed by the researcher, sometimes on multiple occasions, as part of the international research programme. Therefore, the risk of *post hoc* rationalisation and social desirability bias also applies to them. Nevertheless, the richness of the data collected coupled with the openness with which these professionals answered potentially sensitive questions (e.g. whether they had any personal experience of abnormality and/or disability) seem to discount it.

Whilst it is important to remain cognisant of the research's limitations, these are unlikely to have had a significant impact upon the research outcomes. Whether women post rationalise or feel pressurised to communicate their experience in a particular way and/or whether they only represent a specific group (in terms of demographics and membership to ARC) does not alter the fact that a significant proportion of women experience high levels of grief following TFA and that those are still manifest some years later. These potential limitations would also not alter the fact that the coping strategies used by women relate to

their psychological adjustment in terms of perinatal grief and posttraumatic growth. Moreover, the research findings on the psychological adjustment to TFA support existing evidence and, therefore, add credence to the methodological approach used to conduct the studies. Importantly, despite these limitations, the research presented in this thesis clearly adds to the body of knowledge about TFA (see section 8.3). In addition to the contribution to knowledge, the qualitative investigation of women's coping strategies provided women with a chance to share their experiences. Many women commented that they welcomed this opportunity and that participating in the study had a therapeutic effect. The research presented in this thesis was purposively exploratory and thus, in addition to extending knowledge, it provides directions for further research.

8.6 Future research directions

Several directions for future research have been identified. These include conducting research among women who are not part of ARC and women who decide to continue with their pregnancy. A longitudinal assessment of women's use of coping strategies, their levels of grief and posttraumatic growth would also provide valuable insights. Finally, further research into posttraumatic growth in the context of TFA would be needed as this area of research is in its infancy.

Comparison groups

Given that the sample in this research exclusively comprised women recruited from ARC, further research should concentrate on examining the coping strategies of women who are not part of a support group, and compare them with the present findings and those of other researchers. It would also be beneficial to assess how different coping with TFA may be in comparison to continuing the pregnancy following a diagnosis of severe fetal abnormality in relation to women's psychological adjustment. The limited research available on women who

choose to continue a pregnancy after a diagnosis of fetal abnormality shows that they experience a range of negative emotions. A study by Jones et al. (2005) indicates that this experience is characterised by ambivalence (towards the pregnancy, the baby and the status of mother), uncertainty about the outcome (whether the baby will live or not and how serious the impairment may be) and loss (of the healthy baby and of the women's identity as some women see themselves as becoming an "incubator" for the baby). Research also indicates that women may experience high levels of anxiety and depression during the pregnancy (Horsch, Brooks, & Fletcher, 2013), and the remainder of the pregnancy may be akin to a grieving process (Lalor et al., 2009). Nevertheless, a recent study by Cope, Garrett, Gregory and Ashley-Koch (2015) looking at adaptation following a diagnosis of the lethal anomaly anencephaly, indicated that parents who chose to continue with the pregnancy adapt better psychologically than those who chose to terminate, and that engaging in organisational religious activities (such as attending church) related to lower levels of grief. This is in opposition to the present research findings that indicate that the use of religion as a coping strategy predicted higher level of grief. Further research would be beneficial to ascertain whether women who continue their pregnancy have better psychological outcomes than women who terminate or not, and whether coping strategies would account for these differences.

Longitudinal assessment of women's coping strategies, perinatal grief and posttraumatic growth

This research was largely based on a cross-sectional design, but a sizeable group of participants ($n = 62$) was surveyed twice thus enabling a longitudinal assessment. The data analysis provided some preliminary insights into the way women's use of coping strategies and levels of perinatal grief may vary over time (e.g. higher levels of 'acceptance' and 'positive reframing' and lower levels of grief over time). Further research on a larger scale and incorporating measures of posttraumatic growth would be needed to determine exactly how the use of coping strategies evolves over time, and the direction of the relationship

between coping strategies, perinatal grief and posttraumatic growth. A longitudinal study would also determine how levels of posttraumatic growth vary over time. This would, in part, contribute to addressing the issue of whether posttraumatic growth is an outcome or a coping strategy.

Posttraumatic growth and the role of rumination

The study into posttraumatic growth (Study 4) is believed to be the first to examine this construct in the context of TFA in a quantitative way. Although it has generated interesting insights, it also calls for further research in this area. The moderate levels of posttraumatic growth recorded in this research warrant a qualitative exploration of the reasons behind these ratings. It would also be useful, in terms of theory development, to explore what posttraumatic growth means for this group of women, and how they conceptualise growth in the context of their choosing to end the pregnancy.

Finally, the research has shown that coping strategies had a moderate predictive value on posttraumatic growth. This suggests that other variables, not measured in this study, also account for this phenomenon. Other variables such as social support, other traumatic events or types of rumination may impact upon women's experience of posttraumatic growth following TFA (Tedeschi & Calhoun, 2004). The role of rumination, in particular, has recently received attention. As mentioned in chapter 1 (section 1.3.3.2), it is thought that rumination, or repetitive thoughts, is the cognitive process whereby a new vision of the world is created and transformation can occur (Allbaugh, 2013; Tedeschi & Calhoun, 2004). Rumination can be linked to personality predisposition (trait-related rumination) or a particular event (event-related rumination), with the latter more closely associated with posttraumatic growth (Calhoun & Tedeschi, 2006). Event-related rumination is itself split into two categories: intrusive rumination and deliberate rumination, with deliberate rumination more conducive to growth (Calhoun et al., 2000; Calhoun & Tedeschi, 2006; Cann et al., 2011; Taku et al., 2008; Treynor, et al., 2003). Deliberate rumination is considered as a key mechanism in processing a traumatic event, which may lead to resolution and deriving

meaning, with meaning relating to greater positive change (Linley & Joseph, 2011). Recent studies on posttraumatic growth have examined the role of rumination on the experience of growth (Allbaugh, Wright, & Folger, 2015; Soo & Sherman, 2015). It would be beneficial to investigate this relationship in the context of TFA.

8.7 Beyond the PhD: Development of an online intervention to support women following TFA

This research has shown that following TFA, many women display high levels of perinatal grief, with a high proportion exhibiting pathological levels of grief. The research also points to a deficit in aftercare. Studies into women's experience of TFA also indicate that many women feel unsupported and isolated in their grief (see meta-ethnography; Asplin et al., 2014; Fisher & Lafarge, 2015; Koponen et al., 2013). Therefore, providing women with the tools to enable them to cope with the termination may promote better, longer-term psychological adjustment. There is currently little research on what women may need and the best way to provide it in the context of TFA. The study by Ramdaney et al. (2015) investigating women's support needs following TFA, suggests that women do not anticipate their needs beyond the termination, but for those who do, the guarantee of anonymity may encourage them to seek support. The research with the health professionals presented in this thesis also indicates that women may prefer to receive support from professionals who are not associated with their termination care. Based on these considerations, an online intervention may be a suitable tool to support women. It may enhance women's psychological adaptation to TFA and may translate into lower use of other health services in the long-term.

8.7.1 Effectiveness of interventions following bereavement and perinatal loss

A scoping review of the literature suggests that there exist many different interventions aimed at promoting psychological adjustment following bereavement. However, despite the

range and extensive use of these interventions, their effectiveness in maintaining or improving mental health is not formally established (Forte, Hill, Pazder, & Feudtner, 2004). Stroebe et al. (2007) reviewed the effectiveness of psychological and psycho-education interventions following bereavement and concluded that interventions that target individuals who are struggling with their grief (secondary or tertiary interventions) are more effective than routine or preventative interventions (primary interventions). This view was corroborated by Currier, Niemeyer and Berman's meta-analysis (2008) into the effectiveness of psychotherapeutic interventions with bereaved individuals. This meta-analysis based on 61 studies underlined the importance of targeting individuals who exhibit symptoms of complicated grief for such interventions.

In the context of perinatal loss, a Cochrane review into the effectiveness of interventions with parents concluded that no suitable study could be included in the review (Koopmans et al., 2013). However, by limiting their inclusion criteria to randomised controlled trials, the authors acknowledged that they had excluded studies which point to the utility and benefits of these interventions on families in the context of perinatal loss. Indeed, several interventions following perinatal loss have yielded positive results. Bennett et al. (2012) examined the effectiveness of an eight-week CBT intervention for perinatal grief following spontaneous abortion, perinatal loss, or infant death. The intervention consisted of psycho-education, emotion regulation (e.g. pleasant events scheduling, cognitive reappraisal), social support enhancement and exposure (revisiting the loss). The results indicate that participants experienced a decrease in symptomatology post treatment (depression and anxiety) and that the cognitive reappraisal and exposure components of the intervention had the most positive impact.

Similarly, an intervention aimed at women who have miscarried also indicates that preventative intervention may be helpful (Sejourné et al., 2010). The intervention consisted of a single session encompassing three elements: empathetic listening and expression (for establishing a therapeutic alliance), psycho-education (covering context and incidence of miscarriage, normal reactions to miscarriage and consequences) and CBT techniques of

cognitive restructuring (e.g. to address guilt) and problem resolution (e.g. disclosure, dealing with insensitive comments). At two weeks follow-up, women who had received the intervention displayed lower levels of anxiety, depression and posttraumatic stress compared to women in the waiting list condition. However, these differences were no longer significant at ten weeks or six months post intervention, and levels of distress were low in both groups. Nonetheless, this study indicates that a preventative intervention may have a protective effect on women.

In the context of TFA, evidence of the effectiveness of psychological interventions is limited. There is little data on prospective interventions and their potential benefits to women (Langer & Ringler, 1989). Similarly there is little information on post-TFA interventions, and most are dated. Several studies have focused on the usefulness of support groups (Suslack et al., 1995), others on counselling (Elder & Laurence, 1991; Lilford, Stratton, Godsil, & Prasad, 1994; Lorenzen & Holzgreve, 1995). However, evidence of their effectiveness is inconclusive (Elder & Laurence, 1991; Lilford et al., 1994; Statham et al., 2001).

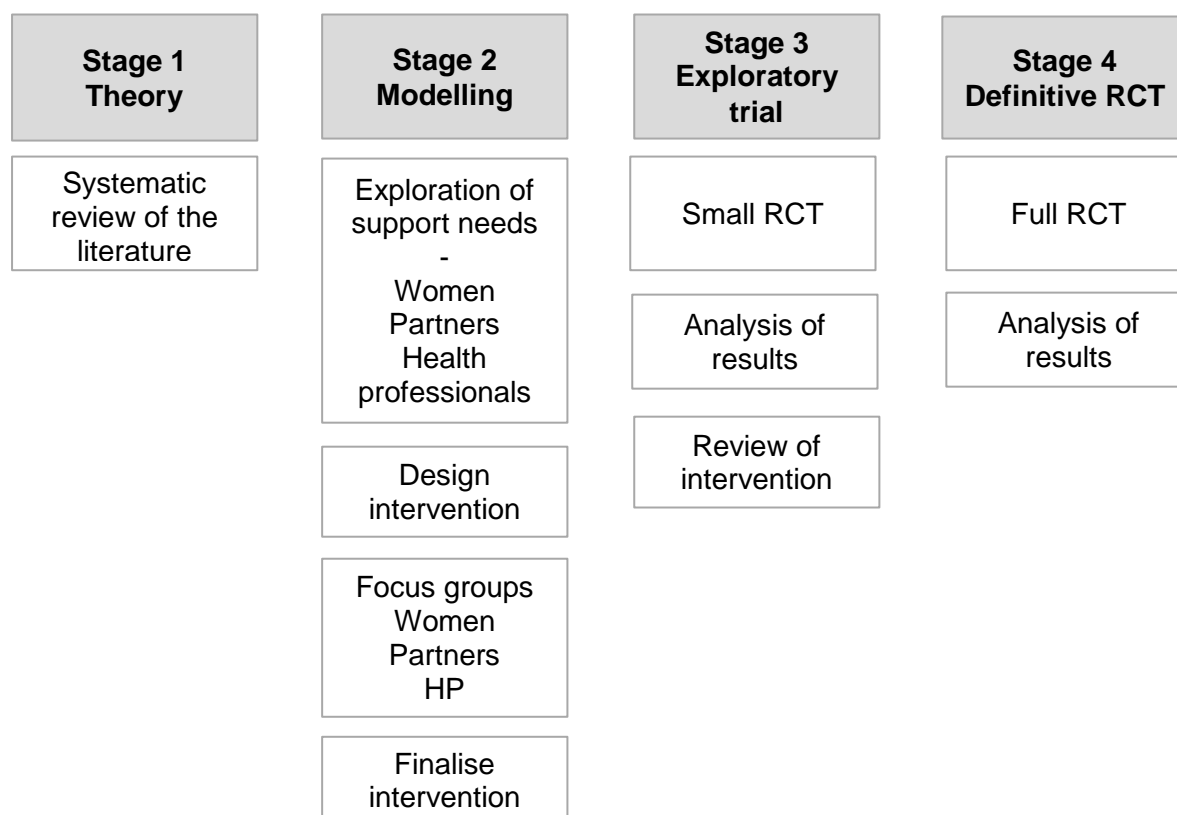
More recently, a study conducted by Kersting et al. (2013) to test the effectiveness of a low-threshold (low demand on the user and frequency of contact) web-based intervention has shown promising results in terms of alleviating distress among women. This intervention was aimed at parents who had experienced perinatal loss, and included participants who had undergone TFA. The intervention was based on a protocol which had been used in previous interventions in the context of bereavement (Wagner et al., 2006) and posttraumatic stress disorder (Lange, van de Ven, Schrieken, & Emmelkamp, 2001). The five-week intervention was based on cognitive behavioural techniques including self-confrontation, cognitive restructuring and social sharing. It involved two weekly 45-minute writing assignments, to which a therapist trained in cognitive behavioural techniques replied. The results indicate that parents in the treatment group exhibited fewer symptoms of posttraumatic stress, grief, depression, and anxiety following the intervention than parents in the waiting list group, and that these levels were maintained over time (at 3-months and 12-months post treatment).

In summary, evidence of the effectiveness of interventions aimed at women who have undergone TFA is limited and dated. Although, the most recent intervention (Kersting et al., 2013) shows encouraging results, an analysis of the data by type of perinatal loss was not provided. Furthermore, the intervention sample mainly comprised participants who had experienced other types of perinatal loss, with only 30 out of 228 participants having experienced TFA. Therefore, an intervention specifically targeting women who have undergone TFA would be needed to ascertain whether it would reduce women's levels of distress. The next section focuses on the development and evaluation of an intervention to support women post-TFA.

8.7.2 Development and evaluation of the effectiveness of an intervention to support women following TFA

A psychological intervention is needed to support women following TFA. Specifically, this intervention will need to provide tools to enable women to cope with the termination in the long-term, and provide psychological support to women at risk of poor psychological adjustment. The intervention will be aimed at any woman who has undergone TFA. Therefore, women will need to be recruited from several sources, including NHS fetal medicine units and obstetrics and gynaecology departments providing fetal medicine services, and support organisations (including ARC). It is proposed that four research stages will be required to design and evaluate the intervention before it can be implemented (see Figure 8.1).

Figure 8.1. Research stages for developing and evaluating an online intervention to support women following TFA (adapted from Campbell et al., 2000)



The first stage of research will involve conducting a systematic review of the effectiveness of psychological interventions aimed at women undergoing TFA and/or following perinatal loss. The second stage of research will consist of undertaking qualitative research to explore women's needs in terms of support, and test the intervention concept with key stakeholders. After refinement of the intervention, a pilot study (stage three) will be conducted through a small scale randomised control trial to test the intervention. The last research stage will involve a large scale randomised controlled trial. Baseline measures will be collected prior to the intervention (T0). The effectiveness of the intervention will be measured at T1 (post intervention), T2 (three months) and T3 (a year after the termination). If the intervention is deemed effective, it can then be implemented. Guidance for developing and evaluating interventions such as the guidelines issued by the Medical Research Council

(Campbell et al., 2000; Craig et al., 2008) will be used to inform the design, implementation and evaluation of the intervention. The research stages are discussed in the next sections in more detail.

8.7.2.1 Intervention design

The first two stages of the research process (systematic review and qualitative work) will be essential to inform the design of the intervention. A scoping review of the interventions conducted in the context of bereavement and perinatal loss (see section 8.7.1) indicates that some types of interventions (e.g. CBT-based) may be beneficial for women who have undergone TFA. Nonetheless, a systematic review will be required to ensure that all evidence available is used to inform the development of this intervention. Given the dearth of research in the area of TFA, it is anticipated that the systematic review will focus on psychological interventions following perinatal loss, rather than TFA alone. The second research phase will focus on the exploration of women's support needs in the context of TFA. It is proposed that this information will be gathered through face-to-face semi-structured interviews with women who have undergone TFA, their partners and the health professionals responsible for their care. The information from both the systematic review and qualitative research will be used to design the intervention, whose initial concept will be evaluated through a series of focus groups with women, their partners and health professionals.

Although the research stages described above will be essential to design the intervention, in the absence of this information, we can turn to the present research's findings and the wider literature to start formulating the intervention's blueprint. Collectively, the research presented in this thesis and the wider literature on bereavement interventions indicate that an online intervention providing psycho-education and psychological support based on CBT techniques may be beneficial to women. It is this proposition which is explored in the next sections.

8.7.2.1.1 Psycho-education component

The present research has shown that women are unprepared for the magnitude of the loss and the emotional roller-coaster that follows. Women also report feeling isolated, experiencing interpersonal difficulties, and feeling ambivalent about their decision and what to disclose to others (chapter 2). These findings suggest that women would benefit from a psycho-educational intervention, with information about the termination itself, the decisions that have to be made following the termination, and the potential impact upon their relationship. Women would also benefit from information about the nature of the recovery process following TFA, the various coping trajectories (including the potential experience of positive outcomes), various coping strategies that may be useful and ways to implement these (e.g. remembering the baby, token acts), potential gender differences in grieving as well as the psychological impact of the termination on the family (e.g. other children, grandparents). Although some of this information is currently available from ARC (ARC, n.d.), it is important that it is accessible to all women who undergo TFA. The present research also indicates that promoting 'acceptance' and helping women 'reframe' their experience may be beneficial to alleviate distress and facilitate growth. It also points to the importance of addressing issues of self-blame, as self-blame was related to higher levels of grief. It is likely that women would also benefit from information on these elements. Thus, the psycho-educational component of the intervention may need to be both loss- and restoration-orientated.

8.7.2.1.2 CBT-based psychological support

The research has also demonstrated that a large group of women experience high levels of distress. In line with the literature on bereavement interventions, the provision of additional psychological support for a targeted group of women at risk of poor psychological adjustment would be helpful. Given the importance of 'acceptance' and 'positive reframing' on women's psychological adaptation in this study, an intervention based on CBT techniques would be appropriate. The intervention conducted by Kersting et al. (2013), itself based on

previous interventions (Lange et al., 2001; Wagner et al., 2006) provides a valid framework for this intervention. Kersting and colleagues (2013) designed a five-week intervention comprising two-weekly writing assignments. These assignments covered three elements: a) self-confrontation, which consisted of encouraging participants to write about the circumstances of the loss; b) cognitive reappraisal, in which participants were asked to write a letter to help a hypothetical friend reflect on and reframe their experience as well as gain new perspectives on it; c) social sharing, which involved participants reflecting on difficult memories, working through those memories and defining potential coping strategies that may be useful going forward. These exercises cover several CBT techniques such as emotion regulation, cognitive restructuring, problem solving and exposure, which have been shown to be helpful in other interventions following perinatal loss (see Bennett et al., 2012; Sejourne et al., 2010). Similarly to the psycho-education component, the CBT-based psychological support may also need to be orientated towards loss (e.g. self-confrontation) and restoration activities (e.g. cognitive reappraisal, and social sharing).

8.7.2.1.3 Online medium

Based on the evidence discussed in section 8.7.1, an online medium may be suitable for such intervention, as it offers several benefits. It may encourage women to access the resource anonymously, without time constraints or geographical restrictions and, for women receiving the CBT-based support, the asynchronous nature of the exchanges between women and the counsellor may encourage higher levels of reflexivity. It is possible that the psycho-educational resource would also benefit health professionals. A recent evaluation of helplines designed to provide support to individuals with mental health issues (Morgan, Chakkalackal, & Cyhlarova, 2012) has shown that health professionals also access these resources for their own information needs. The evaluation further indicates that health professionals view this type of support positively and regard it as a complement to the care they provide. Therefore, an online intervention providing psycho-education and a CBT-based psychological support may constitute a valid resource, which can be used by women on its

own or alongside other forms of support. It may also constitute a cost-effective source of support and reduce the use of other health support services in the long-term, although more research is needed into the cost effectiveness of internet interventions (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006; Lintvedt, Griffiths, Eisemann, & Waterloo, 2013; Tate, Finkelstein, Khavjou, & Gustafson, 2009). The next section outlines a research proposal for evaluating the effectiveness of an online intervention consisting of psycho-education and CBT-based psychological support.

8.7.2.2 Evaluating the effectiveness of an online intervention to support women following TFA

The aim of this intervention will be to promote healthy psychological adjustment to TFA and reduce women's levels of distress. The intervention will have two components: psycho-education and CBT-based support for women at risk of poor psychological adjustment. Each component will be assessed when used independently and together (i.e. psycho-education only, CBT-based support only, or psycho-education and CBT based support), using a randomised control trial. Prior to the full evaluative study being carried out, a small scale trial will be run to pilot the intervention (see Figure 8.1 stage three). Women will be allocated to one of six conditions: psycho-education only versus control, CBT-based support versus control and full intervention (psycho-education and CBT-based support) versus control. For ethical reasons, participants in the control groups will be placed on the waiting list condition (or delayed intervention). The final stage of the research will consist of running a full scale randomised control trial to evaluate the effectiveness of the different components of the intervention.

Similarly to the qualitative research stage (stage two), women will be recruited from NHS fetal medicine units or obstetrics and gynaecology departments providing fetal medicine services and support organisations such as ARC. After a brief explanation about the study, women will be directed to the study website, where they will be provided with detailed information about the study, its aims, what it entails and participants' rights. Power

calculations will be conducted to ensure that a sufficient number of participants are recruited from each sampling source, to account for attrition and enable statistical comparisons between groups.

After gaining consent, women will undergo screening procedures similar to those used by Kersting et al. (2013). Inclusion criteria will include: being over 18 years old, having undergone TFA, being fluent in English and having internet access. Exclusion criteria will comprise substance abuse or dependency, being currently pregnant, already receiving treatment for mental health issues or complicated grief, and exhibiting very high levels of distress. Women will be asked to complete a series of psychological measures to determine their levels of distress. Scores on these measures will be used to both allocate women to the type of intervention they would most benefit from (psycho-education only or CBT-based psychological support), and screen out those exhibiting very high levels of distress. In line with the intervention by Kersting et al. (2013), women displaying very high levels of distress will be followed-up by phone to check the severity of their symptoms and assist them in seeking appropriate help.

Several psychological measures may be appropriate for screening purposes and to be used as outcome measures (T0). These include measures of complicated grief (e.g. Short PGS [Potvin et al., 1989], the Inventory of Complicated Grief [Prigerson et al., 1995]), anxiety and depression (e.g. HADS [Zigmond & Snaith 1983], Brief Symptoms Inventory [Derogatis, 1993]), and/or PTSD (e.g. Impact of Events scale [Horowitz, Wilner, & Alvarez, 1979]). Women below the cut off points indicating symptomatology will be directed to the psycho-education intervention only. Women scoring above the cut off points will be randomly allocated to the CBT-based component only or the full intervention (psycho-education and CBT-based support). In addition to psychological measures of distress, information relating to the terminated pregnancy and women's obstetric history will be collected alongside demographics. A measure of perceived social support will also be included.

Women in each of the three groups (psycho-education only, CBT-based support only or full intervention) will be randomly allocated to the treatment or waiting list/delayed

condition. Intervention for control participants will be delayed by two weeks in the psycho-education only group, five weeks in the CBT-based only group, and seven weeks in the full intervention group. Effectiveness of the intervention will be measured at three time points: post treatment (T1), at three months (T2) and after one year (T3) and compared with baseline measures (T0). Data will be analysed to assess the effectiveness of the three interventions post treatment (i.e. immediate vs. delayed intervention at T1), and over time (T2 and T3).

8.7.2.3 Limitations of the intervention

There are several limitations to such an intervention. The most obvious one relates to the fact that it will exclude women who choose not to engage in online activities. It is hoped that given that the target audience comprises women of childbearing age, women will be familiar with using the internet and will not object to an intervention being delivered in this way. Another possible limitation lies in the risk of demographic bias as online interventions have been shown to be biased towards well-educated participants (Kersting et al., 2013; Stroebe et al., 2008; Wagner et al., 2006). It is hoped that recruiting women from different sources may mitigate that risk. The reliance on written assignments in the CBT-based component may also discourage participation as some women may not feel comfortable or proficient using this method of interaction. Finally, another limitation of this type of intervention is that they rely exclusively upon online self-report questionnaires to measure the outcomes (Wagner et al., 2006). Wagner et al. (2006) argued that interviews and/or independent assessments could add validity to the results by providing a more balanced evaluation of the severity of the symptoms. This has to be balanced with the advantages of using an online approach. Furthermore, it may be argued that women's perceptions of their own suffering is perhaps more relevant to their psychological adjustment than independent assessments of their psychological wellbeing. A thorough research process, informed by acknowledged research guidelines such as those from the Medical Research Council (Craig et al., 2008), will ensure that the risks of bias and other limitations inherent to an online intervention are

minimised. In addition, considerations will be given to the sustainability of the intervention, should it be successful. In particular, an evaluation of which aspect of the intervention was particularly effective, how this aspect could be rolled out and whether it would be cost-effective, will be carried out.

8.8 Conclusions

The research presented in this thesis furthers our understanding of women's experience of coping with TFA. The research provides further evidence of the impact of TFA on women's psychological wellbeing, by highlighting the distress experienced by women post termination, which is manifest through the high levels of perinatal grief recorded in the studies. The research also makes important and novel contributions to knowledge. It provides new insights into the holistic experience of TFA and indicates that women regard TFA as a traumatic event and a unique form of bereavement. The research also shows that TFA is a social as much as an individual experience and that the politico-socio-legal context both reflects and shapes the environment within which women experience TFA. The research also demonstrates the relationship between women's use of coping strategies and their psychological adjustment, and highlights the relevance of positive psychological outcomes such as posttraumatic growth in the context of TFA. It also indicates that health professionals have a valid understanding of women's experience of coping with TFA, but limited insights into women's long-term coping processes.

The dissemination of this body of research has already contributed to informing health professionals and the wider professional community about women's experience of coping with TFA. Three papers have been published in peer reviewed journals (Prenatal Diagnosis [2013]; Qualitative Health Research [2013]; and Reproductive Health Matters [2014]). In addition, the research findings have been presented to various academic and professional audiences (British Psychological Society [2012, 2013]; British Maternal and Fetal Medicine Society [2015]; International Health Conference [2015]; Reproductive and

Infant Psychology Society [2013]; University of West London Midwifery Seminars [2013, 2014]).

An important corollary of this research programme is to further inform practice and policy making. Firstly, the knowledge gained from the research needs to translate into healthcare practice through the implementation of woman-centred, integrated care pathways. Importantly, it calls for the development and implementation of a psychological intervention to support women post-TFA. The need for such intervention is underpinned by the deficiency in aftercare and the high levels of distress, which were evidenced in the research. A psychological intervention such as the one described in this chapter (section 8.7) would, in part, address the deficit in aftercare and promote women's psychological adjustment. In doing so, it would also benefit women's families and potentially reduce women's use of other health services in the long-term. Providing support to women post termination is particularly important because the number of TFAs is likely to rise further with the development of new technologies in prenatal screening and diagnosis that enable earlier detection of fetal abnormalities, and the increase in women's childbearing age in the UK (see chapter 1). This is particularly relevant in light of new evidence indicating the likely implementation of the non-invasive prenatal testing (NIPT) within the NHS screening programme for Down's syndrome (Great Ormond Street Hospital, 2015; BBC, 2015).

Secondly, the research presented in this thesis needs to translate into policy making. In 2013, NHS England restructured the way it develops and commissions its services, and created Clinical Reference Groups (CRGs) tasked with providing clinical advice for developing specialised services such as fetal medicine (NHS England, 2013a). The CRG for Complex Obstetrics (the result of the merger in April 2015 between two CRGs: Fetal Medicine and Specialised Maternity Services) defines its ambition for fetal medicine as "providing patient focused high quality evidence-based care to women with complex pregnancies or whose fetus (or fetuses) has a confirmed or suspected disorder" (NHS England, 2013b, p.2). One of the overarching aims of the research is to contribute to

informing policies and service delivery, such as those specified by CRGs in England. In doing so, it will optimise the care women receive when undergoing TFA and afterwards.

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Appendix I: Critical Appraisal Skills Programme Checklist

Screening questions

1) Was there a clear statement of the aims of the research?

Consider: What was the goal of the research? Why it was thought important? Its relevance

2) Is a qualitative methodology appropriate?

Consider: Does the research seek to interpret or illuminate experiences? Is qualitative research the right methodology for addressing the research goal?

Detailed questions

3) Was the research design appropriate to address the aims of the research?

Consider: Has the researcher justified the research design (e.g. have they discussed how they decided which method to use)?

4) Was the recruitment strategy appropriate to the aims of the research?

Consider: Has the researcher explained how the participants were selected? Has the researcher explained why the participants selected were the most appropriate to provide access to the type of knowledge sought by the study? Are there any discussions around recruitment (e.g. why some people chose not to take part)?

5) Were the data collected in a way that addressed the research issue?

Consider: Was the setting for data collection justified? Is it clear how data were collected (e.g. focus group, semi-structured interview etc.)? Has the researcher justified the methods chosen? Has the researcher made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or whether they used a topic guide)? If the methods were modified during the study, has the researcher explained how and why? Is the form of data clear (e.g. tape recordings, video material, notes etc.)? Has the researcher discussed saturation of data?

6) Has the relationship between researcher and participants been adequately considered?

Consider: Has the researcher critically examined their own role, potential bias and influence during (a) the formulation of the research questions and (b) the data collection, including sample recruitment and choice of location? How has the researcher responded to events during the study (if applicable) and has the researcher considered the implications of any changes in the research design?

7) Have ethical issues been taken into account?

Consider: Are there sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained? Has the researcher discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how the researcher has handled the effects of the study on the participants during and after the study)? Has approval been sought from the ethics committee?

8) Was the data analysis sufficiently rigorous?

Consider: Is there an in-depth description of the analysis process? Is it clear how the categories/themes were derived from the data? Has the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process? Are sufficient data presented to support the findings? To what extent contradictory data are taken into account? Has the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?

9) Is there a clear statement of findings?

Consider: Are the findings explicit? Is there an adequate discussion of the evidence both for and against the researcher's arguments? Has the researcher discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)? Are the findings discussed in relation to the original research question?

10) How valuable is the research?

Consider: Has the researcher discussed what the contribution the study makes to existing knowledge or understanding e.g. does the researcher consider the findings in relation to current practice or policy? Or in relation to relevant research-based literature? Does the researcher identify new areas where research is necessary? Has the researcher discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used?

Appendix II: Questionnaire - Study 2b (chapter 5)

Thank you very much for taking the time to answer this survey. We hope that this information will be used to improve the care offered to women who face a termination for fetal abnormality in the future.

First of all, I would like to ask you a few questions about the termination itself before we go on to exploring your experience in more detail. These questions may seem 'clinical', they are, however, necessary to put the findings into context.

In the event that you have had more than one termination for fetal abnormality, please answer on the basis of the most recent one.

Q. When did the termination take place?

In the last 6 months (October 2010-March 2011)

September 2010

August 2010

July 2010

June 2010

May 2010

April 2010

March 2010

February 2010

January 2010

December 2009

November 2009

October 2009

September 2009

August 2009

July 2009

June 2009

May 2009

April 2009

March 2009

Before March 2009 – Specify month and year

Q. At how many weeks gestation did you end your pregnancy?

Q. How was the abnormality detected?

By chance – part of a routine scan (12 weeks or 20-22 weeks anomaly scan) or routine care

Through directed search – specific scan or tests undertaken due to pre-existing medical conditions, genetic family history or previous pregnancy history

Q. What diagnosis were you given? Please describe briefly below

Q. Was this abnormality ...

- Lethal, i.e. incompatible with life
- Serious but compatible with life
- Other – specify
- Don't know
- Prefer not to answer

Q. How was the pregnancy terminated?

- Medical termination (pill)
- Surgical termination (dilatation and evacuation)
- Induced labour
- Other – specify
- Prefer not to answer

Q. Was this your first termination for fetal abnormality?

- Yes
- No, the second one
- No, the third one
- No – specify

Q. Was this your first pregnancy?

- Yes
- No, the second one
- No, the third one
- No, the fourth one or more

Q. How many living children did you have at the time of the termination?

Q. What best describes how you feel about your decision to end the pregnancy?

- I would make the same decision again
- I would not make the same decision
- Don't know
- Prefer not to answer

Q. What best describes your situation with regards to having another child? *Tick all that apply*

- I have had another child since the termination
- I am expecting another child
- I suffered another loss
- I am not pregnant but I would like another child
- I have decided not to have another child
- Other - specify

Q. The next section deals with the way you have coped with the termination and focuses on what happened after the procedure. It is similar to the questions you answered before but covers the subject from a different angle. It lists some ways of coping with stressful life events that people have reported using. As people deal with life events in different ways, some items will apply to you and some won't. I would like to know to what extent you've been doing what the item says; how much or how frequently.

Please don't answer on the basis of whether it seemed/seems to be working or not, just whether or not you were/are still doing what the item says. Please try to rate each item separately from the other and make your answers as true FOR YOU as you can. (Statements randomised)

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

- 1. I've been turning to work or other activities to take my mind off things.
- 2. I've been concentrating my efforts on doing something about the situation I'm in.
- 3. I've been saying to myself "this isn't real".
- 4. I've been using alcohol or other drugs to make myself feel better.
- 5. I've been getting emotional support from others.
- 6. I've been giving up trying to deal with it.
- 7. I've been taking action to try to make the situation better.
- 8. I've been refusing to believe that it has happened.
- 9. I've been saying things to let my unpleasant feelings escape.
- 10. I've been getting help and advice from other people.
- 11. I've been using alcohol or other drugs to help me get through it.
- 12. I've been trying to see it in a different light, to make it seem more positive.
- 13. I've been criticizing myself.
- 14. I've been trying to come up with a strategy about what to do.
- 15. I've been getting comfort and understanding from someone.
- 16. I've been giving up the attempt to cope.
- 17. I've been looking for something good in what is happening.
- 18. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
- 19. I've been accepting the reality of the fact that it has happened.
- 20. I've been expressing my negative feelings.
- 21. I've been trying to find comfort in my religion or spiritual beliefs.
- 22. I've been trying to get advice or help from other people about what to do.
- 23. I've been learning to live with it.
- 24. I've been thinking hard about what steps to take.
- 25. I've been blaming myself for things that happened.
- 26. I've been praying or meditating.

Q. Finally, I would like to ask you a question about how you currently feel in relation to the termination. Each of the items below is a statement of thoughts and feelings that some people have concerning a loss such as yours. Please note that there are no right or wrong responses to these statements. For each item, tick the box which best indicates the extent to which you agree or disagree with it at the present time. You can use the “neither” category but only if you truly have no opinion.

Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree

- 1- I feel depressed
- 2- I find it hard to get along with people
- 3- I feel empty inside
- 4- I can't keep up with my normal activities
- 5- I feel a need to talk about the baby
- 6- I am grieving for the baby
- 7- I am frightened
- 8- I have considered suicide since the loss
- 9- I take medicine for my nerves
- 10- I very much miss the baby
- 11- I feel I have adjusted well to the loss
- 12- It is painful to recall memories of the loss
- 13- I get upset when I think about the baby
- 14- I cry when I think about him/her
- 15- I feel guilty when I think about the baby
- 16- I feel physically ill when I think about the baby
- 17- I feel unprotected in a dangerous world since I lost the baby
- 18- I try to laugh, but nothing seems funny anymore
- 19- Time passes so slowly since I lost the baby
- 20- The best part of me died when I lost the baby
- 21- I have let people down since I lost the baby
- 22- I feel worthless since I lost the baby
- 23- I blame myself for the loss of the baby
- 24- I get cross at my friends and relatives more than I should
- 25- Sometimes I feel like I need a professional counsellor to help me get my life back together again
- 26- I feel as though I'm just existing and not really living since I lost the baby
- 27- I feel so lonely since I lost the baby
- 28- I feel somewhat apart and remote, even among friends
- 29- Its safer not to love
- 30- I find it difficult to make decisions since I lost the baby
- 31- I worry about what my future will be like
- 32- Being a bereaved parent means being a “Second-Class Citizen”
- 33- It feels great to be alive

Finally, a few demographic questions:

Q. Are you

Female

Male

Q. How old are you?

Q. What is your marital status?

- Married/living together
- Divorced/separated
- Widow
- Single
- Prefer not to answer

Q. Which of the following is your highest educational qualification?

- GCSEs, O levels or equivalent
- A levels or equivalent
- First degree (BA, BSc)
- Postgraduate qualification
- No qualifications

Q. What is the profession of the main income earner in your household? Note – If the main income earner is retired, please state the last profession before retirement

- High managerial/administrative/professional
- Intermediate managerial/ administrative/professional
- Supervisory/clerical/junior managerial/administrative/ professional
- Skilled manual worker
- Semi-skilled and unskilled manual worker
- On state benefit, unemployed, casual unskilled work
- Prefer not to answer

Q. Finally, would you like to add anything about your experience or add any comments on the survey?

No additional comments

Thank you very much for taking part to this survey. Your answers are very valuable and I very much appreciate you taking the time to speak about your experience.

Q. Would you like to receive a short summary of the findings?

- Yes
- No

If yes, please leave your contact details

Q. Would you like to take part in further research on this topic?

If yes, please leave your contact details

First name
Surname
E-mail address

Appendix III: Questionnaire - Study 4 (chapter 7)

FOR THOSE WHO HAVE ALREADY COMPLETED STUDY 2B (not in text)

Thank you very much for taking the time to answer this survey. We hope that this information will be used to improve the care offered to women who face a termination for fetal abnormality in the future.

Some of the following questions may be familiar to you. This is because some were included in the study you took part in previously. However, it is important that you answer these questions again. – GO STRAIGHT TO COPING QUESTIONS

FOR THOSE WHO HAVE NOT COMPLETED STUDY 2B (not in text)

First of all, I would like to ask you a few questions about the termination itself before we go on to exploring your experience in more detail. These questions may seem 'clinical', they are, however, necessary to put the findings into context.

In the event that you have had more than one termination for fetal abnormality, please answer on the basis of the most recent one.

**Q. When did the termination take place?
Please write in month and year**

Now, please code below:

- In the last 6 months
- In the last 7 to 12 months
- In the last 13 to 24 months
- Over 24 months ago

Q. At how many weeks gestation did you end your pregnancy?

Q. How was the abnormality detected?

- By chance – part of a routine scan (12 weeks or 20-22 weeks anomaly scan) or routine care
- Through directed search – specific scan or tests undertaken due to pre-existing medical conditions, genetic family history or previous pregnancy history

Q. What diagnosis were you given? Please describe briefly below

Q. Was this abnormality ...

- Lethal, i.e. incompatible with life
- Serious but compatible with life
- Other – specify
- Don't know
- Prefer not to answer

Q. Was this your first termination for fetal abnormality?

- Yes
- No, the second one
- No, the third one
- No – specify

Q. Was this your first pregnancy?

- Yes
- No, the second one
- No, the third one
- No, the fourth one or more

Q. How many living children did you have at the time of the termination?

Q. What best describes how you feel about your decision to end the pregnancy?

- I would make the same decision again
- I would not make the same decision
- Don't know
- Prefer not to answer

Q. How was the pregnancy terminated?

- Medical
- Surgical
- Other - Specify
- Don't know
- Prefer not to answer

Q. Which method of termination were you offered

- Medical
- Surgical
- Both
- None, the method of termination was not discussed
- Other – Please specify

Q. What best describes your situation with regards to having another child? *Tick all that apply*

- I have had another child since the termination
- I am expecting another child
- I have suffered another loss (spontaneous or induced)
- I am not pregnant but I would like another child
- I have decided not to have another child
- Other - specify

COPING

The next section deals with the way you have coped with the termination and focuses on what happened after the procedure. It lists some ways of coping with stressful life events that people have reported using. As people deal with life events in different ways, some items will apply to you and some won't. I would like to know to what extent you've been doing what the item says; how much or how frequently.

Please don't answer on the basis of whether it seemed/seems to be working or not, **just whether or not you were/still doing what the item says**. Please try to rate each item separately from the other and make your answers as true FOR YOU as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real".
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
19. I've been accepting the reality of the fact that it has happened.
20. I've been expressing my negative feelings.
21. I've been trying to find comfort in my religion or spiritual beliefs.
22. I've been trying to get advice or help from other people about what to do.
23. I've been learning to live with it.
24. I've been thinking hard about what steps to take.
25. I've been blaming myself for things that happened.
26. I've been praying or meditating.

PERINATAL GRIEF

Now, I would like to ask you a question about how you **currently** feel in relation to the termination. Each of the items below is a statement of thoughts and feelings that some people have concerning a loss such as yours. Please note that there are no right or wrong responses to these statements. For each item, tick the box which best indicates the extent to which you agree or disagree with it at the **present time**. You can use the “neither” category but only if you truly have no opinion.

Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree

- 1- I feel depressed
- 2- I find it hard to get along with people
- 3- I feel empty inside
- 4- I can't keep up with my normal activities
- 5- I feel a need to talk about the baby
- 6- I am grieving for the baby
- 7- I am frightened
- 8- I have considered suicide since the loss
- 9- I take medicine for my nerves
- 10- I very much miss the baby
- 11- I feel I have adjusted well to the loss
- 12- It is painful to recall memories of the loss
- 13- I get upset when I think about the baby
- 14- I cry when I think about him/her
- 15- I feel guilty when I think about the baby
- 16- I feel physically ill when I think about the baby
- 17- I feel unprotected in a dangerous world since *I lost the baby*
- 18- I try to laugh, but nothing seems funny anymore
- 19- Time passes so slowly *since I lost the baby*
- 20- The best part of me died when *I lost the baby*
- 21- I have let people down *since I lost the baby*
- 22- I feel worthless since *I lost the baby*
- 23- I blame myself for the loss of the baby
- 24- I get cross at my friends and relatives more than I should
- 25- Sometimes I feel like I need a professional counsellor to help me get my life back together again
- 26- I feel as though I'm just existing and not really living *since I lost the baby*
- 27- I feel so lonely *since I lost the baby*
- 28- I feel somewhat apart and remote, even among friends
- 29- Its safer not to love
- 30- I find it difficult to make decisions *since I lost the baby*
- 31- I worry about what my future will be like
- 32- Being a bereaved parent means being a “Second-Class Citizen”
- 33- It feels great to be alive

POSTTRAUMATIC GROWTH (NEW)

The final part of the study focuses on potential positive outcomes of traumatic events. Each of the items below is a statement of thoughts and feelings that some people have reported following a traumatic event. Indicate for each of the statements below the degree to which this change occurred in your life as a result of **the termination**, using the following scale.

0= I did not experience this change as a result of the termination.

1= I experienced this change to a very small degree as a result of the termination.

2= I experienced this change to a small degree as a result of the termination.

3= I experienced this change to a moderate degree as a result of the termination.

4= I experienced this change to a great degree as a result of the termination.

5= I experienced this change to a very great degree as a result of the termination.

1. I changed my priorities about what is important in life.
2. I have a greater appreciation for the value of my own life.
3. I developed new interests.
4. I have a greater feeling of self-reliance.
5. I have a better understanding of spiritual matters.
6. I more clearly see that I can count on people in times of trouble.
7. I established a new path for my life.
8. I have a greater sense of closeness with others.
9. I am more willing to express my emotions.
10. I know better that I can handle difficulties.
11. I am able to do better things with my life.
12. I am better able to accept the way things work out.
13. I can better appreciate each day.
14. New opportunities are available which wouldn't have been otherwise.
15. I have more compassion for others.
16. I put more effort into my relationships.
17. I am more likely to try to change things which need changing.
18. I have a stronger religious faith.
19. I discovered that I'm stronger than I thought I was.
20. I learned a great deal about how wonderful people are.
21. I better accept needing others.

Finally, a few demographic questions:

Q. Are you

Female

Male

Q. How old are you?

Q. What is your marital status?

Married/living together

Divorced/separated

Widow

Single

Prefer not to answer

Q. Which of the following is your highest educational qualification?

- GCSEs, O levels or equivalent
- A levels or equivalent
- First degree (BA, BSc)
- Postgraduate qualification
- No qualifications

Q. What is the profession of the main income earner in your household? Note – If the main income earner is retired, please state the last profession before retirement

- High managerial/administrative/professional
- Intermediate managerial/ administrative/professional
- Supervisory/clerical/junior managerial/administrative/ professional
- Skilled manual worker
- Semi-skilled and unskilled manual worker
- On state benefit, unemployed, casual unskilled work
- Prefer not to answer

Q. – What is your ethnicity?

- White British
- White Irish
- Any other white background
- White and black Caribbean
- White and black African
- White and Asian
- Any other mixed background
- Indian
- Pakistani
- Bangladeshi
- Any other Asian Background
- Caribbean
- African
- Any other black background
- Chinese
- Any other ethnic background
- Prefer not to say

Q. – What is your religion?

- No religion
- Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Any other religion, please describe
- Prefer not to say

Q. Finally, would you like to add anything about your experience or add any comments on the survey?

No additional comments

Thank you very much for taking part to this survey. Your answers are very valuable and I very much appreciate you taking the time to speak about your experience.

Q. Would you like to receive a short summary of the findings?

Yes

No

If yes, please leave your contact details

First name

Surname

E-mail address

Appendix IV: Information sheet - Studies 2a and 2b (chapters 4 and 5)

RESEARCH INTO WOMEN'S EXPERIENCES OF COPING WITH TERMINATION OF PREGNANCY DUE TO FETAL ABNORMALITY

PLEASE READ THE FOLLOWING INFORMATION

You are being invited to take part in a research study. This document provides you with information about the research aims and what it entails. Please read this carefully and take time to decide whether you wish to participate. Should you have any queries, please feel free to contact us (see contact below).

WHAT ARE THE STUDY'S AIMS?

Terminating a pregnancy for fetal abnormality is a complex decision to make, which may have profound psychological consequences. However very little is known about the way women practically cope with terminating their pregnancy and how this might relate to their experience of grief.

This research aims to examine how women cope with a termination for fetal abnormality. We hope that this information may be used to improve the care offered to women who face a similar experience in the future.

WHO ARE THE PARTICIPANTS?

We are looking to speak to women who have had a termination for fetal abnormality. The interviews will take place online, through a secure and dedicated website.

DO I HAVE TO TAKE PART?

No, participation is entirely voluntary. If you decide to take part, you will be asked for your consent at the beginning of the survey. If you decide to take part, you are still free to withdraw at any time. If you prefer not to take part, you do not have to provide a reason. It is entirely up to you.

WHAT WILL THE RESEARCH ENTAIL?

The survey consists of:

- a series of open ended questions
- a brief questionnaire, with simple ticks, where you will be asked to indicate which statement you agree most with
- some general questions about the termination to put the findings into context

The survey should take about 40 minutes to complete. You can leave and re-enter the survey at any point providing that you access it from the SAME computer, otherwise data will be lost.

WHAT ARE MY RESPONSIBILITIES?

We would be grateful if you could complete the questionnaire within the next 2-3 weeks.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

We do not anticipate any direct benefit to you as such, but we are hoping that this survey will provide you with a forum to share your experiences. We are also hoping that it will benefit women who are faced with a termination for fetal abnormality in the future, by tailoring the care they receive in a more efficient way.

WHAT ARE THE POSSIBLE DRAWBACKS OF TAKING PART?

Given the sensitive nature of the study, it is possible that you may feel emotional. Should you feel distressed, please contact the ARC Helpline on 0845 077 2290 or 0207 713 7486.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

Yes. All data will be stored securely. Identities will be kept confidential and data will not be shared with any other party.

WHAT WILL HAPPEN TO THE RESULTS?

The results from this study will be used to identify potential improvements to the care provided to women during and after the termination. It is anticipated that the results will be reported in professional publications or meetings.

If you would like to receive a short summary of the results, please leave your contact details at the end of the questionnaire. A short summary of the results will be e-mailed to you once the analysis is completed.

WHO IS THE RESEARCHER?

The researcher is part of a multidisciplinary team at the University of West London. The research has obtained ethical approval from the University of West London Psychology Ethics Committee. The researcher is also a member of ARC and of ARC support network of trained volunteers.

Contact: Caroline Lafarge, University of West London, Tel: 0208 209 4088, e-mail: caroline.lafarge@uwl.ac.uk

WHAT HAPPENS NOW?

If you wish to take part, please click on NEXT at the bottom of the page.

Thank you for taking the time to read this information.

Appendix V: Information sheet - Study 4 (chapter 7)

WOMEN'S PSYCHOLOGICAL RESPONSES TO TERMINATION OF PREGNANCY FOR FETAL ABNORMALITY

PLEASE READ THE FOLLOWING INFORMATION

Many thanks for your interest in the research. The information below summarises the study's aims and what it entails. Please read this carefully and take time to decide whether you wish to participate. If you have any queries, please feel free to contact us (caroline.lafarge@uwl.ac.uk).

WHAT ARE THE STUDY'S AIMS?

The present research builds on a previous study conducted over a year ago. We are examining the different ways women respond to termination of pregnancy for fetal abnormality, how they cope with it and how this affects the way they feel about their loss. Some of you may have taken part to the first previous study, which means that some questions may be familiar to you. This is because they were included in the previous study. However, it is important you answer these questions again in the context of how you CURRENTLY feel.

We hope that the information collected will be used to improve the care offered to women who face a similar experience in the future.

WHO ARE THE PARTICIPANTS?

We are looking for women who have had a termination for fetal abnormality.

DO I HAVE TO TAKE PART?

Participation is entirely voluntary. If you decide to take part, you will be asked for your consent at the beginning of the questionnaire. If you decide to take part, you are still free to withdraw at any time. If you prefer not to take part, you do not have to provide a reason.

WHAT WILL THE RESEARCH ENTAIL?

The survey consists of a questionnaire, hosted on a secure website. The questions only need simple ticks. You will be asked to indicate which statements you agree most with. You will also be asked some questions about the termination to help put the findings into context. The questionnaire should take about 20-25 minutes to complete.

WHAT ARE MY RESPONSIBILITIES?

We would be grateful if you could complete the questionnaire within the next 2 weeks. You can leave and re-enter the survey at any point providing that you access it from the SAME computer.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

We do not anticipate any direct benefit to you as such, but we hope that this survey will provide you with a forum to share your experiences. We also hope that it will benefit women who are faced with a termination for fetal abnormality in the future.

WHAT ARE THE POSSIBLE DRAWBACKS OF TAKING PART?

Given the sensitive nature of the study, it is possible that you may feel emotional. Should you feel distressed, please contact the ARC Helpline on 0207 7137486.

WILL MY TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

Yes. All data will be stored securely. Identities will be kept confidential and data will not be shared with any other party.

WHAT WILL HAPPEN TO THE RESULTS?

The results from this study will be used to identify potential improvements to the care provided to women during and after the termination. It is anticipated that the results will be reported in professional publications. If you would like to receive a short summary of the results, please leave your contact details at the end of the questionnaire.

WHO IS THE RESEARCHER?

The researcher is part of a multidisciplinary team at the University of West London. The research has obtained ethical approval from the University of West London Psychology Ethics Committee. The researcher is also a member of ARC and of ARC support network of trained volunteers.

Contact: Caroline Lafarge, University of West London, Tel: 0208 209 4088, e-mail: caroline.lafarge@uwl.ac.uk

WHAT HAPPENS NOW?

If you wish to take part, please click on NEXT at the bottom of the page

Thank you for taking the time to read this information.

Appendix VI: Consent form - Studies 2a, 2b and 4 (chapters 4, 5 and 7)

WOMEN'S COPING AND PSYCHOLOGICAL RESPONSES TO TERMINATION OF PREGNANCY FOR FETAL ABNORMALITY

Thank you very much for taking the time to answer this survey. We hope that this information will be used to improve the care offered to women who face a termination for fetal abnormality in the future.

Please tick each of the following statements in order to carry on with the survey

- I confirm that I have read and understood the information sheet for the above study and have asked and received answers to any questions raised

- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my rights being affected in any way

- I understand that the researcher will hold all information and data collected securely and in confidence and that all efforts will be made to ensure that I cannot be identified as a participant in a study

- I agree to take part in the study

Appendix VII: Topic guide - Study 2a (chapter 4)

In addition to the questions relating to the terminated pregnancy and demographics, participants were asked the following open ended questions.

I would like to ask you some more detailed questions about your experience and particularly about the way you coped with terminating your pregnancy. **Please give as much detail as possible** and remember there are no right or wrong answers. You can choose to leave the survey for a while and come back to it at a later stage if you so wish.

First, I would like to ask some general questions about ending this pregnancy

Q. What does ending this pregnancy mean to you? How has this changed over time?

Q. What other event (whether experienced by yourself or not) would you compare to terminating this pregnancy? Why?

Q. How would you describe the process of coping with ending this pregnancy at the time and afterwards? How has this changed over time?

The next few questions focus specifically on how you coped with the termination: first, during the termination procedure itself and then, afterwards. Please be as specific as possible in describing what you have done to cope with this event, whether big or small things, and regardless of whether they were successful or not in helping you.

Q. Regardless of whether they were successful or not, what things did you do to get through the termination procedure itself? E.g. having someone with you, a photograph, etc. and it may relate to specific time (e.g. delivery)

Q. Regardless of whether they were successful or not, what things did you do to come to terms with the aftermath of terminating the pregnancy? E.g. having a memory book for your baby, actively trying not to think about your baby, making yourself busy with other things, etc.

Q. Did you find any of these things particularly helpful? How were these helpful? At which stage? Has this changed over time?

Q. Did you find any of these things particularly unhelpful? How were these unhelpful? At which stage? Has this changed over time?

Q. In what way is your coping process influenced by time? Any particularly important dates? Any milestones you would like to reach?

Q. How would you describe the support you received before, during and after the termination? This includes support from the medical staff but also from partner, friends, family, colleagues and any organisations/support group.

Q. To what extent has this event influenced other aspects of your life? How?

And now, some questions about the future.

Q. What does 'moving on' mean to you? Why?

Q. What's next for you?

Q. Is there anything you would like to add or comment on?

Appendix VIII: Topic guide - Study 3 (chapter 6)

Introduction:

Interviewer introduces herself and gives a quick summary of the study's objective (taking care to use broad language as not to bias the participant's answers)

Opening question

Q1 - Could you describe your journey to fetal medicine?

Perceptions of women's coping with a diagnosis of fetal abnormality and HP's own coping style.

Q5 – Could you describe the way you perceive women cope with a diagnosis of fetal abnormality? This includes your perception of how they adjust to it and what they actually do in practical terms to cope with it?

If necessary, prompt: Any coping strategies observed? Any differences?

Q6 – Some women decide to terminate their pregnancy following a diagnosis of fetal abnormality, how do you think they cope with the termination? And afterwards?

If necessary, prompt: what coping strategies do they use, what support do they get (including medical support), what about subsequent pregnancies

Q7 – Could you describe your own coping processes when: breaking bad news, discussing the different options with the patients, and (for consultant and if applicable) the procedure of termination itself?

If necessary, prompt: any specific strategies used, anything you would have liked to do more of/less of? Any challenges?

Before closure:

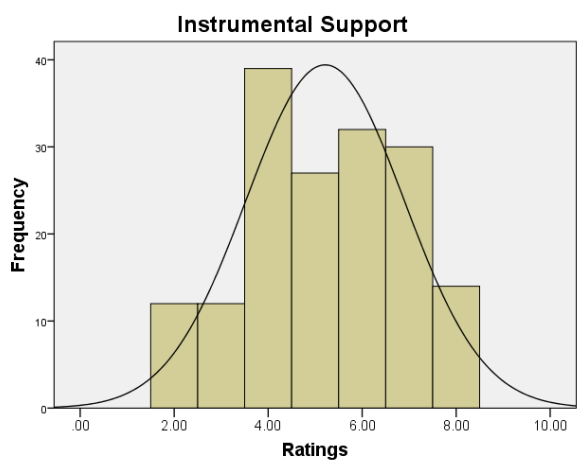
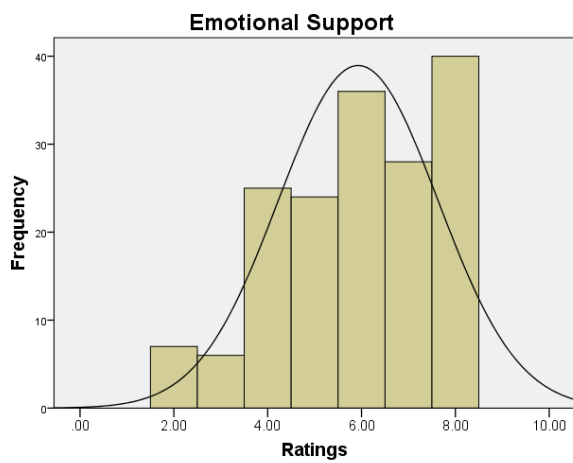
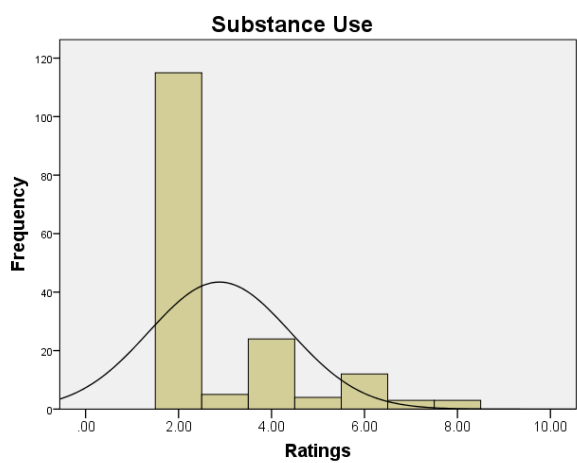
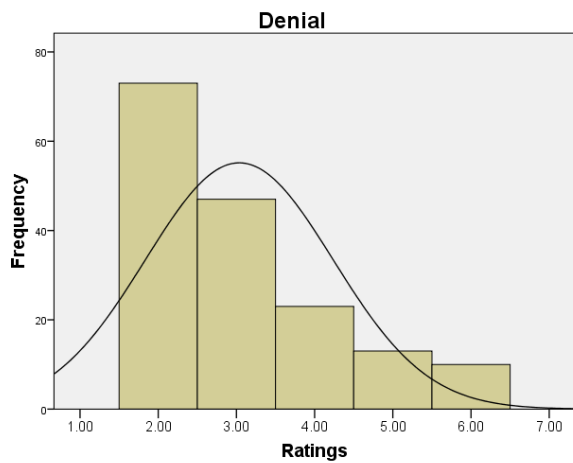
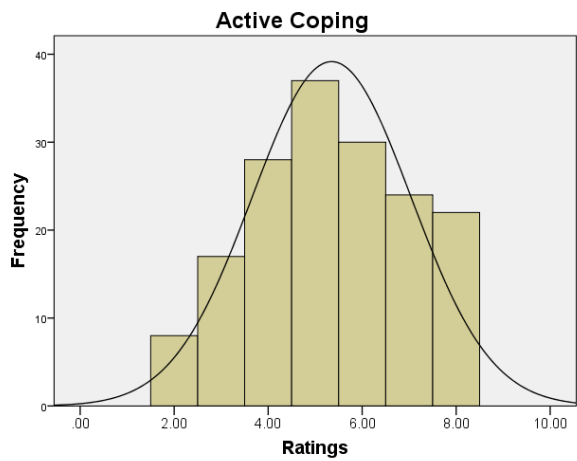
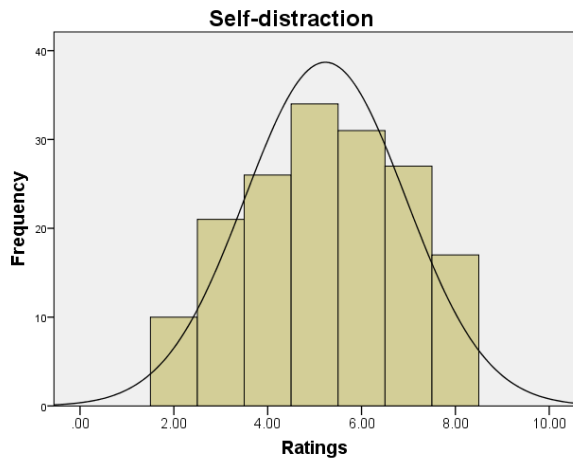
Background questions if not clear from opening statement such as age, activity (sectors involved).

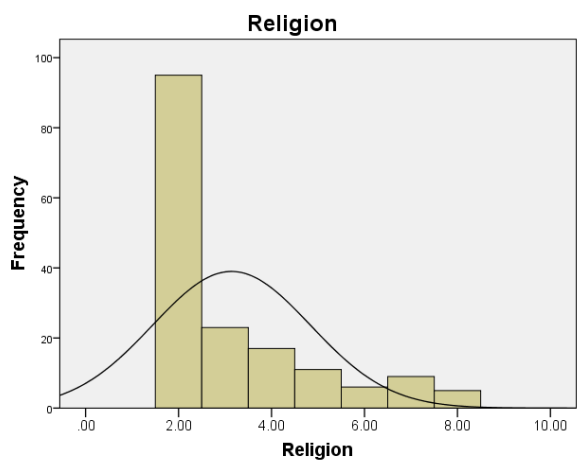
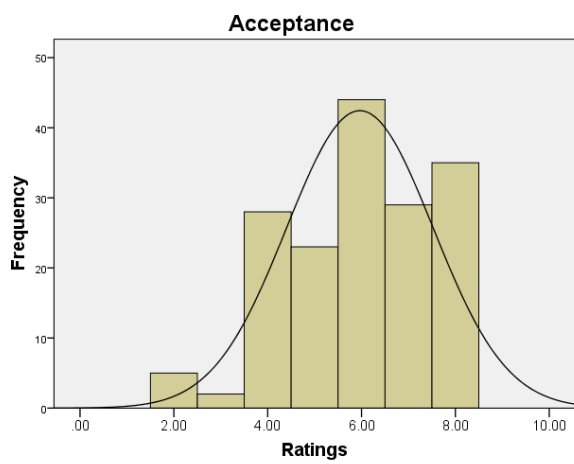
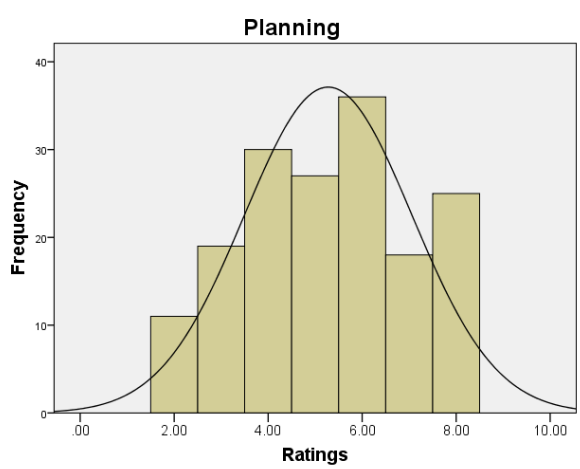
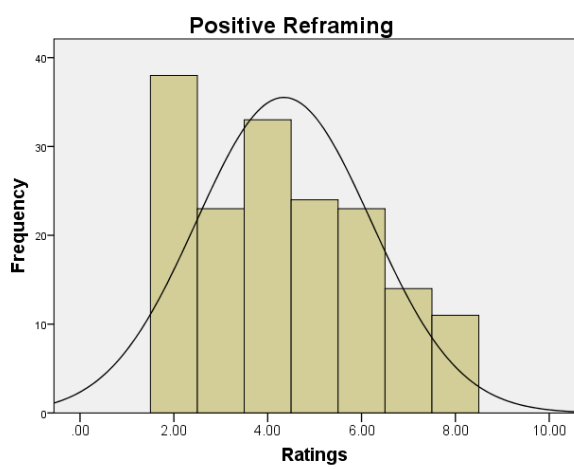
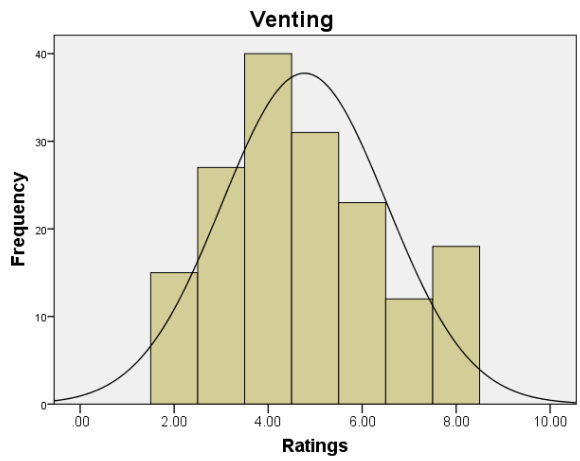
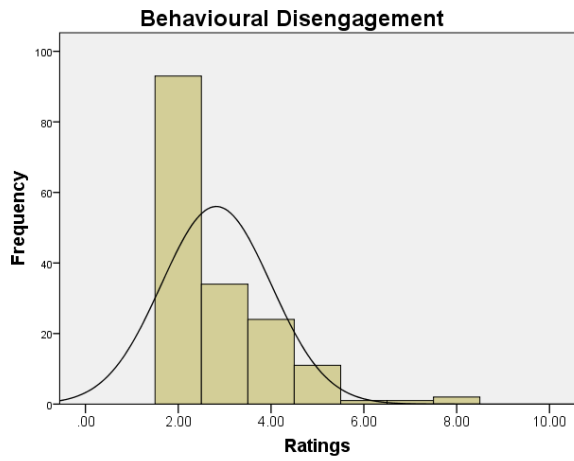
Q8 - Personally do you have any insight or experience of question of abnormality/disability?

Thank participant and close the interview

Appendix IX: Histograms illustrating the data distribution for the Brief COPE and the Short Perinatal Grief Scale (Study 2b)

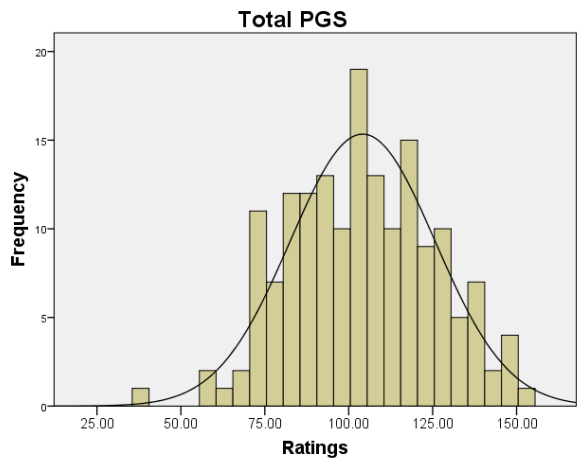
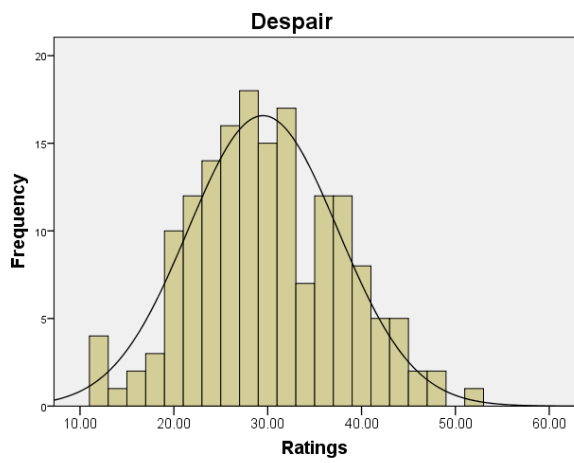
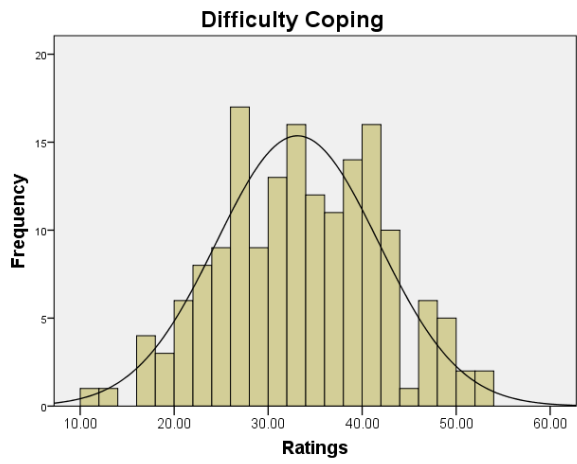
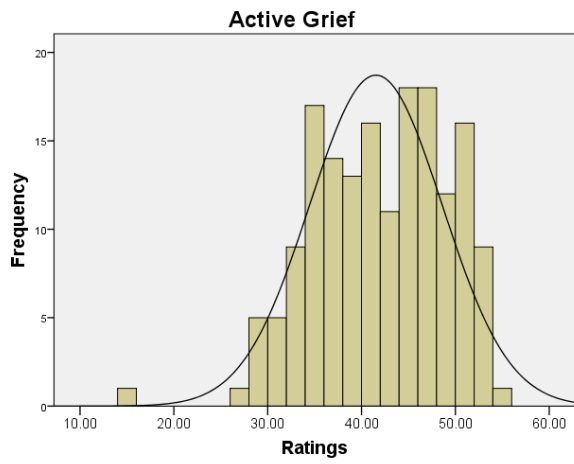
The Brief COPE







The Short PGS

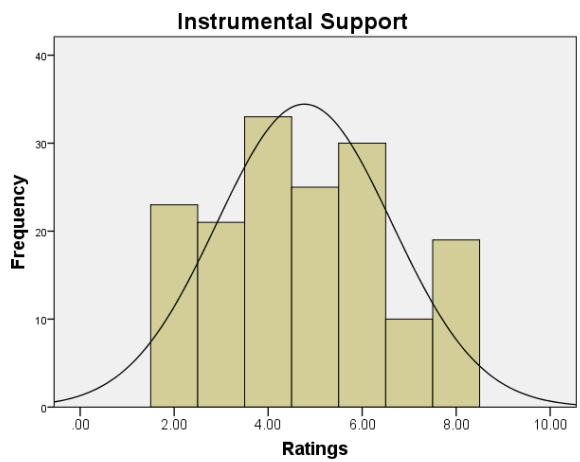
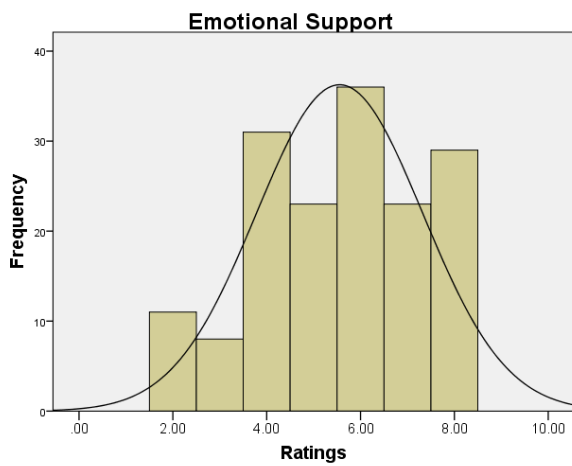
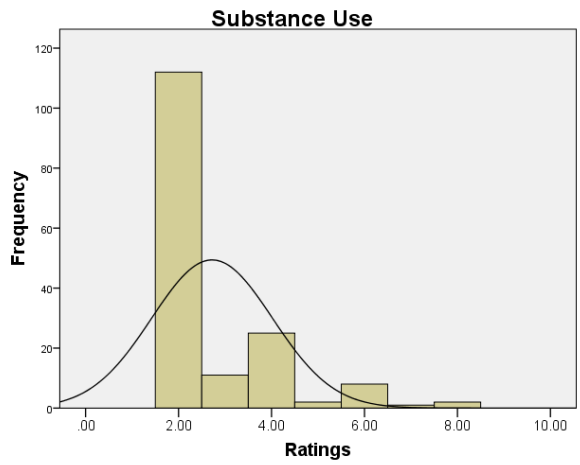
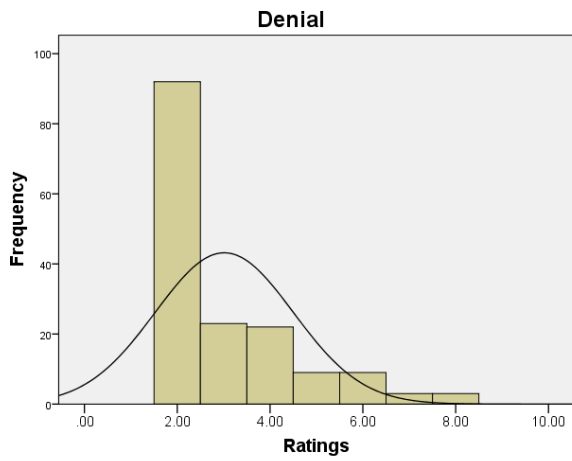
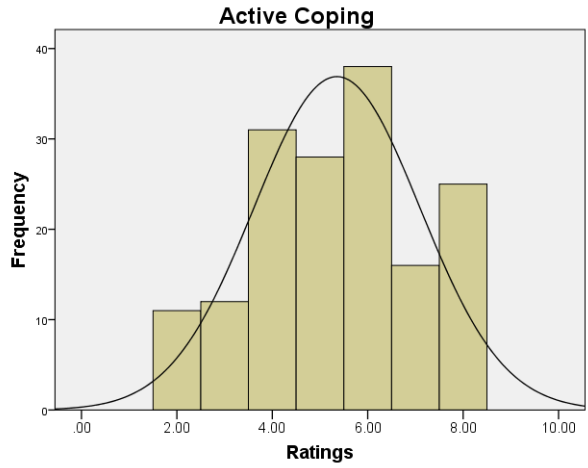
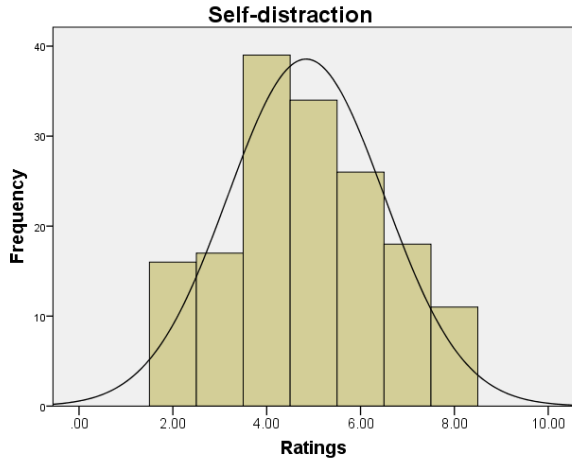


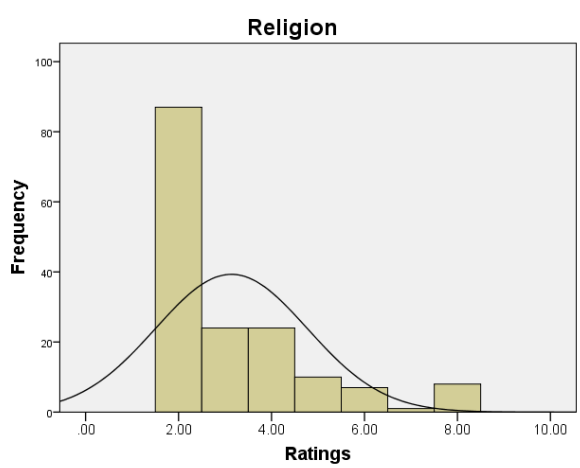
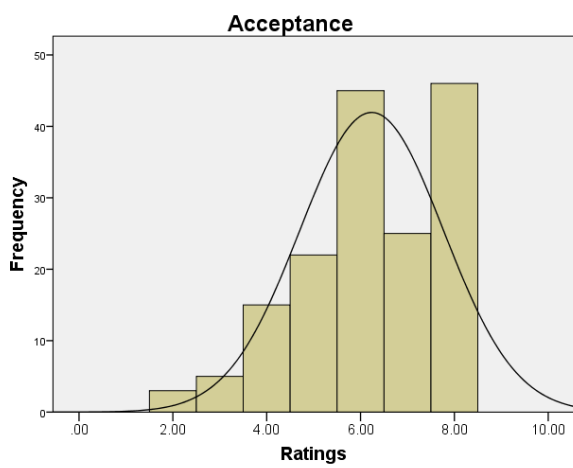
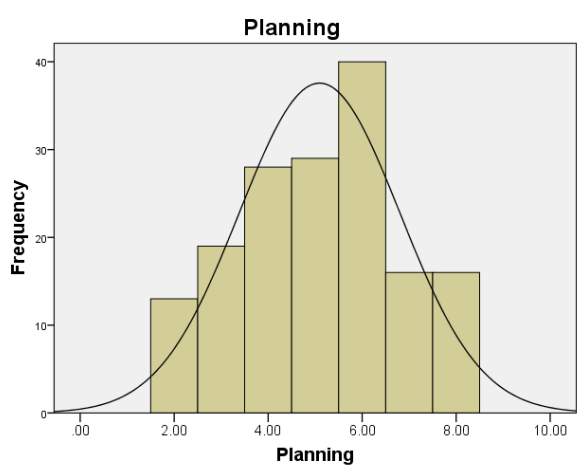
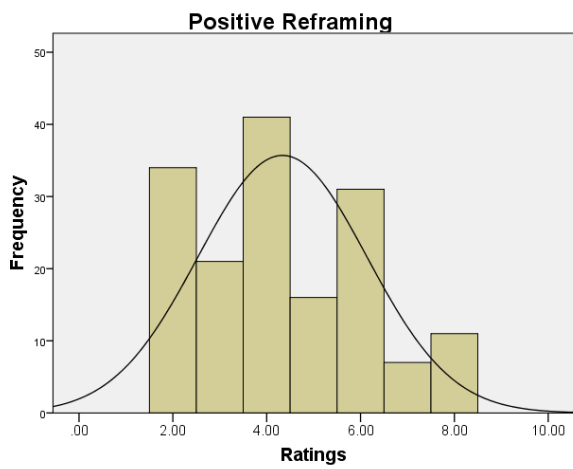
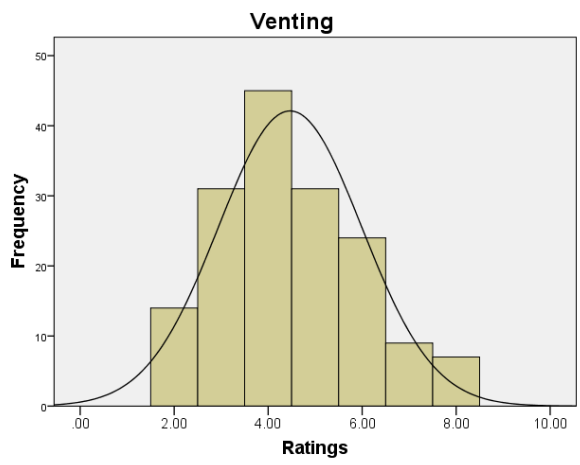
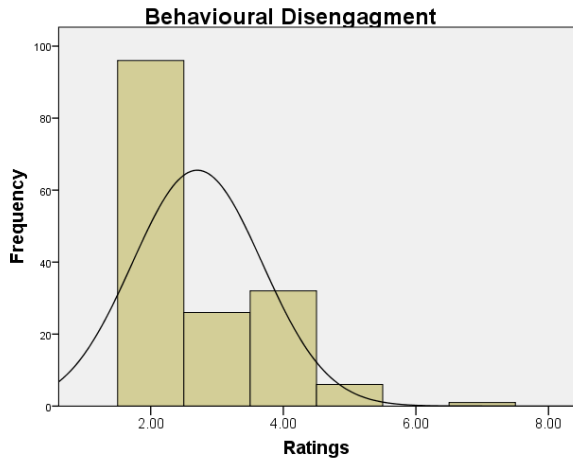
Appendix X: Group differences in levels of perinatal grief by key termination-related variables based on parametric (*t* test) and non-parametric (Mann-Whitney U) tests

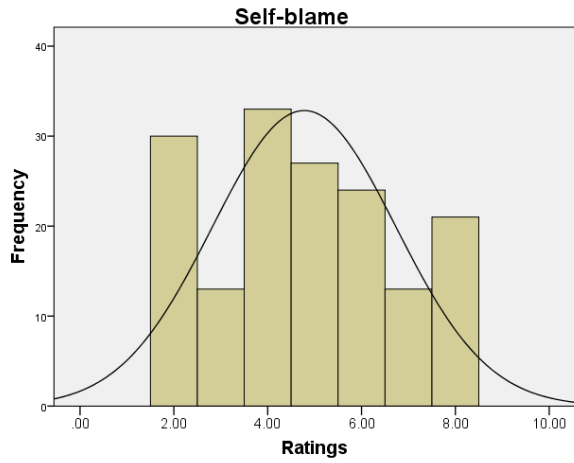
<i>Variables</i>	<i>Categories</i>		<i>t test</i>		<i>Mann-Whitney U</i>
			<i>t-value</i>	<i>p-value</i>	<i>p-value</i>
Children at TFA	No children	Children			
Short PGS	n = 89 (53.61 %)	n = 77 (46.39%)			
Active grief	42.73 (SD = 6.56)	40.14 (SD = 7.44)	2.382	<i>p</i> = 0.018*	<i>p</i> = 0.028*
Difficulty coping	34.75 (SD = 8.24)	31.22 (SD = 8.71)	2.681	<i>p</i> = 0.008**	<i>p</i> = 0.007**
Despair	31.34 (SD = 7.99)	27.36 (SD = 7.49)	3.289	<i>p</i> = 0.001**	<i>p</i> = 0.001**
Total PGS	108.82 (SD = 20.58)	98.72 (SD = 21.58)	3.081	<i>p</i> = 0.002**	<i>p</i> = 0.003**
First Pregnancy	Yes	No			
Short PGS	n = 70 (42.17%)	n = 96 (57.83%)			
Active grief	43.33 (SD = 6.11)	40.22 (SD = 7.46)	2.856	<i>p</i> = 0.005**	<i>p</i> = 0.007**
Difficulty coping	34.86 (SD = 7.93)	31.84 (SD = 8.92)	2.251	<i>p</i> = 0.026*	<i>p</i> = 0.022*
Despair	31.50 (SD = 7.85)	28.03 (SD = 7.81)	2.820	<i>p</i> = 0.005**	<i>p</i> = 0.006**
Total PGS	109.69 (SD = 19.69)	100.09 (SD = 22.10)	2.890	<i>p</i> = 0.004**	<i>p</i> = 0.006**
Children since TFA	No children	Children			
Short PGS	n = 113 (68.07%)	n = 53 (31.93%)			
Active grief	42.52 (SD = 6.40)	39.42 (SD = 8.00)	2.686	<i>p</i> = 0.008**	<i>p</i> = 0.015*
Difficulty coping	34.26 (SD = 8.20)	30.68 (SD = 9.06)	2.533	<i>p</i> = 0.012*	<i>p</i> = 0.015*
Despair	30.18 (SD = 7.58)	28.04 (SD = 7.58)	1.16	<i>p</i> = 0.108	<i>p</i> = 0.68
Total PGS	106.96 (SD = 19.98)	98.13 (SD = 23.75)	2.494	<i>p</i> = 0.014*	<i>p</i> = 0.012*
Feeling about decision	Comfortable	Uncomfortable			
Short PGS	n = 122 (73.49%)	n = 44 (26.51%)			
Active grief	41.10 (SD = 7.02)	42.73 (SD = 7.18)	-1.312	<i>p</i> = 0.191	<i>p</i> = 0.203
Difficulty coping	32.05 (SD = 8.39)	36.07 (SD = 8.67)	-2.701	<i>p</i> = 0.008**	<i>p</i> = 0.020*
Despair	27.98 (SD = 7.58)	33.68 (SD = 7.66)	-4.262	<i>p</i> < 0.001***	<i>p</i> < 0.001***
Total PGS	101.13 (SD = 20.73)	112.48 (SD = 21.95)	-3.064	<i>p</i> = 0.003**	<i>p</i> = 0.007**

Appendix XI: Histograms illustrating the data distribution for the Brief COPE, the Short Perinatal Grief Scale and the Posttraumatic Growth Inventory (Study 4)

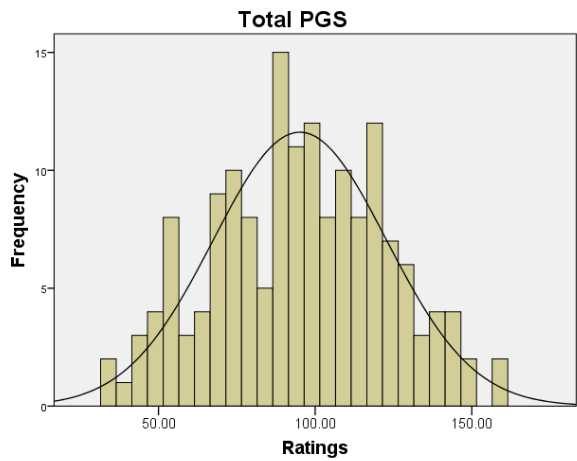
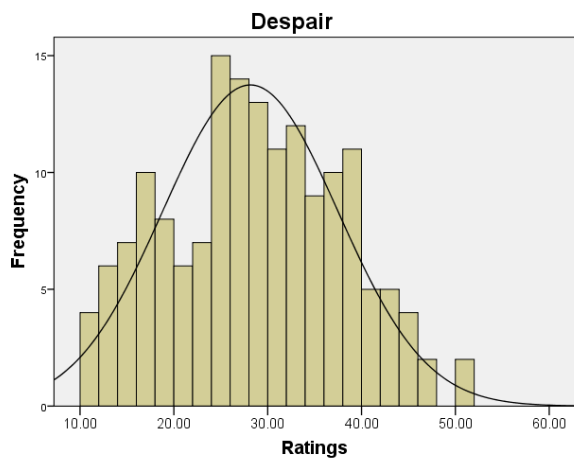
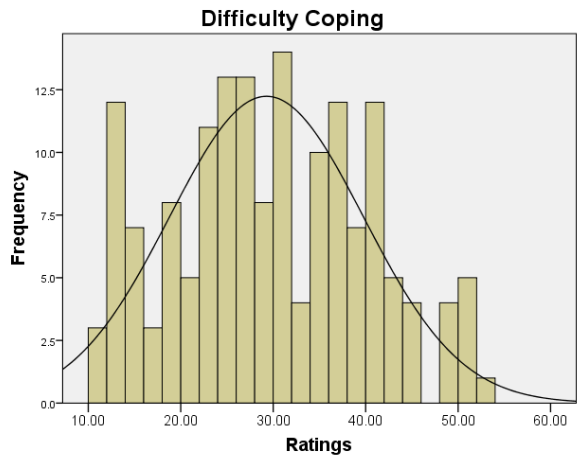
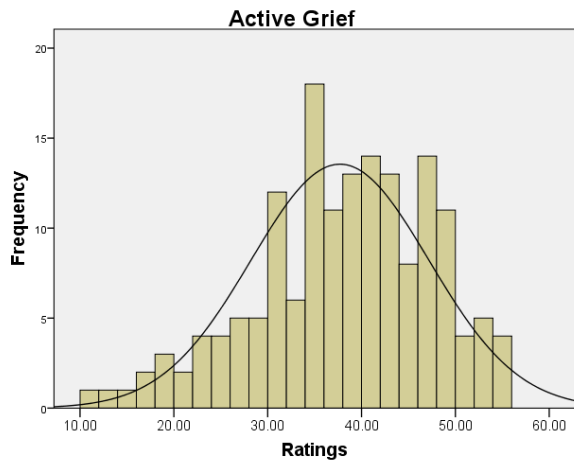
The Brief COPE



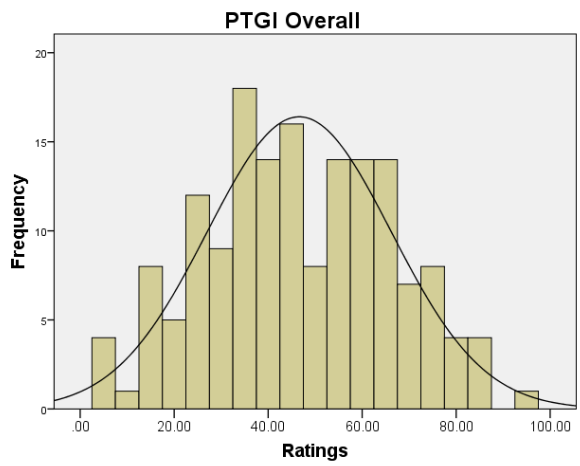
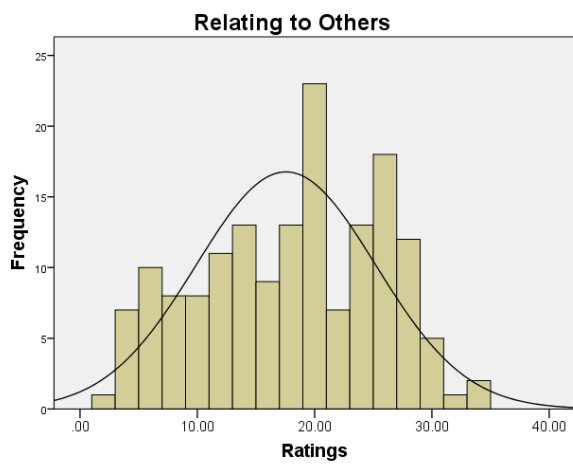
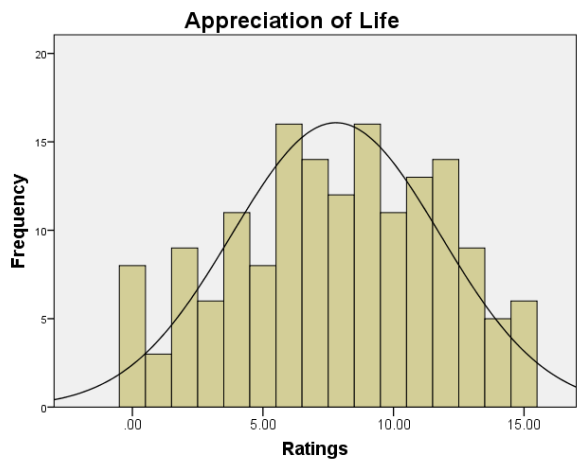
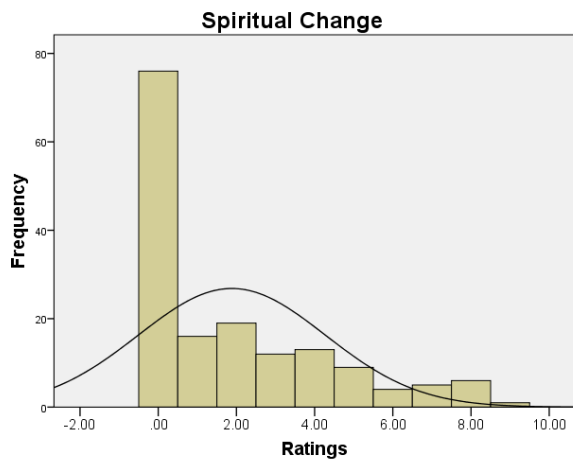
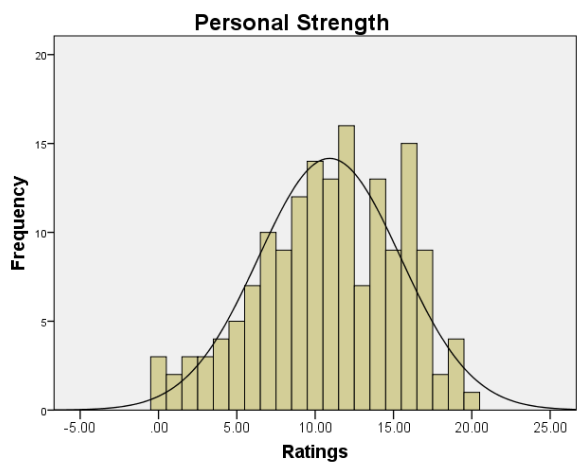
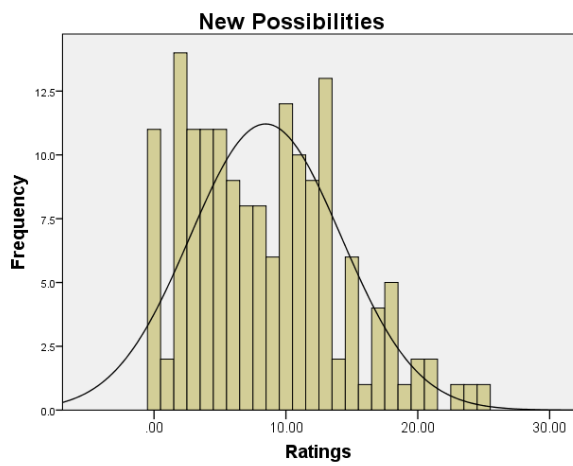




The Short Perinatal Grief Scale



The Posttraumatic Growth Inventory



Appendix XII: Differences in posttraumatic growth based on whether participants had participated in Study 2b or not

<i>Variables</i>	<i>Participants re-contacted</i>	<i>New participants</i>	<i>t-value</i>	<i>p-value</i>
PTGI	<i>n</i> = 62 (38.50%)	<i>n</i> = 99 61.50%)		
Relating to others	16.68 (<i>SD</i> = 7.57)	18.10 (<i>SD</i> = 7.71)	-1.148	<i>p</i> = 0.253
New possibilities	8.77 (<i>SD</i> = 5.58)	8.26 (<i>SD</i> = 5.84)	.550	<i>p</i> = 0.583
Personal strengths	11.29 (<i>SD</i> = 4.77)	10.69 (<i>SD</i> = 4.39)	.821	<i>p</i> = 0.413
Spiritual change	1.84 (<i>SD</i> = 2.36)	1.91 (<i>SD</i> = 2.42)	-.181	<i>p</i> = 0.857
Appreciation of life	8.18 (<i>SD</i> = 4.19)	7.56 (<i>SD</i> = 3.87)	.961	<i>p</i> = 0.338
PTGI overall	46.76 (<i>SD</i> = 20.22)	46.52 (<i>SD</i> = 19.27)	.076	<i>p</i> = 0.939