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Pregnancy termination for fetal abnormality: do coping strategies predict perinatal grief and posttraumatic growth?

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# **COPING WITH PREGNANCY TERMINATION FOR FETAL ABNORMALITY**

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# Acknowledgements

## Dr Pauline Fox (University of West London) & Professor Kathryn Mitchell (University of Derby)

Article

### Women's Experiences of Coping With Pregnancy Termination for Fetal Abnormality

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#### Abstract

Pregnancy termination for fetal abnormality (TFA) can have significant psychological consequences. Most previous research has been focused on measuring the psychological outcomes of TFA, and little is known about the coping strategies involved. In this article, we report on women's coping strategies used during and after the procedure. Our account is based on experiences of 27 women who completed an online survey. We analyzed the data using interpretative phenomenological analysis. Coping comprised four structures, consistent across time points: support, acceptance, avoidance, and meaning attribution. Women mostly used adaptive coping strategies but reported inadequacies in aftercare, which challenged their resources. The study's findings indicate the need to provide sensitive, nondirective care rooted in the acknowledgment of the unique nature of TFA. Enabling women to reciprocate for emotional support, promoting adaptive coping strategies, highlighting the potential value of spending time with the baby, and providing long-term support (including during subsequent pregnancies) might promote psychological adjustment to TFA.

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#### SYSTEMATIC REVIEW

### Termination of pregnancy for fetal abnormality: a meta-ethnography of women's experiences

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**Abstract:** Due to technological advances in antenatal diagnosis of fetal abnormalities, more women face the prospect of terminating pregnancies on these grounds. Much existing research focuses on women's psychological adaptation to this event. However, there is a lack of holistic understanding of women's experiences. This article reports a systematic review of qualitative studies into women's experiences of pregnancy termination for fetal abnormality. Eight databases were searched up to April 2014 for peer-reviewed studies, written in English, that reported primary or secondary data, used identifiable and interpretative qualitative methods, and offered a valuable contribution to the synthesis. Altogether, 4,281 records were screened; 14 met the inclusion criteria. The data were synthesised using meta-ethnography. Four themes were identified: a shattered world, losing and regaining control, the role of health professionals and the power of cultures. Pregnancy termination for fetal abnormality can be considered as a traumatic event that women experience as individuals, in their contact with the health professional community, and in the context of their politico-socio-legal environment. The range of emotions and experiences that pregnancy termination for fetal abnormality generates goes beyond the abortion paradigm and encompasses a bereavement model. Coordinated care pathways are needed that enable women to make their own decisions and receive supportive care. © 2014 Reproductive Health Matters

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PRENATAL DIAGNOSIS

#### ORIGINAL ARTICLE

### Perinatal grief following a termination of pregnancy for foetal abnormality: the impact of coping strategies

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#### ABSTRACT

Objective: Pregnancy termination for foetal abnormality (TFA) can have significant psychological repercussions, but little is known about the coping strategies involved in dealing with TFA. This study examined the relationships between women's coping strategies and perinatal grief.

Method: A total of 166 women completed a survey online. Coping and perinatal grief were measured using the Brief COPE and Short Perinatal Grief Scales. Data were analysed through multiple regression analyses.

Results: Despite using mostly adaptive coping strategies, women's levels of grief were high and varied according to obstetric and termination variables. Grief was predicted by behavioural disengagement, venting, planning, religion, self-blame, being recently bereaved, being childless at the time of TFA, not having had children/being pregnant since TFA and uncertainty about the decision to terminate the pregnancy. Acceptance and positive reframing negatively predicted grief.

# CONTENT

- Background
- Objectives
- Overview of the studies
- Conclusions & implications



# BACKGROUND

- Pregnancy termination for fetal abnormality (TFA) amounts to 2% of all terminations in England & Wales (DH, 2015)
- Number increasing (DH 2008-2015) due to:
  - Technological progress in prenatal diagnosis (e.g. NIPT)
  - Rising age of childbearing
- Political context important. TFA linked to:
  - the wider abortion debate
  - the concept of eugenics



# RESEARCH SO FAR

- **Focused on negative psychological adjustment to TFA:** depression, post-traumatic stress, complicated grief (Kersting et al., 2009; Salvesen et al., 1997; Statham et al., 2001)
- **Evidence of mental health disorders** up to 16 months post termination: 20% (PTSD, Korenromp et al., 2009), 14% (complicated grief, Kersting et al., 2009)
- **Little on actual coping processes**, despite link between coping & psychological adjustment (Carver, 1989; Folkman & Lazarus, 1988)
- **Little on potential positive psychological outcomes** despite evidence in posttraumatic growth after trauma (Bonanno, 2008; Joseph, 2011; Tedeschi & Calhoun, 2004)



# MY RESEARCH

- Systematic review of the qualitative literature about women's experience of TFA
- **Exploration of women's coping strategies when dealing with TFA**
- **Assessment of the relationship between coping strategies & psychological adjustment:**
- Health professionals' perceptions of women's coping with TFA

# OBJECTIVES

1. To explore women's coping strategies used at the time of the termination and afterwards
2. To assess the relationship between coping strategies and psychological adjustment: perinatal grief and posttraumatic growth



# KEY CONCEPTS

- Coping
- Perinatal grief
- Posttraumatic growth

# COPING

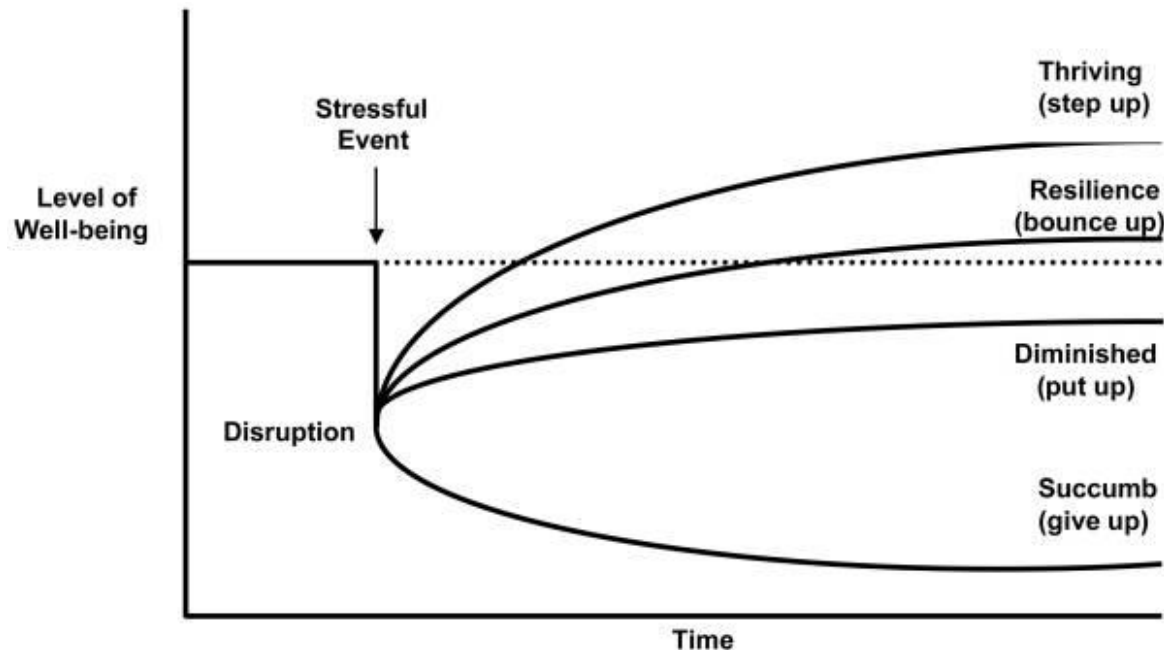
- People facing similar events adjust differently
- Lazarus & Folkman's (1984) cognitive stress theory
  - Appraisal of threat
  - Coping *per se*
- Certain types of coping associated with better psychological outcomes (Carver, 1997; Harper et al., 2014; Schnider et al., 2007)

# PERINATAL GRIEF

- **Grief:** normal reaction following a loss – most resume normal functioning within a year but **complicated grief** experienced by 10/15% of individuals (Gupta & Bonanno, 2011)
- **Perinatal grief:** particular type of bereavement (Kersting & Wagner, 2012)
  - feelings of guilt and self-blame, loss of reproductive self-esteem, limited experience of contact with the fetus, and disenfranchisement
- **Specificities of TFA**
- Evidence that 10-20% women experience complicated grief (Kersting et al, 2009; Korenromp et al., 2009) up to 18 months after TFA

# POSTTRAUMATIC GROWTH

- Different from 'Resilience' which is often defined as the ability to recover readily/maintain levels of functioning
- PTG is a “new level of functioning or a better way of being” (Tedeschi & Calhoun, 2004), a “transformation” (Joseph, 2011)



# A BIT ABOUT POSTTRAUMATIC GROWTH

- **PTG involves a transformation:** rebuilding worldviews, personal core beliefs to accommodate new information arising from trauma (e.g. vulnerability)
- **PTG coexists with personal distress** and goes hand in hand with moderate degree of posttraumatic stress
- It is the **struggle with adversity** which initiates growth
- **PTG involves 3 main reconfigurations:** (Joseph, 2011)
  - Personal changes, Philosophical changes, Relationship changes
- **30%-70%** of trauma survivors report some form of benefits (Joseph, 2011)
- **PTG following bereavement** (Callhoun et al., 2010; Taku, et al., 2015) and parental bereavement (Engelkemeyer & Marwit, 2008; Riley et al., 2007).

# THE STUDIES

To measure the coping strategies used by women to deal with TFA and examine the relationship between coping and perinatal grief and posttraumatic growth



# METHODOLOGY

- Retrospective cross-sectional online quantitative study with **166 women** (from ARC)
- Coping measured with the **Brief COPE** (Carver, 1997) and Perinatal grief with the **Short Perinatal Grief** scales (Short PGS, Potvin et al., 1989)
- Demographic profile: Age (22-46; mean: 34, SD 4.9), 70.5% university educated, 97% white
- Obstetric profile: Gestational age at TFA: 12-35 weeks (mean: 18, SD: 4.9), 53% had TFA 6 months prior, 46.3% had children, 42.3% first pregnancy, 73.5% would make same decision again



Brief COPE	Mean	SD	Brief COPE	Mean	SD
Self-distraction	5.22	1.71	Venting	4.77	1.75
Active coping	5.35	1.69	Positive reframing	4.34	1.86
Denial	3.04	1.20	Planning	5.28	1.78
Substance use	2.88	1.52	Acceptance	5.96	1.56
Emotional support	5.93	1.70	Religion	3.14	1.70
Instrumental support	5.21	1.68	Self-blame	4.81	1.90
Behaviour. disengagemt	2.82	1.18			

Short PGS	Mean	SD	Short PGS	Mean	SD
Active grief	41.53	7.08	Despair	29.49	7.99
Difficulty coping	33.11	8.62	General grief	104.14	21.58

- Compared to other studies using the PGS, levels of grief in this study were higher
- They were above the threshold usually used for pathology: 34 'active grief', 30 'difficulty coping', 27 'despair', 91 'total PGS' (Toedter et al., 2001)



# WHICH COPING STRATEGIES PREDICT GRIEF?

Variable	Active grief	Difficulty coping	Despair	General grief
Step 1 - predictors	$\beta$	$\beta$	$\beta$	$\beta$
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
F model	15.33***	30.50***	23.73***	28.91***
R <sub>2</sub> on step 1	0.38	0.52	0.45	0.54
Step 2: predictors				
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**
F model	17.86***	25.41***	21.92***	28.36***
R <sub>2</sub> on step 2	0.51	0.60	0.53	0.65
<sup>a</sup> Change in R <sub>2</sub>	0.13***	0.09***	0.09***	0.11***

# COPING AND POSTTRAUMATIC GROWTH METHODOLOGY

- Retrospective cross-sectional online quantitative study with **161 women** (from ARC)
- 62 already interviewed for the perinatal grief study
- **Brief COPE** (Carver, 1997) and **Short Perinatal Grief** scales (Short PGS, Potvin et al., 1989), **Posttraumatic Growth Inventory** (Tedeschi & Calhoun, 1996)
- Demographic profile: Age (20-47; mean: 35.5,  $SD = 5.3$ ), 69.5% university educated, 89.4% white British
- Obstetric profile: Gestational age at TFA: 11-34 weeks (mean: 18.1,  $SD = 4.7$ ), 29.2% had TFA 6 months prior, 49.7% had children, 43.1% first pregnancy, 76.3% would make same decision again

Brief COPE	Mean	SD	Brief COPE	Mean	SD
Self-distraction	4.84	1.67	Venting	4.47	1.52
Active coping	<b>5.35</b>	1.74	Positive reframing	4.34	1.80
Denial	3.01	1.49	Planning	<b>5.09</b>	1.71
Substance use	2.72	1.30	Acceptance	<b>6.23</b>	1.53
Emotional support	<b>5.55</b>	1.77	Religion	3.14	1.63
Instrumental support	4.77	1.86	Self-blame	4.78	1.96
Behaviour. disengagemt	2.70	0.98			

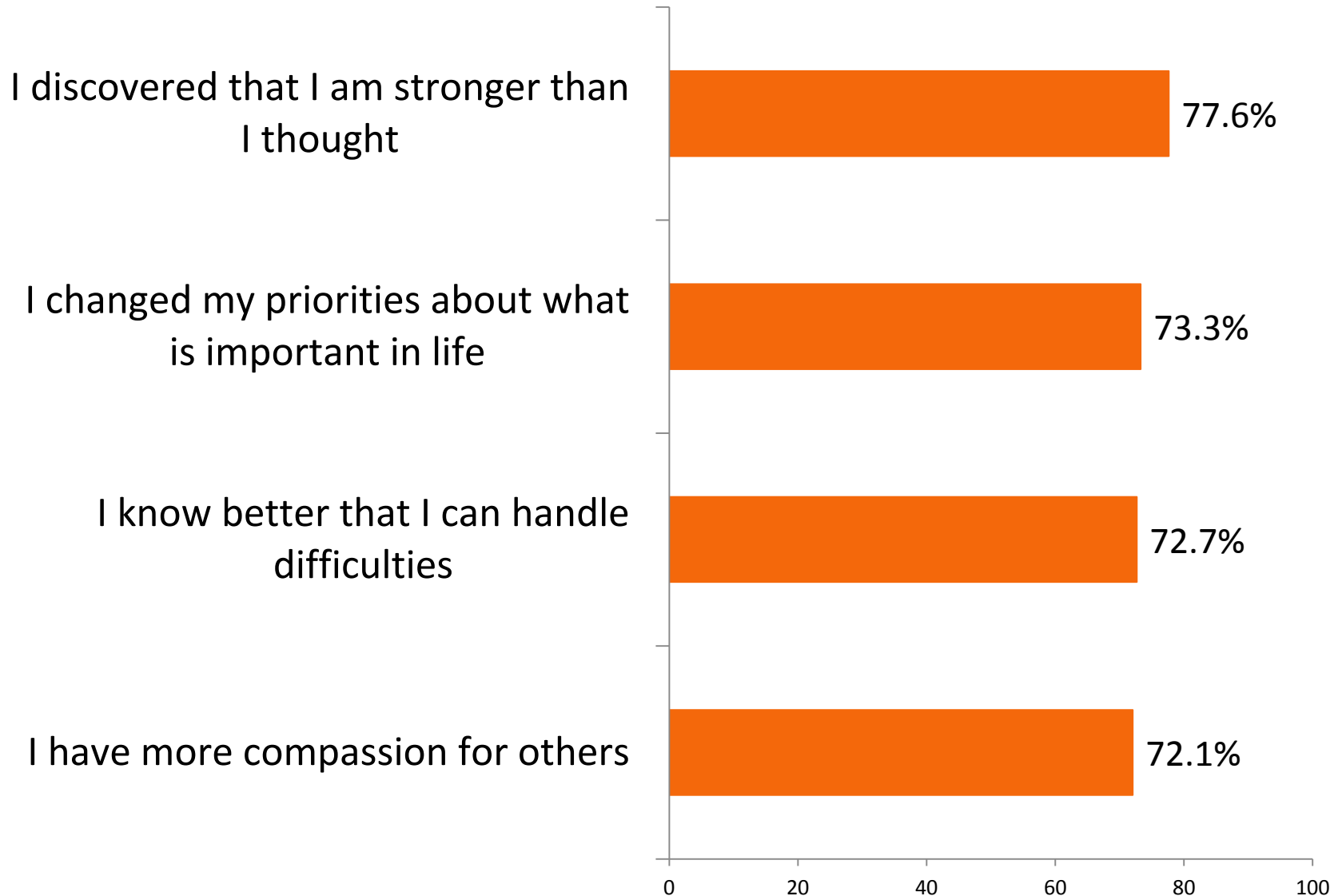
Short PGS	Mean	SD	Short PGS	Mean	SD
Active grief	37.70	9.48	Despair	28.14	9.34
Difficulty coping	29.27	10.50	General grief	95.11	27.65

PTGI	Mean	SD	Short PGS	Mean	SD
Relating to others	<b>17.55</b>	7.66	Spiritual change	1.88	2.39
New possibilities	8.46	5.73	Life appreciation	<b>7.80</b>	3.99
Personal strengths	<b>10.92</b>	4.53	PTGI overall	46.61	19.58

# CHANGES EXPERIENCED TO A MODERATE, STRONG OR VERY STRONG DEGREE



# CHANGES EXPERIENCED TO A MODERATE, STRONG OR VERY STRONG DEGREE



Variable	Relating to others	New possibilities	Personal strengths	Spiritual change	Life appreciation	PTG overall
Step 2 - Other predictors	$\beta$	$\beta$	$\beta$	$\beta$	$\beta$	$\beta$
Active coping	0.07	0.08	0.08	n/a	0.07	0.07
Emotional support	0.26*	-0.05	0.06	0.04	n/a	0.09
Instrumental support	0.04	0.18	n/a	n/a	n/a	0.08
Positive reframing	0.29***	0.34***	0.19*	n/a	0.27**	0.31***
Acceptance	-0.00	-0.04	0.17	n/a	0.05	0.04
Religion	n/a	n/a	n/a	0.71***	n/a	0.20**
Venting	n/a	n/a	n/a	-0.06	n/a	n/a
Self-blame	n/a	n/a	0.07	n/a	n/a	n/a
Total Grief		-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
F model	10.34***	7.60***	8.00***	38.89***	6.72***	9.16***
R <sup>2</sup> on step 2	0.23	0.20	0.21	0.55	0.15	0.26
<sup>a</sup> Change in R <sup>2</sup>		0.01	0.02*	0.01	0.02	0.01

# WHY MODERATE LEVELS OF PTG?

- High level of distress may inhibit growth
- Self-blame
- Element of control / self-perpetuated
- Social desirability bias

# WHY MODERATE LEVELS OF PTG?

- Particularly resilient sample?
- High level of distress may inhibit growth?
- Nature of the loss (kinship, anticipated)?
- Self-blame?
- Disenfranchised grief, thus disenfranchised growth?
- Social desirability bias?



# CONCLUSIONS AND IMPLICATIONS

- Women used mostly 'adaptive' coping strategies, but grief levels were high → Identifying women vulnerable to poor psychological adjustment is important
- Levels of distress still high over time → Need for more aftercare and importance of support groups
- Acceptance and positive reframing negatively predicted grief → Promoting 'adaptive' strategies to reframe (CBT or ACT), while minimising self-blame
- Positive reframing positively predicted growth → Need for women-centred care
- Potential for growth has to be acknowledged

**CALL FOR AN INTERVENTION TO SUPPORT WOMEN**

# LIMITATIONS & FUTRE DIRECTIONS

- Limitations:
  - Sample drawn from support organisation
  - Demographic bias
  - Post hoc rationalisation
  - Social desirability bias
- Future directions:
  - Comparison group of women who go to term, longitudinal element, non support organisation sample
  - Development of an intervention to support women post TFA

**THANK YOU!**

**QUESTIONS?**