Personhood as projection: The value of multiple conceptions of personhood for understanding the dehumanisation of people living with dementia

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Title

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Abstract

We examine the concept of personhood in relation to people living with dementia and implications for the humanity of care, drawing on a body of ethnographic work. Much debate has searched for an adequate account of the person for these purposes. Broad contrasts can be made between accounts focusing on cognition and mental faculties, and accounts focusing on embodied and relational aspects of the person. Some have suggested the concept of the person is critical for good care; others suggest the vexed debates mean that the concept should be abandoned. We argue instead that the competing accounts illuminate the very tensions in personhood which are manifest for all of us, but especially for people living with dementia, and argue that our account has explanatory power in shedding light on how precisely dehumanisation and constraints on agency may arise for people living with dementia, and for staff, within an institutional context.

Key words

Dementia
Personhood
Dehumanisation
Hospitals
Person-centred care

Introduction

This paper critically addresses complex debates regarding the notion of personhood and its use in relation to people living with dementia. A stance that centres the notion of the person and advocates person-centred care for people living with dementia has been influential. Alongside this, it has also strongly been argued that a standard model of the person centred on rational autonomy fails to capture the lived experience and capabilities of people living with dementia, and that a more embodied and relational concept of the person is needed. In response to debates about competing conceptions of personhood, it has more recently been argued that the concept of the person should be abandoned in relation to dementia. Against this, we argue that diverse and even competing conceptions of the person have different and crucial roles to play in understanding the often difficult position of people living with dementia; embodied and relational conceptions of personhood are valuable in understanding the richness of humanity, but if we abandon the rational autonomous person presented as an 'ideal', we will fail to understand fully the pressures upon people living with dementia which contribute to the common perception that they are experiencing not simply various cognitive and other difficulties, but diminished personhood. Although we focus here on people living with dementia, our arguments have relevance for other groups, including, as we shall indicate, for care staff.

There are long standing debates, in various contexts, concerning dehumanising attitudes towards people living with dementia. Here we address these through the lens of conceptions of personhood and associated terms, and their presumed implications for treatment and care. Our ultimate concerns are practical, focused on the quality of care that people living with dementia receive both within institutions and in the community, but we also consider that the investigation of underlying philosophical models of the person is of importance in understanding certain problems and in finding ways to address practical questions of care. One source of debate is the claim that the pathologies of dementia and their effects upon the brain erode or destroy the essence of the person, given the essential link of the brain with the mind (see e.g. Mitchell et al. 2020; Dalziel 1994; Behuniak 2010; Peel 2014; Zeilig 2014; Caddell and Clare, 2009), with claims that dementia 'by definition then seems to threaten the identity and self-hood of the individual at risk' (Higgs and Gilleard 2016, 773). In response, accounts of personhood which either support or counter such claims are frequently discussed, and following from this, come various practical responses.

This paper draws on work of our research team which conducts ethnographic research on the care of people living with dementia on hospital wards, with the aim of improving the quality of care for patients as well as improving experiences for staff. Completed projects have focused on refusal of everyday care and on continence care (Featherstone et al. 2019; Featherstone et al. 2022), and our current project focuses upon restraint practices. The symbolic interactionist tradition of ethnography informs our work; this focuses on how meaning and action are constructed in the social world (Featherstone et al. 2022). Our team has conducted, to date, 405 days of close observation over an eight year period on a variety of hospital wards across England and Wales. We envisage this as a scoping paper, outlining methodological issues shaping the debates around personhood and dementia, which we use to lay the groundwork for further work examining issues pertaining to findings from our ethnographic research.

In broad summary, our team has found that routine aspects of hospital care for people living with dementia may have the unintended effects of worsening decline in both physical and mental health and wellbeing. Alongside this we have observed many factors of unintended dehumanisation, relating to various aspects of care including poor continence care (Northcott, Featherstone, and Boddington 2022), lack of attention to personal appearance and dress (Boddington, Featherstone, and Northcott 2021), failures of communication, and restrictions of movement (Featherstone and Northcott 2021). These factors can all arise in the course of normal routine care. We trace many of these to institutional factors such as timetabling pressures and the necessity of meeting quantifiable organisational targets (Featherstone and Northcott 2021).

We will draw out some of the implications for conceptions of the person and the root sources of dehumanisation in this paper, raising questions about how the concept of ‘the person’ is understood, and the impact that the use of such a concept may have on the treatment of certain individuals or groups. Overt models as well as implicit assumptions about the person can influence policy and practice; in turn, policy and practice can both influence and embody beliefs and attitudes about personhood. However, exactly how these lines of influence might operate is a complex question which merits further attention.

Background to the debates about the concept of a person and dementia

There are considerable differences between various philosophical accounts of the person, differences which are visibly manifest in discussions in relation to people living with dementia and in discussions of the ethical implications. These range from work arguing that in dementia care we should centre the notion of the person (Kitwood 1997a), to suggestions that the conflicts in different philosophical accounts of the person are such that it would be better to abandon use of this term with regard to people living with dementia (Higgs and Gilleard 2016, 2014).

We argue against abandoning the use of the term ‘person’ in relation to people living with dementia, not in spite of, but precisely *because of* its varied meanings and usage. The contradictions and tensions between different accounts of what it is to be a person can function as a valuable clue to important philosophical and ethical issues, and are not a reason to discard the notion of the person or to replace it with an alternative concept. This is indeed reflected in the extensive and often heated literature on personhood and dementia. There are underlying reasons for the contradictions and tensions, and understanding these can lead to important insights into the care and treatment of people living with dementia and into the functioning of our institutional culture of care and treatment. However, we need to look carefully at what precise role any concept of the person is fulfilling.

Our own approach, developed from our ethnographic work as well as that of others, draws upon certain rich notions of personhood which stress embodiment and social aspects of personhood, but in addition, we consider that more cognitive accounts of personhood stressing rational agency and autonomy are also vital to explain what is happening on the hospital ward with the care of patients. Key lines of disagreement in contemporary debates around personhood in relation to people living with dementia can help to illuminate how recurring problems of dehumanisation and less than optimal care and treatment may arise. We explore some of these here, although it is important to note that the questions concerning personhood are both complex and vexed and hence we can here only address some of the important debates.

The tensions within accounts of personhood reflect, in part, tensions which are perhaps inevitable concerning what it is to be a person, tensions which may be part of the human condition but which may be especially acutely manifest in people living with dementia. We hope to present an account with greater explanatory power than many other accounts, insofar as it explores how the question of personhood and the linked issues of dehumanisation and constraints on agency may arise not only for people living with dementia but also for the staff who care for them, how these questions are linked to many factors within institutions placing various stressors upon both patients and staff, and in turn, how these institutional factors echo key elements informing certain conceptions of the person.

The institutional pressures of the ward are well documented (Featherstone and Northcott 2021, Featherstone et al. 2019) and cover almost all aspects of ward activity. Nursing and medical teams are under pressure from bed managers to transfer and discharge patients to maintain the patient flow around the hospital, adverse events (such as falls and pressure ulcers) are highlighted on wall displays with staff constantly working to avoid them, nurses and care teams must work to get their rounds completed before medical rounds are scheduled, all areas of the ward must be prepared for spot infection control inspections and this all occurs against a background of significant paperwork, digital record keeping and changing monthly targets. These pressures are worsened by the obstacles of low staffing and high patient volume, all occurring outside the main role of the hospital, delivering patient care.

How we use the term 'person' and its cognates in this paper

There are various terms used for the broad idea that is captured here by the concept of a person, including the related ideas of the self and of the individual. We are interested in broad theories about personhood, and related ideas about what it is to treat a person with respect and with care and humanity, and conversely with neglect and dehumanisation, what these are, how they arise and are manifested. Hence, we also consider work which examines the language used to describe people living with dementia, since this has implications for underlying conceptions of the person and for how these concepts are used. We bring together multiple overlapping treatments of the topic in order to disentangle what is helpful about these debates for our purposes of describing, analysing, and addressing the care of people living with dementia and attitudes towards them.

The concept 'person' is not simply one of abstract interest, but is a value concept with implications for action. When we attempt to analyse, unpack, and apply it, we do so as persons ourselves. One aspect of personhood commonly thought to be core is the capacity for reciprocal recognition of other persons qua persons (Strawson, 2008). But one recurring observation of actual humanity is that we habitually fail in this reciprocal recognition, to some degree or other. One critical question then, is not simply what constitutes a person, but how we recognise other persons in ways that enable such reciprocity; and how the potential for such reciprocity is recognised in accounts of what it is to be a person (Taylor, 2008). This thus brings epistemological questions right into the heart of any conceptual analysis of personhood, because unless the question of the recognition of other persons is addressed, an account can say little about the reciprocity between persons, a core element of most accounts.

A key question concerns the relationship between the metaphysical and the moral aspects of personhood. For some, attempts to describe and define the person can be separated out into either metaphysical or moral. For example, Higgs and Gilleard critique others, such as Kitwood, for presenting personhood as a 'statement of moral fact' and for 'treating personhood as a status demanding of rights' (Higgs and Gilleard 2016, 774, 778; Kitwood 1997b). The element of reciprocity and recognition of other persons suggests that moral questions will always arise in relation to any metaphysical account of the person and hence that any easy distinction between the two cannot be drawn. Likewise, when asserting the moral relevance of the notion of the person, we need more than an assertion of moral certitude, we need our conceptual framework to accommodate both the importance of recognising the person, and the ease with which such recognition may be disrupted.

When we consider these issues, we are taking certain stances towards others, located in certain points of view, which will have epistemic significance. The contexts in which accounts of personhood are offered is thus, we argue, of significance in fully understanding the complex and often tangled debates around the idea of personhood and its ethical implications, and this is especially so in relation to the question of the personhood of people living with dementia. Questions of epistemology, point of view, purpose, context, and accountability all need to be examined here, rather than simply attempting to address how the concept of the person should or should not be defined. The context within which questions of personhood are posed appears to influence the philosophical models proposed and favoured, as we shall attempt to indicate.

It will be necessary here to introduce simplification of complex philosophical issues in order to focus on our argument. Outlining some broad distinctions may be useful in this large and disparate field of debate. A rough-and-ready distinction can be drawn between accounts which focus broadly upon mental capacities and cognition, and those which adopt a more embodied account of personhood. A broad group of work focuses on psychological or mental criteria, often proposing a cognitive, rational agency model stressing autonomy or self-directed behaviour, awareness including awareness of the self, and the ability to communicate (sometimes stipulating linguistic communication) (see e.g. Warren 1973; Dennett 1988). The particular focus on cognition in such accounts has given rise to questions concerning cases of so-called 'marginal' personhood for individuals whose capacities for cognition may be diminished, such as those living with dementia (Wasserman et al. 2017).

An alternative position, sometimes advanced in direct opposition to the former approach, uses notions of embodiment and of social connection, drawing on philosophical work in the phenomenological tradition such as the work of Merleau-Ponty, and often referred to in relation to people living with dementia (Kontos 2004, 2005; Fuchs 2020; Dzwiwa-Ohlsen, 2021). Such approaches may claim to provide a richer account of the person, to provide a more humane basis for care, and may claim to address epistemological issues concerning our knowledge of and connection to individual persons. For example, research by Kontos and Naglie finds that an embodied notion of personhood assists health care practitioners to enhance care (Kontos and Naglie 2007).

It is also useful to note two related issues: that of the concept of the person, and the question of the continuity of personal identity over time. Indeed, the latter question arises forcibly in philosophy from the problem that a concept of the person based upon mental criteria thereby gives rise to the purported conceptual possibility that the body may persist in the absence of 'the person', as well as the well-worn 'problem of other minds' since we cannot directly observe minds other than through physical manifestation. The literature shows polarised extremes, that personhood can continue to exist without the mind, through belongings and presentation (Buse and Twigg 2015, 2018), to the view of the person living with dementia as a zombie (Schweda and Jongsma 2022), a label loosely and carelessly applied in this case and generally indicating a reaction of horror, but nonetheless suggesting that dementia produces a diminishing or even total absence of personhood, a view that is highly distasteful towards people living with dementia. We will argue that the question of the continuity of personal identity over time plays a role in the notion of personhood projected onto the older person living with dementia on a hospital ward, one that has little relation to the actual person's life.

Epistemological questions and conceptions of the person

Also shaping discussions are differences of approach in how conceptual models are constructed and applied, that is, the relationship between concept and theory on the one hand, and practice and observation on the other. A focus may be on a model to describe the world; or the focus may be on developing a model that is useful for action. There is no sharp division between these two approaches, but nonetheless it is possible to discern considerable differences in methodological approach, albeit with overlaps in many instances.

These contrasting approaches also tend to arise in answer to different questions, and may be developed using different epistemologies, as can be seen in the context of discussions of personhood in relation to dementia. There are broad differences between how models of the person are arrived at methodologically. Much philosophical work in this area appears to proceed as if it were developing a generalised model of the person, then holding it up against certain individuals or groups to see if they 'match' the personhood model. In other words, 'standard' models of the person match a generality of putative persons, but not all; some may fail to measure up. Dewing notes, '… as soon as attributes or criteria for being or not being a person are used, a values-based hierarchy develops. In effect not all humans attain or maintain the status of being a person' (Dewing 2007, 5).

Contrasting with this, approaches deriving in the main from care and practice, and typically drawing upon observational work involving qualitative research methods such as ethnography, start with an assumption of personhood and of full humanity within certain individuals or groups as they search to construct a model of what it means to be a person; to understand what is there, to see it in more depth, to rate and rank different ways of treating people. Such work may explicitly operate in consciousness of ways in which personhood and humanity has been elided for certain individuals or groups.

However, because of the very nature of what it is to be a person, because of the issue of reciprocal recognition in constituting personhood, precisely because of the possibility of dehumanisation of others, we have to understand the complex interactions possible between these two broadly-sketched approaches.

Previous work by one of the authors has examined how those from different disciplinary backgrounds may have very different aims and questions in addressing issues of personhood in relation to vulnerable groups, contrasting the abstract approaches of philosophers considering whether or not certain individuals might fit a standard conception of the person, with psychologists working in practice on the assumption that there is a person with whom one must relate and communicate no matter how challenging this may be ([redacted] 1992). In a broadly similar manner, Hughes, a consultant in old age psychiatry, writes of his clinical work as involving human beings whom he regards as persons, and that our concept of the person must arise from what he calls, borrowing from Wittgenstein, the ‘hurly burly of clinical experience’ (Hughes 2001, 87). By this he refers to the realities of his interactions at the bedside with patients, arguing that a situated, embodied notion of personhood is preferable to notions influenced by Locke and Parfit (and hence in the cognitive-rational mould of accounts of personhood) which views the person in terms of psychological states and highlights the importance of memory. However, Hughes also notes, ‘Grounding our metaphysical conception of the person in the hurly-burly of clinical practice makes the notion of the person as insecure (i.e. as lacking in objectivity) as the reality of that practice’ (Hughes 2001, 87). In such work, the very factor of concrete and particular relationships with others forms part of the working environment through which our concept of the person is formed and examined. It is, however, from the very ‘realities of practice’ as observed in our team’s ethnographic observations that our own views have been formed. Indeed, in considerable contrast to Hughes’ claims, Sabat and Harré present a constructivist view of the self manifested in reciprocal social interaction (Sabat and Harré, 1992; Sabat, 2008).

We now turn to present an overview of key discussions in this wide area, divided for pragmatic reasons into broad themes, which will be used to build up our explorations of the question.

Negative language and attitudes, dementia, and the person

A focus of some research work has been on disparaging attitudes towards people living with dementia, whether in the media or among the general public. For example, Low and Purwanigrum (2020) present a systematic review of ways in which people living with dementia are represented in the popular culture and media. They divide common frames for dementia into a few broad categories: biomedical; natural disaster or epidemic; military or fighting, framing dementia as a 'killer' with whom the world is at war; the 'living dead'; and 'burden of care'. They find the frame of the 'living dead' to link the idea that people living with dementia lose their brains, memories, and minds consequent to the loss of their personhood, associated with what they call a 'Western hypercognitive view of the self' whereby '[w]hen the brain/mind deteriorated, then the self deteriorated' (Low and Purwanigrum 2020, 11).[1] In their discussions, they note that these correspond to dementia stigma as experienced by people living with dementia, and call for further research into the impact of literature, news, and social media on dementia stigma.

While reducing stigma is an admirable goal, if we wish to combat its negative effects we need to consider its complex sources. Attempts to counter stigma may simply shift the source of stigma rather than defeating it (Buchanan and Reiner 2009). For our purposes, note the assumed relevance to stigma of underlying models of the person. These may be implicit, via certain assumptions regarding the nature of personhood: that the brain is a key site of our selves/ our personhood, and that cognitive functions especially memory are also key, and perhaps more than this, that they are utterly crucial. This may indicate a broad cultural agreement with accounts of the person focusing on the cognitive. It may be relevant here that Low and Purwaningrum note their work may be limited by their restriction to English language materials.

Consider also a recent paper by Schweda and Jongsma who also present a critique of media accounts of people living with dementia, which they claim amount to 'zombification' or the idea of a 'living death' or 'dead while alive' (2022). Tropes such as these, for instance the 'funeral without end', have been much discussed in the literature about dementia (Mitchell et al. 2020). Schweda and Jongsma argue that the 'dead while alive' trope relates to a narrative life course account which arises from a timeless notion of the person oriented towards the rational agency of the mid-life adult, a notion common in much mainstream bioethical reasoning, and that we should value and use instead a perspective focusing on the whole of human development recognising the normalcy of neediness.

Such work is premised on a concern that language helps to perpetuate underlying conceptual frameworks which may contribute to dehumanisation, and that we have a certain degree of freedom to choose to modify our perspectives and attitudes towards the person. Many have argued that assumptions about the nature of personhood found in philosophical models, and mental attitudes towards the personhood of individuals living with dementia, can impact treatment and care. But to what extent could changing language and underlying conceptual models be successful in combating a 'hypercognitive' view of the self if such a view does indeed arise from broad cultural influences? It may be fruitful to consider the role and reasons for different views of the self and of the person, the different contexts in which these are applied, and the contexts in which dehumanisation and

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[1] We leave aside here the question of whether such a view of the place of cognition in relation to the person is indeed distinctively or uniquely 'Western' while noting that it is commonly seen within strands of Western philosophy at least since Plato and, as noted, is firmly present within what can broadly be called Western analytical philosophy. One may note that very fact of a considerable body of work attempts to combat such allegedly 'hypercognitive' views of the person suggests that multiple attitudes towards the person already exist.

stigmatisation may arise. Indeed, to argue that a change in mental attitudes and language and the conscious choice to adopt different concepts will lead to differences in treatment perhaps itself belongs to a certain cognitive and rational view of the self where we are in control of our thoughts, and these smoothly precede and govern action. We do not dismiss such hopes, but they may often be based upon rather simple notions of the relationship between thought and action, and moreover, it is important to consider what other forces may mitigate against such hopes alongside close consideration of the underlying conceptual models of the person. Here, we focus upon the institutional context of the hospital ward.

Models of the person: From philosophical model of the person to policy / ethics

We now examine the models of personhood which are held up as the underlying culprits in work such as that of Low and Purwanigrum, paying attention to contexts in which different models or aspects of personhood come to the fore. A considerable body of literature addresses the ethical implications of philosophical models of the person. In particular, as we have seen, a focus upon cognition, rational agency, autonomy, and, implicitly, linguistic competence, raises questions regarding moral respect for individuals who are, or appear to be, deficient in certain cognitive capacities (Wasserman 2017).

Alongside discussion of personhood per se, questions of personal identity over time arise in relation to people living with dementia, as indicated above. Note again that it is important to consider the context of any such discussions. The continuity of personal identity over time is naturally treated by some as relevant to practical questions about *future* medical treatment, intervention, and care, such as advanced directives (see e.g. Hughes 2001; Lesser 2006; Lewis 2006; Toomey 2021), meaning that significant decisions of great import may hang on an answer; and an answer confidently delivered may have clear implications for action (conversely, the seriousness of the decisions to be made may be such that any answer needs to be asserted with justifiable confidence). Questions are asked for certain reasons, within a framework of accountability and of rationally justified action. Such work tends to sit within the medical ethics literature, concerning policy, ethical action, or abstract possibility. The questions, ‘is this the same person’, ‘does personhood still persist and to what degree’, may be implicitly or explicitly asked.

The specific requirements of accountability for decision making should also be seen alongside the broad philosophical tradition within which the discussions of the nature of mind have arisen, where scepticism may be a common or even a default position, and where a broadly Cartesian model of the mind tends to present a picture leaning towards a scepticism which hankers after external criteria for the inner mental world of others. This is not, of course, to dismiss or discount requirements of accountability within the context of such serious medical decision-making.

In contrast, for those dealing with day-to-day care, such as within the nursing or care literature which often has a rather different focus to the ‘medical ethics’ literature, the question of personhood and of the continuity of personal identity over time may be implicit and assumed. Here, the question of the continuity of the person over time may be absent, less pressing, or may take on a different complexion: the focus is upon a person and their immediate basic care needs in the here-and-now, rather than on major medical or other decisions concerning their future. This may indeed be an official policy of care institutions and hospitals where ‘person-centred care’ is the ideal against which staff behaviour is held accountable (at least in theory), so that the continued personhood of individual patients is assumed, rather than being up for reasoned discussion and debate. Such a broad tendency can also be found in many research studies dealing with standards of care in care homes and hospitals (Alzheimer’s Society 2016). Where the question of the notion of ‘the person’ does arise in such contexts, there is a strong tendency for it to centrally concern the question of how personhood is recognised, the factors which might enhance or hamper this, and how personhood might best be maintained once certain decline has arisen, or against certain societal or institutional factors. The accountability owed is to uphold and value the continuing person, not to present robust arguments for or against the continued presence of personhood.

In considering how a model of personhood might be related to policy and practice, we should bear in mind that within the hospital, medical models of care may differ in certain respects from models and goals of nursing care. Likewise, institutional goals and priorities of care may not always cohere completely with the practicalities and demands of everyday basic care on the ward; yet there is a complex and ever present relationship between competing institutional forces. These different contexts may produce different responses to models of personhood.

Memory and the discovery and creation of personhood

In illustration, let us consider contrasting approaches to the question of memory, a major issue in relation to dementia, as deterioration of memory both short-term and long-term, including the recognition of others, is a common and significant factor in the condition. Accounts of the person which stress mental and cognitive elements may include memory as an indicator of sustained personal identity over time. This has created well-known philosophical puzzles given that all of us may lose memories, and indeed may later regain some lost memories while losing others (Locke 1690). Memory is an issue for everyone, but even more entrenched issues may arise for people living with dementia whose memories are deteriorating.

One response to such deterioration might be to bite the bullet and consider that this is no longer the same person, or to follow a similar line as Derek Parfit who argues over his extensive work, *Reasons and Persons*, that personal identity is not the thing that necessarily matters, making distinctions between personal continuity and personal connectedness, where the latter represents a manner of concern for past and future selves (Parfitt 1984). This approach obviously would be radically revisionary of many ingrained ways of thinking about ourselves and about others.

Another, markedly different, approach is represented by those who have tried to ensure physical continuity by including a bodily criterion based on the work of McMahon (Lyreskog 2021). This views the brain as the seat of cognition and hence as putatively the carrier of personhood. Such an approach belongs to what is still a very cognitive model based upon mental criteria – the possibility of the loss of limbs and the transplantation of many major organs introduces a complexity, but were there a body part other than the brain which could not be replaced in such a way, it is vanishingly unlikely that any proponents of such a view would have chosen it to mark continuity of personhood; the capacity for cognition has a significance that the capacities to produce urine, insulin, or to digest food, simply do not. The function of the bodily criterion chosen here comes with a particular epistemology – one simply assumes that those around us have brains, even though one has rarely even seen a scan of anyone else's brain to prove this, let alone caught so much of a glimpse of their physical brain. The brain plays a conceptual, and in relation to practical encounters with others an entirely theoretical, role in assuring continuity of personal identity in face of the reality of our important-yet-unreliable memories. (This approach can be contrasted with a very different role for the body in an account of memory which locates it within the habitual structure of the body, through dispositions, skills, and habits (Fuchs 2012.))

Consider now a further approach to the recognition of the important role of memory in personal identity, where personhood and (at least a significant degree of) continued personal identity is assumed, but where efforts are made to elicit and sustain memory as a key marker of personhood within care work. For example, work by Heersmink (2022) assumes the importance of memory to narrative personal identity and seeks to integrate into care work various methods of maintaining and sustaining the memories of people living with dementia. This approach is built upon notions of distributed cognition and distributed memory, a very different model than one which uses the discrete, individual brain to safeguard individual continuity. It extends an account of the mind and of the person to involve, of necessity, the wider world, including the social world. This thus turns the focus away from 'internal' mental capacities, and away from the individual capacities of the person considered in isolation, to embodied and social factors of personhood. This also then means that interactions with others enter the picture, including the recognition (or not) of aspects of personhood.

Importantly too, it recognises that to be a person is to have potential for certain capacities which may not always be fully realised. Their realisation may be encouraged, or damaged, precisely within the contexts of reciprocal recognition by other persons, a reciprocity which itself may falter and fail in various ways, failure which itself may be encouraged by the diminishing of personhood resulting from the very failure of recognition. And hence a vicious spiral may arise.

Models of personhood and standards of accountability

Thus we can see that great differences of approach revolve around such questions. On the one hand, one might be concerned with questions such as 'does my model fit reality?/is this individual a person/are they the same person?' On the other hand, concern focuses on questions such as 'how does my model influence reality/how can we create conditions for personhood to flourish?' Models of personhood which arise from such different approaches cannot simply be contrasted without taking into account the epistemic issues, as well as the questions of context and purpose behind how the issue of personhood is addressed.

It may be helpful to consider different standards and requirements of accountability implied by the contrasting approaches we are outlining, noting that models of accountability may influence approaches to personhood. Note too, that in practice, multiple requirements of accountability may be operating at once and in overlapping and possibly competing ways. There may be a hierarchy of accountabilities, with certain considerations, such as institutional accountability, making claims to override other forms of accountability. Models of accountability involve questions of epistemology, such as standards for the justification of knowledge claims, and social, legal, or institutional accounts of who is accountable to whom and for what. As an example, consider an approach influenced by certain philosophical traditions, and from within certain approaches to medical ethics, in relation to the question of continued personal identity for an individual who has made an advanced directive about treatment options in certain possible future medical circumstances (Jaworska, 2017). Accountability for a particular position would be needed for certain possible future medical circumstances, would require the justification of any conceptual models arguing for continued personal identity or its loss, may require higher levels of justification depending upon the gravity of any decisions, may need to answer to legal questions as embodied in case law and statute, and so on.

On other approaches to the person, those which sit more at home in work arising from care and practice, accountability may be within a frame of practice addressing more immediate care needs, staff and others may be held accountable to general policies of institutions and to work targets and timetables set down by higher management, and may be doing this within less than ideal circumstances where resources and constraints such as limits on time may be at play. We have noted the reciprocal recognition involved in personhood: staff will be accountable to others in direct but often unseen ways in their responses to the presence of the persons within their care.

Care practices and embodied personhood

We can thus move on to consider in some more detail accounts of personhood as embodied and relational, and how these compare and contrast with accounts of the person as rational autonomous agent, outlined above. As mentioned above, there is a considerable body of work concerned with attitudes towards, and treatment and care of, people living with dementia which examines how models of dementia, and of personhood, may influence the quality of care, arising from careful observation of such care in practice, often building upon ethnographies of care.

An embodied and relational account of the person may fit more naturally with a phenomenological approach to personhood. The fine-tuned detail in observation has enabled accounts of the person which are sensitive to the social world and which emphasise the abilities which may remain despite cognitive and linguistic decline. Work such as that of Pia Kontos and many others has found awareness of self, of others, of the social world, and the expression of wishes, emotions, and desires, in situations where these may be overlooked by more blunt consideration of ‘reason’ ‘autonomy’, ‘cognition’, and, often, by the requirement that such be expressed via language and in response to the rigours demanded within certain social or institutional contexts. In addition, such work also observes ways in which the personhood, the rationality, agency, and humanity of those living with dementia is present but is overlooked or countered (Kontos 2004, 2005; Fuchs 2020; Mitchell et al. 2020).

Such research presents several findings of interest to us. Certain individuals may exhibit more of the capacities of personhood such as autonomy and rationality than may be readily apparent, and these capacities may be manifest through embodiment and through participation in a social world. The capacities of personhood may be readily diminished by circumstances and hence may need protection and nourishment by others and by the arrangement of the social world. Hence, accounts of what it is to be a person may be offered to rival the ’rational autonomous agent’ models which focuses so much on the individual and on the brain. In differentiating such approaches, Charles Taylor’s distinction between the buffered self, where there is a firm boundary around self and others, in contrast to the porous self, may also be helpful (Taylor 2007).

Thus, a considerable body of work in recent years has critiqued models of the person that may imply that people living with dementia have lessened personhood. Linked to such work are suggestions that replacing more cognitive models of personhood with models of embodied personhood may enhance practice and care. In critiquing dominant models of the person, Mitchell et al. outline what they argue are two dehumanising and intersecting patterns: ‘The increasing division, judgement, and exclusion of persons based on difference, disability, and undesirability’ and ‘the increasing attention to management and control and their links to ageism, healthism, and consumerism’ (2020, 2). They relate this to accounts of the individual person, in particular to the rise of the ‘modern self’ linked to the brain and memory, and to individualistic accounts of autonomy, arguing against dualist accounts which split mind from body and which ‘hold cognition to be the guarantor of selfhood’, which they claim harmfully shape the experiences of people living with dementia and their families. Mitchell et al. propose applying a concept of citizenship which recognises relationality and embodiment – what Kontos and others call ‘embodied selfhood’ – in care practices. This would take careful note of power practices within care and caring relationships. Their position thus amounts to a favouring of certain approaches to understanding the individual, the self, the citizen, over others.

Tom Kitwood’s work on personhood and dementia has been extremely influential on practice. He argued that a notion of the person overly focused upon cognition, agency, autonomy, and rationality, can be damaging to people with intellectual impairments, and strongly suggests widening our notions of what it is to be a person to include relationships and moral solidarity. As we have seen, standard accounts of what it is to be a person include the capacity to respond reciprocally to others as persons. Such relationality is greatly strengthened in accounts such as that of Kitwood and other advocates of person-centred care, focusing on paying acute attention to the individual needs of the person as a whole human being and at the conditions under which personhood develops and flourishes. While advocates have noted the necessity of valuing person-centred care at both the individual and the organisational level given the obstacles to achieving such care (Clisset et al. 2013), randomised control trials have confirmed that interventions including person-centred care, together with psycho-social intervention and anti-psychotic review, can have tangible effects and improvement on quality of life for people living with dementia (Ballard et al. 2018). However, we do not wish to oversimplify this as a solution. In practice this ideal may fail to manifest, and often boils down to a proxy of personhood, a third person account given by someone close to the person who provides their own projection of how that person lived or who they felt they were to construct an account of the likes, dislikes, and interests of an individual person (Featherstone and Northcott 2021).

The models that emphasise embodied personhood in the context of care are doing something quite different from many of the more cognitively based models applied within the context of medicine. The emphasis on careful observation of individuals especially within a social context, and on embodied aspects of personhood, show how more cognitively focused models, especially those which rest heavily on language, may fail to see aspects of agency and personhood even where they exist. So to this extent, such embodied models of personhood are rivals to other more cognitive, 'rational autonomy' accounts – hence the work of those such as Mitchell et al. (2020) suggesting they should replace such accounts. But such models also fit better within a different epistemology, not simply one which observes and sees agency and personhood within the behaviour, appearance, and lived embodiment of the human being, but one which emphasises a phenomenological account of direct perception of the other as person. An ethnographic methodology which aims to observe the meanings of actions within a social world presents a very different view to the 'checklist' of competencies, which latter may fit better with more cognitively based accounts of personhood.

Rejecting personhood

Because of the variety of different approaches to, and models of, personhood in this field, Gilleard and Higgs have suggested we should ditch the concept entirely, deeming it unhelpful to act as the foundation for care of people living with dementia (Gilleard and Higgs 2016). They look at different putative constituents of the person as suggested by various philosophers and practitioners, including agency, autonomy, consciousness, memory, self-hood, personal identity. They argue, as do others, that differences between such positions lead to the conclusion that the entire idea of personhood is 'logically confused and morally objectionable' (Sapontzis 1981, quoted in Higgs and Gilleard 2016), and suggest rather using the term 'abjection', a term first introduced to sociology by Bataille (1999), as a central social imaginary of the fourth age. Abjection does not refer specifically to any particular issues of dementia. It may simply refer to physical frailty.

They consider there is an unhelpful gap between a professional rhetoric of person-centred care and the realities of care practice, arguing that 'placing such a confused and confusing concept as personhood at the centre of any set of organisational practices of care … risks undermining the basic moral imperative of care that is central to society's responses to disabling old age' (2016, 774). The relationship between a rhetoric or conceptual model of personhood, and the realities of care practice, seems to be the crux of the matter for Higgs and Gilleard. An underlying assumption appears to be that in order for the notion of personhood to be of benefit in understanding and improving care practices, one must produce an (agreed) set of necessary and sufficient conditions for a model of personhood which is then applied in the concrete manifestations of practice. Kitwood, they argue, 'sidesteps' this issue by treating personhood as an assumed moral status (2016, 778).

Higgs and Gilleard give a condensed and varied account of work on persons from a wide range of periods and of approaches to philosophy, marking a difference between metaphysical and moral accounts. They note the difficulties of producing a metaphysical account of the person based upon a set of necessary and sufficient criteria, which they call a ‘components approach’, concluding that there is no overall coherent account of ‘the person’. They distinguish philosophical accounts of the constitution of personhood, from accounts which consider the conditions for the existence of personhood, for example accounts which see it as grounded in reciprocal relationality such as that of Martin Buber’s based upon the ‘I-Thou’ relationship, or developmental accounts of human psychology and growth (Buber 1970).

Yet this division seems to be dubious, or at least an odd way of explaining such accounts, since these are accounts of the recognition of personhood, and the possibility of such recognition as well as conditions for the flourishing and growth of persons as persons, must be closely related to any account of how personhood is constituted. As we have seen, reciprocal recognition of other persons is a core feature of accounts of the constitution of personhood, and even an account based upon purely mental criteria must allow that these are manifest in the world in some way. It may be that Higgs and Gilleard are working within a ’buffered self’ model of personhood, whereby the recognition or otherwise of persons by others, and the consequent impacts upon an individual’s flourishing as a person threatens the very idea of personhood, in ways which it would not within a more ‘porous self’ model.

Higgs and Gilleard further argue that Kitwood confounds the metaphysical and moral accounts of personhood, ‘treating personhood as little more than a moral entity, “a valid object of our moral concern”’ (p. 779). Given that, according to many mainstream accounts, some people living with dementia lack some of the criteria of metaphysical personhood, and hence concluding that there is no sufficiently coherent metaphysical concept that can adequately sustain appropriate moral attitudes towards people living with dementia, their approach is to argue that the concept of the person is hence obviated, because ‘we also recognise that many people with dementia lack some of the capabilities deemed to constitute metaphysical personhood – such as self-awareness, reflexivity, second-order volition and narrative unity and that such deficits increase with time’ (p. 779), suggesting as a replacement, the strategy of contesting the malign social imaginary of the fourth age. Conversely, Kitwood, they argue, fails to distinguish presenting an account of what it is to be a person which will conceptually include people living with dementia as persons, from the pragmatic care strategy of acting in ways to help sustain the personhood of people living with dementia.

The necessity of personhood

But Higgs and Gilleard’s argument only holds insofar as we can hope and expect that we can produce a coherent and accepted metaphysical account of the person, *and* that this will match best care practice, insofar as it also provides a moral account of the standing of the person. This already shows a bent towards a certain account of what it is to explicate a concept, one characteristic of certain strands in analytic philosophy. But it is also more fundamentally flawed insofar as it omits fully to grasp the implications not just of the attitudinal stance of care that those such as Kitwood propose, but of the phenomenological and relational accounts of the person, of encounters with the other, which are proposed by certain philosophers whose approaches to conceptual explication and epistemological discovery of the person differs so radically from those working in what for the sake of simplicity we can describe as more analytic traditions. Higgs and Gilleard expect a tight connection between metaphysical and moral accounts; but in doing so, they perpetuate a philosophical model in which our actions follow from a conceptual map of the world, preferably clearly defined, which, moreover, we ought to be able to explain, and on the basis of which we act. This in itself tallies closely to a certain conception of the person.

We suggest, instead of ditching personhood, that these *different* strands and understanding of the person are essential to retain and understand how it is that fissures arise and how it is that difficulties for people living with dementia are almost inevitable. Contrary to Higgs and Gilleard's claim that the multiple meanings attached to the term 'personhood' in metaphysics and moral philosophy render the concept relatively unhelpful, the different accounts of personhood in fact help to illuminate the precarious and ambiguous position of humanity. The common methodological approach of attempting to assert that there must be one central or essential account of necessary and sufficient conditions for personhood perhaps expresses one response to that precarity: a striving to unify our precarious and troubled state. We are, as persons, precisely located in a liminal space, 'a little lower than the angels' as the psalmist put it (Psalm 8, World English Bible), and as many others have pointed out in a range of different but related ways. Our dual nature as creatures who can reflect on ourselves both as individuals and as members of a group or groups, our capacity for incapacity, our reason and our failures to reason, our recognition of each other and our need for a morality of some sort to address our very failures to recognise each other fully, are part and parcel of our very condition as persons.

Our own observations suggest that neither strand of thought regarding personhood, the cognitive rational agent, nor the embodied relational person, are straightforwardly visible in the hospital wards where people living with dementia are often found, although both are perhaps there to be discovered. Personhood as a concept and a goal has been embedded in the discourse of the ward and of practice for over twenty-five years (Kitwood 1997), but our observations show a setting where the individual person is always subservient to the needs of the institution. Despite the discussion on the personhood of the patient living with dementia, the reality of the ward and the expectations of the person within it still share striking resemblance to those conditions described by Menzies Lyth (1959) in the middle of the last century, a setting where personhood is at best a distraction and at worst a nuisance to be minimised at the behest of organisational need.

Any sense of the rational actor model of the person is overridden by the implicit structure of the ward whereby the doctors or senior nurses are the only rational actors, and the cognitively impaired patient living with dementia is irrational, however much their embodied personhood is realised and promoted through clothing, signs, mementos and descriptors. Rational action, such as attempting to leave the bedside to go to the toilet, to leave the ward to go home, to call out for a family member or to challenge intimate care from a stranger is medicalised and recorded as such (wandering, refusal of care) rather than understood as expression of the person and their needs and fears.

What we see instead is a third form of personhood emerge, one distinct from the physical, the cogent or the metaphysical. The personhood we then observe is a projection. Within these settings personhood is an institutional ideal or target, a notion of 'good' personhood, of an idealised older person whom the medical team seeks to restore, and who is assumed to share this aim, even if their own agencies and actions belie this. This projected rational person may have never existed, but is required by the ward and will be rebuilt by its practices. This notion of personhood, dressed up on the ward as an archetype between the good patient and dated stereotypes of old age is often an impossibility for the patient to manifest, a test designed for them to fail, and a situation where notions of personhood do more to diminish the person than embody it.

The issues we have discussed here are complex and merit much more profound discussion and elaboration than space here permits. The debates about personhood we have outlined raise questions in metaphilosophy about how to approach these issues. The questions about which model of personhood is 'correct' arise from a problem, or set of problems, at the heart of our human condition – we are 'metaphysical animals' (MacKinnon 1941), who find it difficult to escape the notion that we somehow exist between two closely related but mysteriously incongruous worlds: we eat, we sleep, we defecate, we huddle together for comfort, we respond to stimuli in the world; and we are aware of this, we reason, we strive for meaning. We are also normative creatures, who desire, discriminate, and deliberate, and are perpetually liable to fail in all we attempt to do.

But as difficult and as entangled such questions are, a clear advantage of continuing to use the concepts of personhood and of the person is precisely because it is so embedded in pre-existing debates within philosophy, psychology, law, and cognitive science, and because the fractures and tensions between different accounts inform us much about the fractures and tensions of the human condition, and hence in particular, the difficulties that all of us, and the most vulnerable in particular, have in navigating the demands placed on us by our own standards as well as by those of others around us including institutions and wider society.

By drawing upon more than one broad model of personhood, we can see at once different but closely linked phenomena: certain aspects of the deterioration experienced by people living with dementia, the institutional forces which fail to recognise the difficulties that they have with fitting in to the requirements of the hospital ward which we have briefly indicated above, the strength of and reason for these forces, and ways of recognising and of combatting this even within the institution.

The picture of the person which foregrounds rational cognition is also (roughly) aligned with the values of the operation of institutions and of the goal-oriented functioning of much medicine. We abandon attention to such models of personhood and the drivers behind them at our peril because this means we will have lost a tool for understanding the clashes and the contradictions which will arise in any complex and value laden situation. This is especially so where we are dealing with liminal situations, the situations arising towards the end of life, and with people who are vulnerable precisely because they no longer fit very easily with the high demands of our socially regimented and technological society – and this includes the staff who are 'lower' down the hierarchy of an institution and especially those who are seen to do ‘basic’ care and ‘dirty’ bodily work.[2] By extending our account of the clashes to the treatment of the staff we have included more explanatory power in our account. We do not have space here to discuss this in great detail, but pressures on staff involved in basic care include the very assumption that their work must be directed to certain tangible institutional and medical goals where their role is subordinate to the work of others, such that their attempts to care may on occasion be chastised for not keeping up an appearance of ‘busyness’; their own purposive agency thus also denied (Featherstone and Northcott 2021).

Our work is thus very sympathetic to the work of those such as Kontos, Fuchs, and others, who emphasise embodied and relational personhood, while we recognise the critical importance of retaining recognition of more cognitive, rational agency approaches to personhood in order to understand the demands upon people living with dementia within the social and institutional world of the hospital, and the difficulties such individuals may have with keeping up with these demands. One might understand such accounts of personhood as more focused upon (aspects of) the ideal potential of individual persons. But to foster and recognise such potential, and to foster and encourage elements of personhood not captured in these accounts, it is essential to draw upon more phenomenological, embodied and social accounts of personhood.

Our work, together with that of many other researchers, shows that to understand how to combat dehumanisation of people living with dementia, we need to understand both how their humanity is in peril through neglect of elements of embodied personhood; and how it is in peril through the failure to see, or to allow to flourish, elements of rational autonomous agency. There is also an interaction between these aspects. Neglect of one can lead to diminishment of the other, and vice versa.

Theories of embodied personhood can be usefully drawn upon in understanding some of the failure to recognise individuals and to enable them to express their status as members of a social world. For example, the impact of clothing and other aspects of personal grooming is such that neglect of these can mean that a person’s social status within the world of the ward – or elsewhere – is diminished and reciprocal interaction with that person consequently less likely (Boddington, Featherstone, and Northcott 2021; Twigg 2010, Buse and Twigg 2015; Kontos 2015). Addressing such aspects of embodied and relational personhood can help to improve a person’s functioning, moving them closer to an ideal of rational autonomous personhood. But the processes of dehumanisation also involve the failure to see an individual as expressing rational agency, as well as the imposition of constraints which make such expression more difficult. A person attempting to get out of bed and walk around the ward may be trying to get to the toilet, simply wanting a walk, be responding to the boredom of confinement to bed, but for people living with dementia, their behaviour may be seen as irrational, as something to be combatted – they are simply ‘wandering the wards’ and must be stopped (Featherstone and Northcott 2021). They present an obstacle to the functioning of the ward and create the danger of a fall, which must be recorded and for which the institution and staff are held accountable. A person

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[2] The importance and priority of basic bodily care work in recognising and enabling embodied personhood contrasts starkly with a view of the body as somehow the mere substrate of an autonomous rational agent. We will have more to say on basic bodily care and personhood in future papers.

falsely presumed, on the basis of a dementia diagnosis, to be incapable of feeding themselves, may resist being fed; such resistance may contribute to the perception of lack of rationality, when in fact it is a manifestation of autonomous agency.

It is also vital to see that a major reason for the dehumanisation of the people living with dementia on wards is not simply our ‘attitudes’ towards them, but the mandates of the institution towards certain ideals of technical and rational efficiency including for those who work within them. To say this is of course, condensing much and eliding many debates and distinctions, but such ideals are closely akin to the ideals manifest within the autonomous rational agency approach to personhood. We need both to recognise the pull and validity of such ideals while recognising the need to mitigate aspects of their impact. It is found that the demands on people living with dementia on hospital wards to comply with the rigour of the timetables and the requirements of behaviour on the ward can lead to resistance and refusal of care, which in turn may lead to assumptions of irrationality, further entrenching the behaviour deemed problematic, giving rise to ‘looping’ (Featherstone Northcott, and Bridges 2019; Bridges et al. 2019).

Attitudes and assumptions can no doubt play some role. For example, labelling a person as living with dementia can lead to assumptions of incapacity which are often unwarranted (Featherstone, Boddington, Northcott 2020). Such assumptions can lead to the failure to recognise that individuals are capable of rational autonomy and failure to give them a chance to express it (as well as to assumptions about awareness that can lead to the neglect of personal appearance highlighted on embodied personhood accounts). But note that it may be precisely the requirements of a high standard of ‘rational agency’ in service to the institutional requirements to deliver items of care – meals, medicine, etc – on time, that is a partner in crime here. While condensing many debates and distinctions, note too that such institutional ideals are closely akin to the ideals manifest within the autonomous rational agency approach to personhood. Indeed, the difficulties that the care staff experience in attempting to live up to these standards of efficient rational agency is a major source of their workplace stress. But this stress is not simply the stress of having, for example, unmanageable targets to move inanimate goods around a warehouse. It is the impact that this has on their reduced capacity to care for and relate to patients as persons (Featherstone et al. 2019, Featherstone et al. 2020, Featherstone and Northcott 2021).

In summary, cognitive rational autonomous agency is still present as an ideal for some aspects of personhood even for those who promote a notion of embodied and relational agency. One aspect of embodied personhood is indeed the capacity for reason and autonomy; an objection made to a cognitive rational agent account of personhood is that the diminishment of such powers should not in and of itself diminish personhood, because personhood should be understood in a richer way. But the embodied personhood proponents also argue that a certain degree of rational and autonomous agency may be present yet below the level of detection for those who take too literal an approach to rational agency, and they point this out precisely because they value rational autonomy and wish to encourage it. Encouraging its recognition is one strategy among others which may help to raise the possibilities of reciprocal recognition of personhood, a recognition which helps to bring into present and social reality that very personhood.

The demands of the hospital ward to exhibit aspects of personhood understood as rational autonomous agency – generally expressed linguistically or through obedience to the rules of the ward - and to exhibit them in particular ways, and according to particular timetables and goals, paradoxically makes it less likely that people living with dementia will be able to demonstrate them to the satisfaction of the hospital ward. In addition, the focus of the ward on certain goals and aims – e.g. to prevent falls hence to prevent ‘wandering’, to focus on medical aspects of health hence neglecting appearance, leads to a diminished perception of personhood, either because the perceptual cues of personhood such as appropriate attire and comportment are absent or spoiled, or because behaviour elicited in response may be seen in a disapproving way, and as lacking reason, such as attempting to go to the toilet even though a continence pad is in place. In some instances this may lead to the person retreating from social view and from engagement with the world of the ward. In other instances, this may lead to resistance or to behaviour considered irrational which may paradoxically precisely exhibit rational autonomous agency – the desire to go to the toilet rather than use an unnecessary continence pad, the desire to feed oneself, the refusal to take medication that a person does not recognise.

In future work we examine in more depth the development of models of the person and the technical rationality which accompanies it.

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