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Understanding the person with dementia: a clinicophilosophical case discussion

ARTICLE

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SUMMARY

This article examines the notion of personhood and shows how it offers a robust conceptual underpinning to person-centred care. We use a fictitious case vignette to clarify the nature of personhood. Mental health professionals need a broad view of personhood, which we feel is best captured by regarding the person as a 'situated embodied agent'. Using this characterisation, we aim to demonstrate how it can underpin the notion of person-centred care and show the practical implications of this in connection with our fictitious case. The broad view supports a specific approach to people with dementia, but also shows the challenges that face the implementation of good-quality dementia care. Discussion of this case shows both the relevance of philosophy to clinical practice and the ways in which clinical practice can enrich the debates of philosophy.

DECLARATION OF INTEREST

None.

The prevalence of dementia is set to rise inextricably with the ageing of the population (Hughes 2011a). Person-centred care is the watchword of dementia services (Kitwood 1997; Brooker 2004), but it is rarely the reality (Kirkley 2011). We have seen a variety of scandals affecting people with dementia, especially those in long-term care (Parson 2012). It is sometimes asked, therefore, whether the mantra of person-centred care is empty. Alternatives to person-centred care, such as relationship-centred care, have been suggested (Nolan 2004). However, the extent to which these alternatives represent substantial conceptual differences can be questioned (Hughes 2008). It may be that the problems of realising person-centred care in practice reflect deeply conceptual issues, which we hope to point towards in this article.

Our aim is to unpack the notion of personhood and show how it does indeed offer a robust conceptual underpinning to person-centred care. But, in doing so, we also show why, despite its acceptance at the level of policy (Department of Health 2001, 2009; National Collaborating Centre for Mental Health 2007), the radical change suggested by person-centred care means that its successful implementation cannot be achieved in a facile manner. By using a fictitious case vignette, we hope to clarify the nature of personhood in order to show that it:

- underpins the notion of person-centred care
- demonstrates practical implications of this
- supports a specific approach to people with dementia
- shows the challenges that face the implementation of good-quality dementia care.

The SEA view of the person

In this section we introduce the notion of the person as a 'situated embodied agent' (Hughes 2001). This way of characterising what it is to be a person (i.e. personhood) was a reaction to more limited views, according to which the key characteristic of the person is that he or she is consciously able to remember (Box 1).

Locke is probably the best example of this approach (see also Gillett 2008: p. 14; Hughes 2011b: p. 35). He says: 'as far as […] consciousness can be extended backwards to any past action or thought, so far reaches the identity of that person' (Locke 1690; from 1964 reprint: p. 212). Similarly, Parfit (Box 1) has put forward the view that when we speak of persons we are simply speaking of continuing and connected psychological states. The key thing for Parfit is 'psychological connectedness', which involves 'psychological continuity' or 'the holding of overlapping chains of strong connectedness' (Parfit 1984: p. 206).

The worry about this sort of view, as far as thinking about people with dementia is concerned, is that it can readily seem to suggest that personhood is lost in severe dementia. In dementia, that is, the 'chains of strong connectedness' between conscious states of remembering are increasingly loosened. Thus, we find Brock writing:

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BOX 1 Some philosophers on being a person

John Locke (1632–1704), regarded as the first of the British empiricists (who argued that knowledge comes from the five senses, rather than from reason alone), famously described the person as: 'a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking, and […] essential to it' (Locke 1690; from 1964 reprint: p. 211).

David Hume (1711–1776), a Scottish philosopher who continued the tradition of Locke, has been called a 'bundle theorist' because he wrote that when he attempted to find himself, he found 'nothing but a bundle or collection of different perceptions' (Hume 1739; from 1962 reprint: p. 302). He wrote: 'Had we no memory, we never should have any notion of causation, nor consequently of that chain of causes and effects, which constitute our self or person' (p. 311).

Derek Parfit (born in 1942) is a contemporary Oxford philosopher who has also admitted to being a bundle theorist: 'we can't explain either the unity of consciousness at any time, or the unity of a whole life, by referring to a person. Instead we must claim that there are long series of different mental states and events – thoughts, sensations, and the like – each series being what we call one life. Each series is unified by various kinds of causal relation, such as the relations that hold between experiences and later memories of them' (Parfit 1987: p. 20).

> 'I believe that the severely demented, while of course remaining members of the human species, approach more closely the condition of animals than normal adult humans in their psychological capacities. In some respects the severely demented are even worse off than animals such as dogs and horses who have a capacity for integrated and goal directed behavior that the severely demented substantially lack. The dementia that destroys memory in the severely demented destroys their psychological capacities to forge links across time that establish a sense of personal identity across time and hence they lack personhood' (Brock 1988).

BOX 2 Some philosophers on being human in the world

Ludwig Wittgenstein (1889–1951) emphasised that language is an activity or practice in which we are engaged as a 'form of life' (Wittgenstein 1953; from 1968 reprint: §23). Our very understanding, according to him, is only possible in a human-worldly context: 'Only in the stream of thought and life do words have meaning' (Wittgenstein 1946–1948; from 1981 reprint: §173).

Martin Heidegger (1889–1976), in his seminal work *Being and Time*, set out how the nature of a human being is precisely that he or she is a 'being-in-the-world'. Moreover, a human being is not a disconnected observer of the world, but one whose nature is typified in terms of 'being-with'. Heidegger accepts that human beings can be indifferent to one another, but from the point of view of being a human being as such, 'there is an essential distinction between the "indifferent" way in which things at random occur together and the way in which entities who are with one another do not "matter" to one another' (Heidegger 1927; from 1962 reprint: p. 158).

Maurice Merleau-Ponty (1908–1961) was (like Heidegger) another existentialist who characterised our being as 'being-in-the-world', but considered the special role that our bodies play in presenting us to the world. His philosophy is sometimes summed up by the use of the phrase 'body-subject', which suggests both how our subjectivity is embodied and how our bodies are the means by which we gain a subjective purchase on the world: 'The body is our general medium for having a world' (Merleau-Ponty 1945; from 1962 reprint: p. 169).

In response to this rather narrow view of what it is to be a person, the situated embodied agent (SEA) view offers a broader perspective. Whether as embodied beings or as agents, we are always situated or embedded in a context that is always unique, multifaceted and itself provides strong scaffolding for the preservation of personhood.

We are situated in our personal histories, which themselves have biological, psychological, social and spiritual aspects; but we are also situated in particular families, cultures, historical and geographical settings, and we have our uniquely evolved legal and moral codes and so forth. Our bodies, too, contribute in an important way to our standing as human persons; and, of course, as persons we act in and on the world in which we live. But we are not just bodies, nor are we agents simply in the sense that we wish to live autonomous lives. The notion that we are autonomous runs up against our deep rootedness (or embeddedness) in a world of other agents with whom we must interact, interconnect and on whom we are – we have been and always will be – mutually dependent. Hence, the notion of 'relational' autonomy seems more apt (Nuffield Council on Bioethics 2009). But the idea of being embodied is also layered. Thus, the Canadian philosopher, Charles Taylor (born 1931), spells out that:

> 'Our body is not just the executant of the goals we frame […]. Our understanding is itself embodied. That is, our bodily know-how, and the way we act and move, can encode components of our understanding of self and world. […] My sense of myself, of the footing I am on with others, is in large part also embodied' (Taylor 1995: pp. 170–171).

Indeed, for Taylor, rather than particular internal mental states, crucial to our understanding of ourselves are the notions of 'embodied agency and social embedding' (Tayor 1995: p. 169). These thoughts draw on the work of thinkers such as Wittgenstein, Heidegger and Merleau-Ponty (Box 2).

Taylor emphasises that the person must be seen as 'engaged in practices, as a being who acts in and on a world' (Taylor 1995: p. 170). The point to note is that, according to this way of thinking, being engaged with the world is not a mere empirical feature of personhood, i.e. it is not that persons just happen to act like this; it is rather that, at a conceptual level, it is constitutive of persons that they must act 'in and on a world'.

A conception of persons that left out this aspect of our lives would not simply be thin, it would be missing a constitutive feature. That is, our situated embodied agency – our being-with-others, our bodily engagement in and with the world – is not a matter of contingency (Box 3). This is what it is to

BOX 3 Contingent and constitutive accounts

The difference between contingent and constitutive accounts is crucial:

- a contingent account of what it is to be a person might have been otherwise (it is contingently true that one of the authors of this article was born in London and one was born in Whitehaven, but these facts could have been otherwise)
- a constitutive account sets out what constitutes being a person – what it is to be a person as such, whatever one's life history.

be a human being: it is precisely to be a person with a certain sort of standing (as a situated embodied agent) with others in the totality of the world.

If we are giving a constitutive account of what it is to be a person, then person-centred care, if it is to reflect such an account, must engage at this level. As Heidegger might have said (Box 2), if you are indifferent to me, which you can be, if you treat me as a mere object (not as a 'body-subject' as Merleau-Ponty might have said), it is nevertheless a matter of being indifferent and uncaring in the face of our nature as human beings who are, constitutively, mutually engaged, interconnected and interdependent. It is a contingent fact that you can ignore me or not, but there is no getting around the fact that our situated nature as beings of this sort means that our characteristic response to one another should be that of solicitude.

The SEA view in practice

So far we have sketched a characterisation of personhood. We shall now show, using a fictitious case vignette, how this broad view underpins our understanding of real people, including those with dementia.

Case vignette: Mr Walker, part 1

Life story

Mr Walker was one of seven children. He had a poor relationship with his father, who would frequently drink and become violent. When, as a child, Mr Walker wet the bed his father would become very angry, sometimes hosing him down in the backyard, which was very frightening and humiliating. He adored his mother, however, and was devastated when she died relatively young. He left school when he was 15 years old and worked in the building trade. He progressed to supervisory roles and was known as a tough but fair boss. He married Margaret and they had three children. His family describe him as strict and quick to temper: he was frequently intolerant of his own children, but in later life enjoyed spending time with his grandchildren. He also enjoyed being outdoors, working on his allotment.

Personality

Mr Walker was a very private man and disliked visitors in the house. Nevertheless, he spent three or four evenings a week at the local social club, where he drank quite heavily. He was quick-tempered, but rarely physically violent. He was quite possessive and jealous, but also loved his wife dearly. His family describe a mellowing in later years and attribute his parenting style to his own tough upbringing. Alcohol brought out the worst in him. He was normally well mannered in public, disliked bad language in front of women and valued hard work and discipline.

Cognitive health

Mr Walker began displaying signs of memory impairment when he was 76 years old. He was initially thought to be depressed and was treated with an antidepressant. Two years later, he was diagnosed with mixed vascular and Alzheimer's dementia, with frontal lobe involvement. His deteriorating behaviour and aggression led to his admission to long-term care. He can be sexually disinhibited and has paranoid ideas about his family spending money, his wife having affairs or people trying to steal his job. He can become more agitated during periods of high activity and staff changeover. He sometimes tries to follow staff out of the door, because he wants to 'go home' or 'go to work'.

Physical health

Mr Walker suffers from arthritis in his hands and knees, which can cause pain. He is prone to chest infections and urinary tract infections. He is otherwise physically well and his mobility is generally good. Mr Walker has a reasonable appetite, but is not always keen to eat in the company of others. He suffers from urinary incontinence at times and becomes very embarrassed and anxious when this happens.

Understanding Mr Walker

The story of Mr Walker immediately allows us to understand something about him. The more details we have, the greater our understanding. This seems obvious. But we wish to make two points. First, in understanding his narrative, which we might hear from him or from others, we understand him precisely as a person. Second, the understanding we gain from his narrative is not an understanding solely of his conscious mental states, albeit we learn something about these; rather, inasmuch as it is an understanding of him as a person, it is an understanding of a whole lot of things which make up his surround (Hughes 2011b) and which will maintain his standing as a person even if the 'chains of strong connectedness' between his psychological states start to loosen.

Situation

Let us briefly consider how we can characterise Mr Walker as a person using the SEA view. His history situates him. But it does more than this,

because without it we understand nothing. His behaviour as an adult stems from his experience of the world as a child. His whole way of being in the world reflects his embedding in a particular time and culture: the inner city, Newcastle upon Tyne, in the 1930s. But Mr Walker's situated narrative is not just a social or cultural phenomenon; it is embodied in this man in particular ways, which reflect his unique experience of, for instance, his father and his mother. Part of that experience is itself embodied in genetic predispositions, to drink alcohol perhaps, and embodied too in the automatic reactions and thoughts he might have as a consequence of his life experiences. These reactions and ways of thinking are themselves bodily manifestations of psychosocial influences, which have imprinted themselves on Mr Walker's character. There are characterological traits, which predispose him to depression, anger or paranoia under particular circumstances.

Embodiment

Meanwhile, his embodiment shows itself in terms of his arthritic pain, his frontal lobe brain dysfunction and his urinary incontinence. But these are not simply bodily happenings. They are real occurrences in the life of this man right now and their consequences are, at the same time as being biological, also psychological and social. His embodiment is situated in his present context, but it has consequences in terms of his actions.

Agency

Mr Walker's 'agentive' being, his need to be in control and to feel usefully employed, is compromised by his whole situation. But rather than this undermining his standing as a person, it should point us in the direction of how we might help to maintain his personhood.

The sum: a situated embodied agent

These sorts of consideration, which show a deepening of understanding of Mr Walker, also establish the points we wish to make. First, his narrative, which has to be regarded as something situated – it cannot float free from its multifarious surroundings – reveals to us Mr Walker, not as an abstract or disengaged entity, but as a human person embedded in his own unique, multilayered context. Furthermore, part of the appeal of this view of the person is that it is not circumscribed: for any individual, we cannot stipulate in advance what it is that will constitute his or her unique field. Second, because of the way in which the surround or context is constitutive for the individual person, it provides a means by which the individual's personhood can be maintained even in the face of worsening dementia (Aquilina 2006). This stands over against the narrower view of the person according to which personhood is undermined by loss of memory. In which case, the broader view should support any approach that seeks to maintain the person's standing by attention to his or her surroundings: psychosocial, cultural, spiritual, environmental. The list of factors that might be important is, in principle, uncircumscribable.

In the next section, therefore, we shall consider Mr Walker's needs and how they might be met.

Case vignette: Mr Walker, part 2

Current environment

Mr Walker now lives in an all-male care home. He has good relationships with staff and other residents, although he can also react badly to the behaviour of others. He can be very sociable and witty and often enjoys group activities such as bingo or listening to music. But he gets very bored at times and he can become restless, pacing and looking lost. Mr Walker gets little opportunity to go outdoors, which he used to enjoy so much. His wife and children visit weekly.

Behaviour support plan

Target behaviours

Staff have identified the following behaviours as causing themselves and Mr Walker the most distress:

- agitation and aggression, swearing at staff and residents, demanding they leave his home, telling them to get to work and stop being lazy
- embarrassment and distress following urinary incontinence, which can turn to aggression
- agitation and aggression when trying to follow staff out of the building when he thinks he should be going to work or home.

During these episodes Mr Walker can appear angry, frightened and frustrated. Staff have identified that Mr Walker has a need for purpose, independence, and to feel safe and secure.

Interventions

General agitation and aggression. Mr Walker misidentifies other people as family members, old work colleagues or his wife. He can become angry and threatening towards those he is targeting. Staff should attempt to distract Mr Walker with a short walk or a cup of tea and take him to a less stimulating environment. He can respond badly if his beliefs are challenged, so it is best not to do this directly. He can respond well to empathy about how upsetting he must be finding things. He responds better to male staff (he has been described as 'a man's man'). Personalising his room and making him feel more at home might lead Mr Walker to view his room as a place of safety away from others. It might be useful to consider a trial of anti-dementia medication.

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Incontinence. Following urinary incontinence, Mr Walker sometimes tries to disguise what has happened and can be sheepish, embarrassed and fearful of the possible consequences. He was always very private, so the combination of this and the fear of repercussions can cause him to react violently. Staff must deal with these episodes as discreetly as possible, with a minimum of fuss and a maximum of sensitivity. Mr Walker does not mind female staff helping him at these times and responds well to reassurance. He may sometimes deny that he has been incontinent, in which case it may be better to wonder whether there has been some other form of accident, such as some spilt tea, rather than confronting him and drawing attention to what has occurred. This might encourage him to change his clothes while avoiding embarrassment. It can help to compliment him about how smart he always is.

Trying to follow staff out of the building. Periods of high activity and staff changeovers are difficult for Mr Walker. Mealtimes are a known trigger, so one tactic is to offer him meals in a quiet environment where staff can come and go quietly. Staff should also avoid wearing coats in residents' communal areas and shouting goodbye to one another. Sometimes taking time to disengage from Mr Walker can help, with the new staff member sitting for a few minutes with him before the other staff member leaves. Providing meaningful occupation is important. Mr Walker gets bored easily so it is very natural that he feels the need to go elsewhere in search of something to do.

Therapeutic engagement

In the second part of the case vignette, we have described Mr Walker's current circumstances and set out the behaviours that can seem challenging. In addition, we have outlined a behaviour support plan which attempts to identify target behaviours and interventions that might meet the needs that drive the behaviours (James 2011). We wish now to stress the ways in which the broader (SEA) view of the person supports the holistic presuppositions of the sort of model used in part 2 of the vignette. Indeed, the SEA view suggests that such a model is inevitable, since anything less would, by implication, overlook some aspect or other of the individual's standing as a person.

To put this another way, the sort of behavioural model captured in part 2 takes seriously every aspect of Mr Walker's life. If, clinically, we are trying to understand his behaviours, then from the perspective of the SEA view we need to think as broadly as possible. To put it all down to his brain pathology, which is then best treated by altering neurochemicals using psychotropic medication, ignores the profound effects of his early life history. To try to explain his actions simply as deeply ingrained patterns of behaviour and to ignore the effects of his current environment and of the pain he now experiences from his knees seems too crass. To understand the paranoia and anger that accompanies his misidentification of others purely in social constructionist terms (i.e. to look solely for the social causes of his distress) is potentially to ignore the possibility that medication might help him. To deal with his urinary incontinence as if it were simply a physical problem would be to ignore his whole psychosocial history.

Not only does the SEA view support the broadest possible understanding of Mr Walker, which will help in our understanding of his needs and his behaviours, but it also points in the direction of how we might intervene to help him. Providing him with privacy in a space which feels to him to be his own, taking him seriously – these are ways of showing him true respect on the basis of our understanding of his life history, in which his current state is, after all, embedded. His situated being in the world as a man of this sort (biologically, psychologically, socially and spiritually) means that we should take him seriously on these grounds. His embodied nature means that we must look after him bodily; but through our bodily encounters with him we can still show our concern and understanding. Mr Walker remains an agent, someone to whom meaningful activity and human interactions are important.

Discussion

In this article our aim was to clarify the nature of personhood. Once we consider real people, such as Mr Walker, the view of what it is to be a person inevitably broadens. Mr Walker's being-in-the-world is inevitably multifaceted. Moreover, it reaches out and, as a constitutive feature, his situated narrative engages with the world around him in ways that might either sustain or undermine his standing as a self (Sabat 2001). Mr Walker's own understanding of the world, even when he cannot articulate it well, is also an embodied understanding: it is shown by his bodily responses and gestures and will continue to be shown in these ways even when his cognitive skills have significantly deteriorated (Dekkers 2010). He remains a situated agent: a being-with-others who interacts 'in and on a world'. So the philosophy supports clinical practice; but we also see how clinical practice informs the philosophical discussion (Box 4).

The SEA view of the person operates at two levels. First, it encourages a truly holistic, person-centred approach. But this is a contingent level in the sense that things might have been different for Mr Walker and will be different for other people. At a deeper level, the SEA view of personhood

MCQ answers
1 b 2 d 3 a 4 e 5 c

BOX 4 Lessons to be learnt

- What it is to be a person – personhood – cannot be circumscribed; that is, it cannot be narrowed down to one or other facet of our human lives: we are complex biological, psychological, social and spiritual creatures.
- We can characterise the person as a situated embodied agent. This characterisation is useful in terms of contingent matters, but it also gives us a constitutive account of personhood.
- When challenging behaviour occurs, taking the broadest possible view of personhood, which encourages a fuller understanding of the patient's narrative, is likely to enable healthcare professionals to comprehend the patient's unmet needs.
- This broad-view approach is in keeping with and should encourage person-centred dementia care.

presents us with a constitutive account according to which we must try to engage with him in this broad manner because this is intrinsic to our nature as human beings. We can treat him badly or just in a mediocre fashion; but we cannot then claim that this is person-centred care.

Conclusions

We hope to have shown that our view of what it is to be a person underpins the notion of person-centred care. Given a broad notion of personhood, person-centred care must be understood broadly too. There are practical implications, summed up by saying that nothing (from aromatherapy to dolls, from antidepressants to dance) should be ruled out when it comes to seeking ways to help people with dementia. When it comes to behaviours that challenge, the SEA view supports the use of a broad formulation to encourage our understanding of needs which will have to be met in order to help the person with dementia. Moreover, the constitutive nature of the account we have given of personhood means that person-centred care is not a matter of getting things right according to a contingent protocol. It is to do with our deep engagements as people (Hughes 2011b). This is therefore also the challenge to implementing person-centred care. Nonetheless, the challenge cannot be shirked, because our situated nature as mutually dependent human beings suggests the need for solidarity: 'the need to recognize the citizenship of people with dementia, and to acknowledge our mutual interdependence and responsibility to support people with dementia, both within families and in society as a whole' (Nuffield Council on Bioethics 2009: Box 2.1).

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MCQs

Select the single best option for each question stem

1 Person-centred care in dementia:

a is the standard way in which care is provided in the NHS
b is supported by public policies
c is sometimes also known as relationship-centred care
d was previously championed by the philosopher John Locke
e requires a tightly defined notion of personhood.

2 The situated embodied agent view of the person:

a takes the body as the main focus for our understanding of personhood
b establishes psychological connectedness and continuity as essential to personhood
c undermines the emphasis of policy makers on person-centred care
d allows that history and geography are relevant to the nature of personhood
e requires intact cognitive function for gestures to be meaningful.

3 Out of the following, the philosopher primarily associated with the notion of 'being-in-the-world' is:

a Martin Heidegger
b David Hume
c Derek Parfit
d Charles Taylor
e Ludwig Wittgenstein.

4 Behaviours that challenge:

a require only a proper psychosocial response in order to be settled
b should respond to the right psychotropic medication without the need for time-consuming behavioural plans
c always reflect pain and can be treated with analgesia
d usually stem from difficult behaviours manifest in earlier life, which emphasises the need to take a good collateral history
e are suitably approached as manifestations of unmet need.

5 Behavioural support plans are person-centred inasmuch as:

a they target specific behaviours for treatment
b behaviours have to be understood mainly in terms of underlying brain pathology
c they attempt to take into account all of the possible ways in which a person understands their environment
d they are enacted 'in-the-world'
e they reflect an understanding of personhood which champions the distinction between the mind and the brain.