

A narrative analysis of poetry written from the words of people given a diagnosis of dementia

Dementia

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Abstract

This study is underpinned by social constructionist epistemology, which points to the socially constructed character of our worlds, in that we co-create and are co-created by (including experience and identity) our social realities. Through narrative analysis of some poems from the words of people given a diagnosis of dementia, this study engaged in the process of meaning-making in relation to Self-construct and the wider social world. Some narratives evidenced speakers' lack of agency over their experiences, not because of the 'dementia' but due to treatment and care contexts. Some narratives provided instances in which others positioned speakers into identity constructions contradictory to their life-long Self-constructs. Other narratives demonstrated that, through acknowledging and supporting 'personhood', speakers retained a sense of well-being and purpose in their social worlds. It is hoped that focusing on the words of individuals given dementia diagnoses, away from predominant bio-medical discourses, may facilitate professionals' continuous reflection and person-centred practice.

Keywords

dementia, narrative, personhood, positioning theory, self

Background

There are currently 800,000 people with a diagnosis of dementia in the UK (Alzheimer's Society, 2012). Although in recent years the government has made a commitment to dementia care and research (see the National Dementia Strategy (Department of Health, 2009) and the National Health Research Institute's 2011 call for dementia research), the

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main thrust of dementia research has been primarily bio-medical, based on positivist traditions and seeking to provide evidence for cause-effect relationships according to isolated and specific variables, such as orientation to place and time, memory, language skills, attention, visual perception, problem-solving skills – considered to be the main cognitive processes impaired by dementia – and social functioning and activities of daily living. If the predominating biomedical approach to dementia was sufficient, then it should be able to provide a full explanation for the symptoms and course of the condition, however, as highlighted by Kitwood (1990), medically oriented research leaves around 70% of the variance between neuropathology and dementia unaccounted for. Furthermore, the biomedical approach has been critiqued on a number of grounds: for being deterministic and reductive; for incongruities between cognitive functioning as measured by standardised assessments versus that which is observed in social settings; and for its over-reliance on neuropsychological test batteries (McLean, 2007; Sabat, 1998, 2001; Sabat & Gladstone, 2010).

Despite some valuable case studies (e.g., Hydén & Örvulv, 2000; Sabat, 2000, 2001; Sabat & Gladstone, 2010; Sabat & Harré, 1992) and other qualitative research (e.g., (McFadden, Ingram, & Baldauf, 2000; Menne, Kinney, & Mohardt, 2007; Temple, Sabat, & Kroger, 1999; Westius, Andersson, & Kallenberg, 2009), there is still minimal research focus on the psychosocial aspects of dementia. Admittedly, there are studies which have sought to assess the benefits of person-centred approaches to dementia care, but these too are relatively rare (Fossey, 2007; Vittoria, 1998). The dependence upon the biomedical approach to explain the experience of dementia overlooks how social settings, relationships, treatment contexts, and individuals themselves, impact on the progression of dementia diagnoses. Furthermore, a solely biomedical approach to this phenomenon creates an ideology where the view of the person with dementia is unimportant in understanding their experience, resulting in people with a label of dementia losing their voice.

A step beyond

Social constructionism is concerned with the processes by which people describe, explain and account for themselves and their world (Burr, 1995). Following Harding and Palfrey (1997), a social constructionist model of dementia demands an analysis of the prevailing social and cultural messages and forms of knowledge about dementia, how the label of dementia shapes the lives of those diagnosed and how it informs their experiences and constructions of Self. Along these lines, this article focuses on how people given the diagnosis of dementia represent selfhood through their words (regardless of the level of cognitive impairment), how current constructions of dementia and related practices enable or disable particular ways of being and the effects these discourses and practices have on the recipient of diagnosis and their interactions with others.

Three key concepts inform this study:

- Personhood, conceptualised by Kitwood (1997), refers to a status conferred onto an individual by others in the social world, implying esteem and appreciation; Kitwood posited that both bestowing and failing to bestow personhood have measurable consequences.
- Self, as conceptualised in Harré and van Langenhove's Positioning Theory (1999 [1992]), contains Self1, the Self of personal identity, a person's enduring worldview, which forms the basis of one's actions and enables a sense of personal agency in the world; and

personae, a person's discursively and publically produced identity, thus, dependent on recognition, response and confirmation from others in the social sphere. These aspects form an individual's Self-construct, commonly known as 'identity'.

- The act of positioning, another feature of Positioning Theory (Harré & van Langenhove, 1999 [1992]), locates a person's actions and speech acts within particular social categories, impacting on an individual's personae and, therefore, enabling or disabling an individual from inhabiting particular versions of Self.

Methods

Participants and data

The data source for this research was four collections of poems produced and compiled from the words of people with dementia by poet John Killick (1997, 2000, 2008, 2009). Permission was sought from the poet and the publishers; both were granted. This study focused on poems from 12 speakers. Participants were anonymous, given personal details were not readily available; however, at times, the gender of the participant was apparent in the text, in these cases, 'he' or 'she' were used accordingly. In transposing speech into poetry, Killick adds nothing to the speaker's words (Killick, 2011, personal communication); hence, these poems are an unmodified record of the words of individuals given a diagnosis of dementia. Poem lines are numbered and, for conciseness, the symbol [...] is used to denote text omitted from the original publication where meaning would not be lost.

Methodology

Poems were analysed qualitatively through narrative analysis, which encompasses a rich mix of methodologies informed by multiple theoretical positions (see Riessman, 1993). To focus the analysis, Weatherhead's (2011) composite narrative analysis tool was used, removing the concept of 'temporality', as it does not consistently feature in the narratives of people given a diagnosis of dementia and is not, therefore, a helpful site of exploration. Weatherhead (2011) states that there are two core elements to any narrative analysis: (a) an exploration of the Self-construct of the individual, to understand how narrators view themselves, what has shaped these views and, specifically, how the topic being explored contributed to this process; and (b) a consideration of the cultural influences that impact on the narrative under analysis.

Results

There were two themes named: *Theme One: Constructions of Self* presents the narratives of speakers who are attempting to understand their experiences in relation to the *Self* (i.e., identities), and the skills and abilities that can be seen as facets of their personhood. *Theme Two: the Individual in the World* reveals the narratives of speakers who are attempting to understand their Self-constructs and experiences in relation to others in their immediate environment and the wider social context in which they exist; how this shapes them and their experiences, and how the individual attempts to maintain the *Self* in the world. Both themes are split into two broad narratives and these are further organised into sub-headings (see Figure 1). This article focuses on one example from each sub-theme of the coding frame to evidence the analytical point.

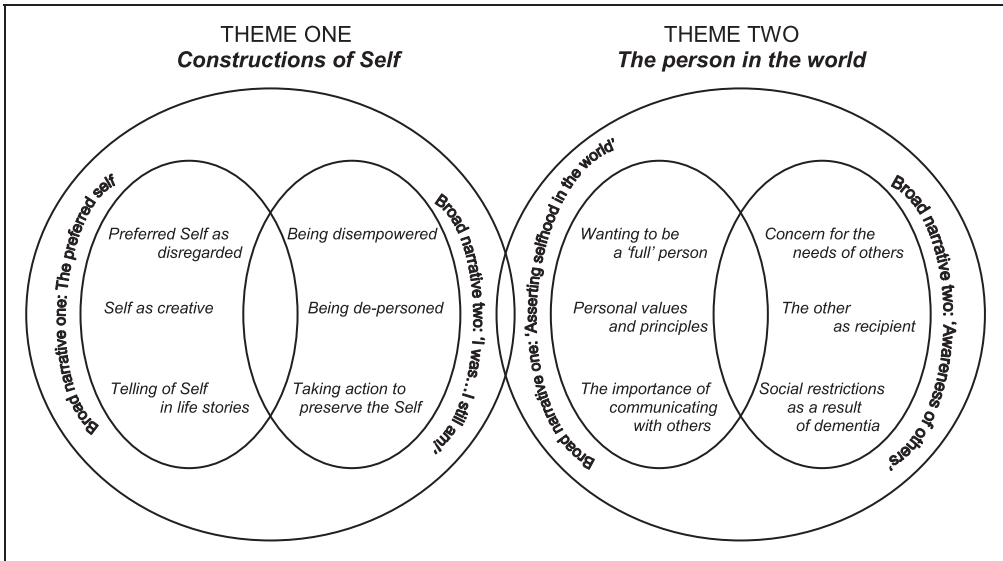


Figure 1. Organisation and interaction of narratives.

Theme one: Constructions of Self

Broad narrative one: 'The preferred self'

Preferred Self disregarded

Narrative extract 1

- 1 I was always singing at school,
 - 2 and singing before the rest of the school.
 - 3 Sometimes I'd stand in the lounge
 - 4 and start singing at the top of my voice.
 - 5 Perhaps the day will come when you will hear me.
 - 6 I was always singing in church.
 - 7 I'm not trying to be biggish, but
 - 8 I can remember when my mother took me there,
 - 9 to the church, and I stood on a chair,
 - 10 and everybody was clapping and shouting.
 - [...]
 - 19 but nobody wants to hear my singing nowadays.
- (Dementia Diary, p. 35)

In this poem, the speaker is sharing attributes in which she has taken and still takes great pride, specifically, her singing ability (lines 1–6). Significantly, in line 5 she reveals a longing for singing (and possibly recognition) to be part of her life again and in line 10 the speaker describes how she was an accomplished and appreciated singer, indicating this is her preferred identity and pointing that to have ones skills positively affirmed by others may

be important for her sense of well-being. However, at present, she is prevented from inhabiting this Self-construct (line 19), because for this to exist it requires the cooperation of others in her social world; without their acknowledgement, the speaker is disabled from inhabiting this Self-construct. From a Positioning Theory viewpoint, there is a disparity between what the speaker believes about herself, *Self1* (that she is a talented singer who brings pleasure to others with her voice), and the *personae* that she is able to occupy in her present circumstances (with her voice currently not valued or regarded by anyone around her). In line 7, the speaker also demonstrates a high degree of insight into appropriate social behaviour, that is, that being boastful about one's abilities is not well-mannered and, thus, she appropriately exercises a disclaimer so she is not perceived as vain, revealing intact social functioning despite the erosion of current context on personhood.

Self as creative

Narrative extract 2

- 1 It's the third year we've been coming here
- 2 and they hadn't got no cushions on the chairs.
- 3 I suggested I put out an appeal for wool
- 4 to make them some cushion covers.
- 5 I took on the challenge to do one
- 6 for each cushion we used, which was twelve,
- 7 and I made one cover a week.

[...]

- 42 The greatest benefit that comes from it
 - 43 Is that it keeps your fingers nimble.
 - 44 And the things people say –
 - 45 they think it's marvellous that you do it!
- (The Elephant in the Room, p. 4)

In this poem, the speaker identified a need for cushions for chairs at the nursing home (lines 1 and 2). He creatively acts to address this need in his environment using his skills at crocheting, and through this experience he feels valued, because a facet of his preferred identity is being given the space to thrive. Crucially, the speaker is able to successfully occupy this creative *personae*, because it is recognised by, and receives the cooperation of others in his social sphere. The speaker's choice of words in lines 3 and 5 reveal the use of purposeful language: 'I suggested' and 'I took on the challenge', indicating that he not only identified but took ownership of the project, positioning himself as useful; further, this discursive act is supported by his seeking out wool and making the cushion covers. In lines 42–45, the speaker recounts the positive consequences of his creative skill; it is evident from his inclusion of the reactions he receives from others who admire his skill, that such affirmation is important to him. This is another example of a speaker whose Self-construct and, therefore, wellbeing is positively impacted upon by the validation of others. However, unlike the previous speaker, this speaker's life-long abilities are still valued by those around him in his present; this successful continuity of valued skills enables him to express himself creatively and retain a sense of control over his life, maintaining his preferred *Self*.

Telling of Self in life stories

Narrative extract 3

- 1 Time goes by and I am still here.
 2 I was a model in my young days – mummy taught me.
 3 I used to put on beautiful clothes and walk about –
 4 north, east, south, west. I used to meet nice people,
 5 some with lots of money. I was 18 at that time.
 6 I sang and was an actress – just small parts.
 7 Memories that bless and burn!
 8 I was set to go to a Stage School, but they said
 9 ‘You’ve got it, just get up and do it’.
 10 I went to a London Fashion School, but they said
 11 ‘You’ve got it, just get up and do it’.
 [...]
 17 My house, I haven’t seen it in ages. I have been here
 18 some time. I think I get lonely because they have all gone.
 19 And I am such an old lady.
 (*Openings*, p. 4)

Line 1 could reveal the speaker’s feeling that she has witnessed the passing of considerable time; however, it could also be an affirmation of the *Self* – reflecting her determination to assert her existence in the world. These words could also indicate how important the process of story telling is to this woman, who (despite memory and other cognitive difficulties) is able to locate her identity in past experiences, thus, retaining a sense of being ‘still here’; an individual with a unique life story. Her choice of the particular telling in lines 2–6 points to a construction of a working, glamorous and well-travelled model as her preferred *Self*. In lines 8–11, the speaker recounts instances when her skills were acknowledged and validated by others; this suggests that having her abilities positively reinforced by others is an important factor for her – much the same as for previous speakers. Line 7 offers a beautifully poetic insight into the poignancy of story telling as someone with a dementia diagnosis: to remember the pleasurable experiences that shaped her identity is a ‘blessing’; however, the retelling of these memories is a bitter-sweet act, because these stories are in her past – the validation and excitement of her identity as a successful model are not features of her present. The speaker further emphasises this in lines 17–19, by drawing a starkly contrasting picture of her present self, as a lonely elderly woman who has been disconnected from her home and the people she knows. The speaker’s ability to explain so articulately this complicated emotional response indicates awareness, comprehension and cognitive processing of her present situation; so her emotional reaction is both fitting and significant.

Broad narrative two: ‘I was ... I still am!’

Being disempowered

Narrative extract 4

- [...]
 7 I don’t need any help.
 8 I can drink my own tea.
 9 I’ve everything I need.
 [...]

16 Everybody says "You can do it."
 17 Of course I can't do it!
 18 But if I'm never given the chance...!
 (*Openings*, p. 30)

In lines 7–9, the speaker is asserting independence, their belief that they do not need looking after for the most basic abilities. This highlights just how much control is being taken away from them and the extent to which they are dispossessed of *personhood*; possibly as a consequence of their diagnosis, since these lines show appropriate use of the first-person indexical, indicating of an intact *Self*. Here, the speaker is standing up against the societal perception that a person with a diagnosis of dementia is not only impaired but disabled. Lines 16 and 17 seemingly contradict initial statements of independence, suggesting the speaker is told by others they *can* do it and it is they who believe it is not possible. This is an example of third-order positioning, in which a story is created outside of the initial narrative by one of the persons performing in the original narrative. This rhetorical re-description constitutes a clear and sophisticated understanding of social positioning. Line 17 also reveals self-doubt and lack of confidence, which could be interpreted as an example of the societal perception of dementia that has been assimilated by the person with the diagnosis. However, line 18 makes clear that the speaker is very aware that they are positioned as helpless and unable to cope, also indicating that despite perhaps feeling that they cannot do it, the speaker is not even given the opportunity to try. This is where the disempowerment stems from; the speaker recognises that it is their right to try and perhaps fail, but this basic process has been taken away from them by virtue of their diagnosis.

Being de-personed

Narrative extract 5

[...]
 15 I'm just a dustbin.
 16 It's all the same here.
 17 Some of the girls grasp you
 18 as if you're a cat or a dog.
 19 They're too young. They can't
 20 understand the problems of age.
 21 It's all the same here.
 22 They're so busy,
 23 they'll help you into anything,
 24 even rags. You're not a person
 25 when you come in here.
 26 Nothing to do, nothing to say,
 27 It's all blackness in front of me.
 (*Openings*, p. 15)

The speaker presents a bleak and painful statement of self-reflection in line 15, with stark insight into how they are constructed as a consequence of their dementia diagnosis. As the narrative develops, the disappearance of the *Self* becomes clear, as the speaker communicates awareness of their context and all that is wrong within it: lack of understanding of old age, staff being too busy and depersonalised treatment. Lines 17 and 18 are particularly striking, as the speaker likens the treatment they receive to that of an

animal rather than a human being. Lines 23–25 further make explicit that the speaker feels their treatment robs them of *personhood* and this is unacceptable. Therefore, the hopeless future to which the speaker refers in line 27, is not linked to the progress of a dementia, rather, it relates to the behaviour of those who are regularly involved in their care. Apparent in this text is a loss of *Self*, the fundamental cause of which is the character of the social interactions with others, and how they position the person with dementia. It is clear that the speaker has insight into what is happening and yet, because of the social positioning of the person with dementia as someone to be cared for without much say in this care, they are powerless to do anything about it apart from recounting what is happening. This narrative is an example of first-order positioning, whereby the speaker has been located within a particular category (as helpless and worthless), which they are unable to renegotiate because it is the predominant positioning of older people, and perhaps particularly of those with dementia diagnoses, by those in charge, thus, it is seen as continuing to evolve without change.

Taking action to preserve the Self

Narrative extract 6

1 I fell in love.
 2 All on me own.
 3 And he fell in love with me.
 4 I didn't believe him.
 5 He wouldn't tell me his name.
 6 He says "I'll come and
 7 I'll see you settled down."
 8 And now he's sleeping with me.
 9 But They've found out.
 [...]

 21 First time I've slept
 22 with anybody since
 23 me husband died.
 24 He makes me happy.
 25 Not right happy, but
 26 happy enough.
 (*Dementia Diary*, p. 33)

In lines 1 and 2, the speaker identifies an experience which she actively sought out for herself and has emotionally enriched her as a human being, falling in love; showing that she has maintained a sense of control and agency over her life and perhaps that she recognised a need for companionship and romantic love in order to feel emotionally fulfilled. Line 4 shows that she was in disbelief about being reciprocated, with lines 5–8 narrating the development of this love story. Line 9 suggests that the speaker felt she needed to hide her relationship from 'Them', presumably those in charge of her care, indicating her awareness of a culture where experiences of love and love-making are not encouraged, even allowed. In lines 21–26, this woman engages in an evaluation of her emotional response to finding love and having her first relationship since her husband's death; clearly identifying the positive impact that the experience of romantic love has on her in line 24. Then, in lines 25 and 26, she further analyses the complexity of emotion by differentiating between the contented sense of happiness she derives from her romantic relationship, as 'happy enough', compared with what she knows as completely or

'right' happy. The speaker recognises that this relationship is satisfying *enough* to make her happy *enough*, displaying a considerable degree of reflection and self-awareness, which undermines the picture painted by the biomedical model of dementia.

Theme two: The person in the world

Broad narrative one: 'Asserting selfhood in the world'

Wanting to be a 'full' person

Narrative extract 7

[...]

37 This place is a school,
38 but they learn you nothing here.
39 There are not men like yourself,
40 men that you can talk to.

(*You Are Words*, p. 34)

The speaker employs a sophisticated use of language in lines 37 and 38, in order to express his feeling that the social world in which he exists does not enable intellectual growth. The use of an extended metaphor to explain this perceived deficiency of his environment is particularly powerful, as it reveals an individual who is capable of abstract thought and is prevented from exploring or developing this aspect of himself due to the lack of learning opportunities in this present context. The use of 'school' as a metaphor for this situation also implies that the speaker feels he is being positioned as child-like; his apparent awareness and articulation of the paradox of a school in which one learns nothing further emphasises that this individual is sensitive to the limitations of his environment and in need of stimulating opportunities. This is another example of second-order positioning, in which the speaker questions the first-order positioning that he (and the other residents of the care home) are incapable of learning or personal development. This challenge to the first-order positioning opens up a dialogue of negotiation with those who have positioned him in this way. In lines 39 and 40, the speaker specifies what he believes is crucially lacking from his environment: interested or engaging people with whom to have a conversation; his desire for a like-minded listener is such a basic one and yet it seems that for this individual this need is not being met within the bounds of his present social situation.

Personal values and principles

Narrative extract 8

[...]

12 A lot of those who come round here
13 are not interested in being kind to others.
14 Kind is the only thing one can do here.
15 It is all there is that can help.
16 I don't *try* to be it.
17 You shouldn't have to *try* to be kind.

(*You Are Words*, p. 11)

In lines 12 and 13, the speaker indicates that kindness is important to her by highlighting that it is a characteristic she looks for in those who share her current social world,

also communicating that kindness is often not expressed by the people with whom she interacts, and revealing a discord between what the speaker believes to be an important life principle and what she experiences in current day-to-day interactions. This perceived failure becomes even more striking when in lines 14 and 15 the speaker pinpoints kindness as the life principle most needed in her present circumstances, as the single most important value that is instrumental to the well-being of people experiencing dementia but, sadly, an unmet need. In line 16, the speaker uses the first-person indexical 'I', to place herself and her value system to exemplify that kindness should come naturally, irrespective of to whom it is being expressed or from whom it comes; demonstrating an aware, morally and humanly intact *Self*. In line 17, the speaker furthers her argument of the intrinsic human capacity for kindness as given by nature and effectively articulates the lack of continuity between the way herself and others around her (i.e., people given a diagnosis of dementia) should be treated with how she feels they are treated.

The importance of communicating with others

Narrative extract 9

[...]
 4 Mum's dead. Dad's dead.
 5 Everything's sold up.
 6 I've got a wonderful wife, though.
 [...]
 10 I had a nice bike, nice pair of breaks.
 11 I was caught by the police
 12 Riding without a licence.
 [...]
 22 Opened the door, let it all out.
 23 That's about all for now.
 24 Put 'etc. etc. etc.' for the rest.
 (You Are Words, p. 14)

In this extract, the speaker recounts some experiences of their present (lines 4, 5 and 6) and some memories from their past (lines 10, 11 and 12). In line 22, the speaker clearly indicates that there is a therapeutic benefit in talking about oneself to a welcoming listener, to being given the space to 'let it all out'. This line also suggests that until now the speaker has kept the door closed against self-expression and has been holding back from sharing their stories and experiences. Perhaps the speaker now feels able to 'open the door' on their life story because the one-on-one meeting with Killick gives them the opportunity to sit with a willing listener who appears to value their voice and the telling of their experiences. Line 23 may suggest that for this speaker the process of talking about oneself is a tiring one, so much so that what they have recounted is all they can manage, but also that the door of self-expression is still open for the future, indicating that the experience is important to them, and one that they wish to repeat. In Line 24, by telling Killick to write 'etc', the speaker is taking control of their own life story and is indicating that there is more to tell, but perhaps on another occasion. Furthermore, these words evidence the speaker's awareness of, and appreciation for, the narrative process that is taking place; also perhaps a recognition of the importance of documenting their story so that it is preserved for the future.

Broad narrative two: 'Awareness of others'

Concern for the needs of others

Narrative extract 10

1 I'd have liked to be in this
 2 of yours. I feel I wasn't quite
 3 last time, though I tried.
 4 I'm not much good at this.
 5 I think you'll have to do
 6 all the work yourself.
 [...]

13 'I don't often speak to my family
 14 now because I really mean to
 15 but it very seldom happens.
 16 I just tell them no,
 17 and I don't for a minute
 18 admit the fact that...
 19 I don't want them to think...
 20 I don't even let them know...

[...]

32 That's a nice little piece
 33 of writing you've done. Its better
 34 that, love, than nothing.
 35 I hope it does something for you.
 (*You Are Words*, p. 63)

In lines 1–3, the speaker indicates to Killick that she wants to help him with his work but she is concerned that the last time they met she was unable to provide what he needed, she emphasises that she did try; however, she warns Killick that she may not be able to give him what he wants (lines 4–6). These lines indicate the speaker's interest in the needs of others and in being helpful and, at the same time, awareness that she may not be able to fulfil them. In lines 13–20, there is a shift in concern to the family, hinting that because her family may be distressed she does not communicate much with them, despite the personal benefits she might gain from doing so. This illustrates the speaker's high regard for others, both her consideration of the feelings and needs of those who share her social world, and her caring action in placing these above her own needs. Then the speaker returns attention to Killick (line 32), offering encouragement that his efforts have been worthwhile. Furthermore, the speaker expresses her hope that the poet will take away something useful from their meeting (line 35); showing that she is able to look beyond the immediate situation and consider how it will impact on another person in the longer term, again articulating her altruistic attitude of helping others.

This narrative demonstrates appropriate use of first-person indexicals, indicating an intact *Self1*. It is also an instance of first-person positioning, in which the speaker positions herself as someone who wants to be useful and helpful; by cooperating with this first-order positioning, Killick can ensure that it continues to evolve, at least for the duration of their meeting, thus, enabling the speaker's desired *personae* to be successfully constructed.

The other as recipient

Narrative extract 11

[...]

3 Sometimes I feel embarrassed
4 talking to anybody, even you.
5 You don't really like to burden
6 other people with your problems.

[...]

12 I want to thank you for listening.
13 Sometimes people don't listen,
14 they give you words back,
15 and they're all broken, patched up.
16 But will you permit me to say
17 that you have the stillness of silence,
18 that listens, and lasts.

(*You Are Words*, p. 10)

The speaker expresses self- and other-awareness in lines 3–6, being self-conscious in communication with others, even when that other is a welcoming listener; by drawing attention to this feeling the speaker is giving importance to this issue. The speaker's words in line 12 add weight to this argument, as they value being listened to and their gratitude that this is taking place. The simple statement of line 13 is deeply revealing of this speaker's present situation and the negative way that this individual feels they are, sometimes, treated by others. It also acts as a social commentary by hinting how the person with dementia is dependent on others in order for their voice to be acknowledged. The words in lines 14 and 15 could be an indication that often the person with dementia is not attended to or is misinterpreted by others, as the messages they are trying to send to others are not accurately responded to – the speaker's articulation of this experience conveys comprehension of this breakdown in communication, which could likely cause frustration or despair. Beautifully, lines 16–18 highlight the validating, and possibly therapeutic, effect of having one's voice heard.

Throughout this narrative, there are examples of appropriate use of first-person indexicals, which demonstrate that the speaker has an intact *Self1*. Furthermore, this narrative is an example of how speech acts can be differentially understood, and have varying social meanings, depending on the positioning of the speaker.

Social restrictions as a result of 'dementia'

Narrative extract 12

[...]

10 I worked as an administrator
11 at Anglia Ruskin University
12 but now I'm unemployed.
13 Once you're diagnosed
14 you have to write to the DVLA
15 and now I can't drive.

(*The Elephant in the Room*, p. 18)

In lines 10 and 11, the speaker demonstrates that prior to her diagnosis of dementia, she was able to assume the position of a fully functioning, employable and employed person.

This is powerfully contrasted with present circumstances, as articulated in line 12, which indicates a social status as unemployed (and unemployable); additionally, her use of 'but now' suggests that the present situation as a person with a diagnosis of dementia is partly responsible for this change. The speaker goes on to elaborate on this change and, indeed, in line 13 she makes it explicit that this has occurred as a consequence of her diagnosis. In line 14, the speaker points to the compulsory and inevitable effect of the social repositioning that a person diagnosed with dementia experiences; she is aware that upon diagnosis, the person will 'have to' write to the relevant authoritative body, with the consequence that even more independence is removed from them by no longer being allowed to drive.

Between lines 12 and 13, the speaker shifts from first-person subject to second-person subject, and in doing so, the speaker lifts her narrative from a personal account to a social commentary on the universality of this social repositioning (for all people who are diagnosed with dementia). In line 15, she returns to the first-person and to an account of personal experience; she again uses the indexical 'now', which emphasises the stark contrast between the social positioning of her past and present. There is a sense of inevitability in this extract, which suggests a feeling of powerlessness as the speaker's social status, that which defines her, is reshaped and redefined by societal forces.

Discussion

Like previous research (e.g., Sabat & Gladstone, 2010; Temple, Sabat, & Kroger, 1999), this study provides evidence that Self and various capacities remain intact in people diagnosed with dementia. For instance, narrative extract 10 is evidence of the capacity to feel concerned for the well-being of others and take action to care for them. Indeed, the speaker demonstrates social sensitivity, emotional intelligence and altruistic motivations. Other common human aspects, such as the capacity for shame and embarrassment, for pride and maintaining dignity and to manifest and experience selfhood, are also evident in the narratives (extracts 11, 3 and 8, 1 and 2, respectively). As Sabat (2001) stated, many of these abilities are highly valued in human society and yet, paradoxically, professionals' assessments of people with dementia do not examine or account for them. Hence, neuropsychological, functional and medical tests should not be used as sole basis for dementia care planning. Instead, these should be understood as elements of a much larger picture of the relationships of each person with a diagnosis of dementia with their social world (including how they are treated by caregivers), in order to arrive at a *truer* (in the sense of more complete) appreciation of each person in the context of their everyday social lives.

These extracts also story how social structures and attitudes play a role not just in prescribing what people with dementia can and cannot do, but also in defining who they are able to be. The analysis highlights that for several speakers, despite retaining capacities and communicating a clear sense of *Self*, as a result of the diagnosis of dementia their *personae* has changed, invariably in a negative direction. For example, in narrative extract 12, the speaker's diagnosis produced a reactive and swift change to her social status and, consequently, life situation. This form of positioning, in which established social structures determine what a person can do, impacts on a person's Self by imposing concrete limitations on them with no accounting for their individuality or their capabilities, thus, presenting a barrier to the successful manifestation of their preferred Self-construct. Experiencing a change (often reduction) in one's status can compromise a person's sense of continuity with valued life-long identity (i.e., personhood), which is fundamental to wellbeing (Kitwood & Bredin, 1992).

Persistence of Self

The analysis shows that, throughout the course of dementia conditions, the *Self* persists. As illustration, extract 3 presents a speaker who is struggling with loss of memory but, nonetheless, effectively uses the process of retelling significant life events to validate their identity. This is a vitally important exercise because, in the narrating of their preferred Self-construct, the *Self* is preserved (Sabat & Harré, 1992). Moreover, the process of storying one's life can help to ensure that an individual's preferred identity is not only maintained but celebrated, which in turn further sustains these preferred identities (White, 2007). Similarly, the analysis highlights that the *personae* of people with dementia labels can persist, so long as it is validated and supported by others in the social world, as in extract 9, which points to a therapeutic benefit in being given a space in which to freely express oneself to an interested listener who, by listening in an engaged manner, validates their story, and identity – since identity is socially constructed (Burr, 1995). Unfortunately, the tendency is for the person with dementia to be positioned as confused (McLean, 2007), leading to their speech acts and other forms of communication being taken by default as indicative of confusion, which is construed as resulting from dementia. Narrative extracts 2 and 8 portray people with a diagnosis of dementia attempting to apply personal life-long values and skills to their current context. Thus, in their effort to thread past and present experiences, they bring continuity and coherence to the course of their lives and their current circumstances.

Creativity

The findings indicate that many of the speakers have a creative identity and the narratives in which the speakers discuss this creative skill are filled with excitement and joy that does not feature so frequently anywhere else in the poems. The narrative *myself as creative* reveals a speaker whose sense of Self is located within their creativity; feelings of self-worth and agency emanate from the speaker's narrative as a result of having a creative identity, an alternative and very personal form of self-expression. This suggests that there is significant emotional and psychological benefit to be gained from being able to access the creative part of one's identity. The analysis also shows that it might be particularly beneficial for people with dementia to have access to a creative outlet which has personal significance, such as a skill learned and used in the past, as this can have an especially positive impact on sense of Self and may enable individuals to feel that they retain control over aspects of their life.

Malignant Social Psychology

The analysis revealed that certain types of interaction foster disempowerment and objectification, which have a negative impact on the person with dementia. Such interactions were described by Kitwood (1990) as 'malignant social psychology', which is severely detrimental to an individual's Self-construct and can lead to an exacerbation of 'problem' behaviours as the individual, understandably, acts out against this harmful treatment. Sadly, but perhaps unsurprisingly, the majority of the narrative extracts offered testimonies of *malignant social psychology*; extracts 1, 4 and 11 clearly exemplify the inability to inhabit the preferred Self, due to obstacles to their discursively and publicly produced identities – referred to as *personae* in Positioning Theory (Harré & van Langenhove, 1999 [1992]). These narratives make explicit how day-to-day care and lack of understanding,

support or valuing from others are barriers to personhood, which may be obscured by the fact that this is due to standard institutional practices (e.g., staff setting tables or making beds in residential/nursing homes, thus, sacrificing residents' autonomy to the advantage of organisational efficiency) and to the absence of 'positive' interaction, rather than active 'malignant' interactions.

Another, more subtle example is extract 7, where the speaker feels they have been confined to an environment which does not facilitate the type of experiences that foster emotional and social growth; highlighting the bad fit between societal assumptions regarding the capacities of people with dementia and their actual capabilities. Indeed, the person exists in a system which functions under the assumption that people with dementia would not benefit from the experiences that 'healthy' people consider a vital part of being a human in the social world and, as a result, are discounted from contributing to the social and emotional fabric of human life. This stands in contrast with the speaker in extract 6, who despite a dementia diagnosis maintains their sense of Self as an emotional and social being by seeking out personally sustaining or enriching experiences; demonstrating that a person with a dementia diagnosis can be an active participant in the complex dynamics of the human social world. Yet a more extreme, and concerning, form of *malignant social psychology* is evidenced in narrative extract 5; the deconstruction of the Self stems from interactions with others, where there is an incongruence between the speaker's self-awareness and their communication of the treatment they receive as though they are not a sentient, feeling being, thus, no longer a person by virtue of their dementia diagnosis.

Critical review

A vital part of the analytical approach, transcribing the narratives into poetic structure, was conducted by poet John Killick; after considered discussions, it was felt that Killick's skill as a poet who has extensively worked with people with diagnoses of dementia, his sensitivity to language and his awareness of the power that it holds, makes this more beneficial than detrimental to the narrative focus of the study.

Additionally, the analysis was undertaken without significant biographical details from the speakers, and such information would have had an impact on how the narratives were interpreted. Whilst this may be seen as hindering the contextualisation of the poems in terms of age, ethnicity, sexuality, class and so on, it also precluded personal assumptions from biasing the analysis and possibly allowed meaning to develop more closely grounded on the narratives and the performative and constructive power of language (Riessman, 1993).

Finally, although the analysis centred on poems developed with just a group of individuals and will not be generalisable to all people with a diagnosis of dementia and, indeed, all care provision, their narratives provide a vivid representation of the complex fabric of human co-constructions within the field of dementia and, hence, can be utilised to think broadly about the issues they raise.

Implications for practice

It is important to consider the relevance of these findings for people with dementia and the proximal and wider contexts in which they live. People with dementia preserve selfhood throughout the course of the condition (Kitwood, 1997) and have the ability to communicate, reciprocate, continue to grow and experience the full range of human

emotions and desires, as evidenced in this study. Policy documents regarding dementia care, such as the National Dementia Strategy (Department of Health, 2009), adopt a largely ‘top-down’, service focused approach. However, because identity is performed socially through language and non-verbal interactions, it is central that relatives, friends and carers (paid and unpaid), professionals and services reflect on the power they have to improve the experiences of people living with dementia – and their own experience of these relationships – by enabling and supporting personhood and, thus, wellbeing at the level of the individual first. In order for this to take place, a person’s preferred *Self* needs to be identified, validated and maintained through:

- Opportunities for narrative expression through creative means, including language but also other medium such as dance and image (which also have a language)
- Assuming that a person with dementia is communicating something worthwhile, taking responsibility to provide a space in which they will communicate to the best of their ability and to respond sensitively (i.e., taking responsibility for misunderstandings)
- Encouraging and facilitating the renegotiation of important aspects of a person’s past, so that that skills and attributes they value continue to inform (and to be performed in) their present
- Respect for choices and preferences, in relation to small things like clothing options and larger matters such as romantic relationships or living environment
- Allowing people with a dementia diagnosis the time to do things for themselves, supported where necessary (even if/when this process takes longer than if someone else were to do it for them)
- Continued opportunities to access emotionally and socially enriching experiences for personal growth and development
- Breaking down social discourses that perpetuate ‘them and us’ attitudes by including people with dementia at all levels in research, services and policy development
- Involving people with the diagnosis of dementia, as equally worthy narrative beings, in reconstructing the dementia diagnosis, assessment and treatment, to reflect the whole-person-in-context
- Investment in supporting family and caregivers so they can maintain relationships that enhance *personhood* and wellbeing

Conclusion

This study highlights that *personhood* and meaningful experiences of people with a diagnosis of dementia can be captured through poetry, which opens up possibilities for interpretation of their narratives and enables a better understanding of their Self-construct; how this is affected by dementia and by interactions with others, and the personal significance of these experiences.

Moreover, these results demonstrate that a dementia diagnosis, and related memory loss or other cognitive difficulties, does not equal a loss of *Self*, nor a loss of the full range of human values, skills, capabilities and needs. It is clear from this study that people with dementia not only have a conscious experience of selfhood, but also of their social position, in terms of what they want to be versus what they are allowed to be. Consequently, these findings add to the evidence mounting against a reductionist

biomedical model of dementia and provide further support to the growing body of literature that demonstrates the need for a whole-person approach to both research and practice with people with diagnoses of dementia. Indeed, these findings demand the formulation of interventions that are not prescribed but, rather, are centred on the person as an individual-in-the-world, whose experiences are inherently tied up with their Self-construct. This also calls for research approaches that continue to develop fuller understandings of people with diagnoses of dementia. Because we are narrative beings (Bruner, 1987), narrative analysis is useful in this regard, giving voice to the people at the centre of this experience, enabling access to the personal world of people with a dementia diagnosis, who are all too often unrepresented and neglected.

To conclude, the present study has demonstrated that conceiving of dementia as residing *within* the individual who carries the neurological impairment, is a short-sighted and limited standpoint, rather, a responsive, accountable and valuing praxis will see the person given a diagnosis of 'dementia' located in its wider interpersonal, social and political context.

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References

- Alzheimer's Society. (2012). *Alzheimer's Society dementia 2012 report*. London: Alzheimer's Society.
- Burr, V. (1995). *An introduction to social constructionism*. London: Routledge.
- Bruner, J. (1987). Life as narrative. *Social Research: An International Quarterly*, 54(2), 11–32.
- Department of Health. (2009). *Living well with dementia: A national dementia strategy*. London: Department of Health.
- Fossey, J. (2007). Enhanced psychosocial care as an alternative to use of antipsychotics in nursing homes for residents with severe dementia: A cluster randomised trial. *The Journal of Quality Research in Dementia*, 1, 26–29.
- Harding, N., & Palfrey, C. (1997). *The social psychology of dementia: Confused professionals?* London: Jessica Kingsley Publications.
- Harré, R., & van Langenhove, L. (1999 [1992]). The dynamics of social episodes. In Harré, R., & van Langenhove, L. (Eds.), *Positioning theory* (Chapter 1, pp. 1–13). Oxford: Blackwell Publishers.
- Hydén, L. C., & Örvulv, L. (2000). Narrative and identity in Alzheimer's disease: A case study. *Journal of Aging Studies*, 23, 205–214.
- Killick, J. (1997). *You are words: Dementia poems*. London: Hawker Publications.
- Killick, J. (2000). *Openings: Dementia poems & photographs*. London: Hawker Publications.
- Killick, J. (2008). *Dementia diary: Poems & prose*. London: Hawker Publications.
- Killick, J. (2009). *The elephant in the room*. Cambridgeshire: Cambridgeshire Libraries.
- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society*, 10, 177–196.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12, 269–287.
- Menne, H. L., Kinney, J. M., & Darby, J. M. (2002). 'Trying to continue to do as much as they can do': Theoretical insights regarding continuity and meaning making in the face of dementia. *Dementia*, 1, 367–382.

- McFadden, S., Ingram, M., & Baldauf, C. (2000). Actions, feelings and values: Foundations of meaning and personhood in dementia. *Journal of Religious Gerontology, 11*, 67–86.
- McLean, A. (2007). *The person in dementia: A study of nursing home care in the US*. Plymouth: Broadview Press.
- Riessman, C. K. (1993). *Narrative analysis*. London: Sage Publications.
- Sabat, S. R. (1998). Voices of Alzheimer's disease sufferers: A call for treatment based on personhood. *Journal of Clinical Ethics, 9*(1), 35–48.
- Sabat, S. R. (2000). Time past, time present, time future. *Theory and Psychology, 10*(6), 787–800.
- Sabat, S. R. (2001). *The experience of Alzheimer's Disease: Life through a tangled veil*. Oxford: Blackwell Publishers.
- Sabat, S. R., & Gladstone, C. M. (2010). What intact social cognition and social behaviour reveal about cognition in the moderate stages of Alzheimer's disease: A case study. *Dementia, 9*(1), 61–78.
- Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society, 12*, 443–461.
- Temple, V., Sabat, S., & Kroger, R. (1999). Intact use of politeness in the discourse of Alzheimer's sufferers. *Language and Communication, 19*, 163–180.
- Vittoria, A. K. (1998). Preserving selves: Identity work and dementia. *Research on Aging, 20*, 91–135.
- Weatherhead, S. (2011). Narrative analysis: An often overlooked approach. *Clinical Psychology Forum, 218*, 47–52.
- Westius, A., Andersson, L., & Kallenberg, K. (2009). View of life in persons with dementia. *Dementia, 8*, 481–499.
- White, M. (2007). *Maps of narrative practice*. London: Norton.

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