

Poetry written from the words of people given a diagnosis of dementia: a narrative analysis

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Abstract

Narrative-based research in dementia is limited. Theorists emphasise certain aspects as core features of ‘analysable’ narratives that are not reliably present in narratives of people diagnosed with dementia (e.g., temporality). This study, underpinned by social constructionist epistemology, demonstrates that attending to such narratives provides valuable understandings. Some narratives evidenced speakers’ lack of agency over their own experiences, appearing to coincide with constructions of low self-esteem, hopelessness, or being positioned by others into identities contradictory to speakers’ Self-constructs. Yet other narratives demonstrated that, through acknowledgement and support of ‘personhood’, speakers retained a sense of control and purpose in their social worlds.

Introduction

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, 2009 and the National Health Research Institute’s 2011 call for dementia research), to date dementia research has been driven almost exclusively by bio-medical, positivist traditions. These seek to provide evidence for cause-effect relationships according to isolated and specific variables (such as orientation to place and time, memory, language skills, attention and so on), considered to be the main cognitive processes impaired by dementia. However, the dependence upon the biomedical approach to explain the experience of dementia overlooks the individual with the diagnosis, their relationships, social settings, treatment and wider contexts.

There is increasing recognition that we need more research exploring the personal, interactional and socio-cultural domains, which recognises the connections between personal experiences in one’s immediate environment and the broader social context,

and how these shape a person's Self-construct (O'Connor et al. 2007). However, this is rarely pursued, with the exception of a handful of valuable case studies (e.g., Sabat & Harré, 1992; Sabat & Gladstone, 2010), some qualitative research (e.g., McFadden, Ingram & Baldauf, 2000; Menne, Kinney & Darby, 2002) and studies assessing the benefits of person-centred approaches to dementia care (e.g., Fossey, 2007; Vittoria, 1998).

Social constructionism is primarily concerned with the processes by which people describe, explain and account for their world, including themselves. Harding and Palfrey (1997) suggest a social constructionist model for dementia research would entail an analysis of how the label of dementia shapes the lives of those diagnosed, and how it informs their experiences and their constructions of Self. Hence, four key concepts from Harré & van Langenhove's (1992, 1999) Positioning Theory inform this study:

1. *Self1*, the 'Self' of personal identity, a person's enduring worldview, the basis of one's actions and sense of personal agency.
2. *Personae*, a person's discursively and publically produced 'Self', dependent on recognition, response and confirmation from others.
3. *Self-construct*, formed by *Self1* and *personae*, commonly known as 'identity'.
4. *Positioning*, which impacts on an individual's *personae*, as the act of positioning can enable or disable an individual from inhabiting particular versions of Self, by locating a person's actions and speech acts within particular social categories.

A fifth key concept in our study is Kitwood's idea of *personhood*, the status conferred onto an individual by others, implying esteem and appreciation, which is important because bestowing and failing to bestow personhood has measurable consequences (Kitwood, 1997).

Methods

Participants and data source

The data source for this research is four collections of poems from the words of people with a diagnosis of dementia compiled by poet John Killick (1997a, 2000,

2008, 2009). In transposing speech into poetry, Killick goes with the speaker and their concerns, keeping as quiet as possible but occasionally offering affirmations and some words of encouragement (Killick, 1997b). The texts begin as prose; a 'sense of poetry' comes from the feelings and experiences expressed within the narratives, so that the process of applying poetic form is an unforced one (Killick, 1999:page number). Killick read poems to the original speakers and sought their permission for publication. Killick adds nothing to the speaker's words (Killick, personal communication), therefore, these poems are an unmodified record of these individuals' accounts. Due to their length, it was not possible to cite the poems in full within this chapter; therefore, the symbol [...] is used to denote text missing from the original publication. Speakers have remained anonymous, as personal details were not available (the implications of this are discussed in the critical review section); however, at times when the gender of the participant was apparent in the poem, 'he' or 'she' were used accordingly.

Methodology – Narrative Analysis

As Riessman (1993) states, much of the theory on how to conduct narrative analysis emphasises a preference for performing the analysis on narratives that are temporally or sequentially organised, i.e., with a beginning, middle and end. This sort of structure may not be apparent in the narratives of people with dementia, or not in a way that is commonly understood or valued. Nonetheless, they convey something about the negotiation of identities during everyday encounters (Hydén & Örvulv, 2009), making the present data a most appropriate and rich source for narrative analysis.

Weatherhead (2011) sees two core elements in narrative analysis. First, an exploration of the Self-construct, to understand how the narrators view themselves and what has shaped this view; specifically, how the topic being explored has contributed to this process. Second, a consideration of cultural influences impacting on the narrative under analysis, which can only be properly explored by accepting the narrator's preferred presentation of their narrative. For the present study, this means considering the narratives of people with dementia as valid and informative as any other narrative, without attempting to distinguish between 'true' and 'untrue'. In order to be sensitive to the unique nature of the narratives of individuals with a diagnosis of dementia, there was some adaptation of Weatherhead's (2011) model. For example, since

‘temporality’, discussed above, does not consistently feature in these narratives, this was not a site of exploration; fortunately, the poetic re-transcription of stories enables their existence unrestricted by such construct. Other initial points for narrative exploration, such as ‘life chapters’, ‘significant people’, ‘key events’, ‘future script’ and ‘life theme’ (Crossley, 2000) have been reformulated to be more directly applicable to the narratives of people with dementia (see diagram 1).

Context

Following Elliott, Fischer and Rennie’s (1999) evaluative criteria for qualitative researchers, we cannot divorce our analysis from our values and beliefs, we have to be aware of these biases and own our perspective to allow readers to interpret the analysis and to consider possible alternative interpretations. Reflexivity can be cultivated through supervision, which provides a space to consider the values implicit in our actions; giving meaning to our actions highlights what is important to us and opens particular identity conclusions (White, 2007). Kitty saw a close relative diagnosed with Alzheimer’s Disease struggle with communication, but also witnessed reminiscing and story-telling where their character and uniqueness remained unchanged. This influenced her choice to explore alternative understandings of dementia in her MSc research thesis. Kitty was directed to Killick’s poetry by her research supervisor, Maria, who has researched and worked with people with diagnoses of dementia, their families, NHS and social care service provision, for the last ten years, from a post-structuralist narrative therapeutic framework.

Results and discussion

There were two main themes named: *Theme One, Constructions of Self*, presents the narratives of speakers attempting to understand their experiences in relation to the Self (i.e., identities). *Theme Two, The Individual in the World*, captures the narratives of speakers attempting to understand identity and experiences in relation to others in their immediate and wider context. Both themes were split into two broad narratives and these were further distinguished into sub-headings (see Diagram 2).

Constructions of Self

These narratives are examples of speakers attempting to understand their experiences in relation to the Self, to their identities, and to the skills and abilities that they associate as facets of their personhood. They show that, throughout the course of dementia conditions, the Self persists:

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.”

(*Openings*, p. 4)

With the words “I am still here”, the speaker affirms their *Self*, and demonstrates their determination to assert their existence in the world. These words may also indicate the importance of the process of story-telling for this individual, who (despite memory and other cognitive difficulties) is able to locate her identity in the memories and experiences of her past, thus, retaining a sense of present and still being an individual with a unique life story. The speaker constructs herself as working, glamorous and well travelled, signalling this as preferred *personae*. The words “memories that bless and burn” offer a beautifully poetic insight into the experience of story-telling for someone with a dementia diagnosis; to remember and recall her memories is pleasurable, because these are important moments of her life that have shaped her identity. However, this telling is a bittersweet act, perhaps because the validation and excitement that punctuated her past identity as a working-woman are not features of her present. The recognition of this complicated emotional response, and the speaker’s ability to explain it so articulately, indicates that she is aware of, and can comprehend and cognitively process her present situation, so that her

emotional reaction is both fitting and significant. Here is a speaker struggling with loss of memory, who, nonetheless, effectively uses the process of telling significant life events to validate her identity. This is a vitally important exercise because, if a person can retain in their mind their preferred Self-construct, then the Self can be preserved (Sabat & Harré, 1992). Moreover, the process of telling and retelling one's life stories 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), pointing to the importance of narrative therapy in this area of work.

The findings of this study also indicate that creativity is valuable in enabling greater recognition of an individual's valued aspects of Self. An example of this can be seen in the narrative below:

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)

This poem demonstrates that for this speaker, one of their valued aspects of Self is located within their creativity; feelings of self-worth emanate from the narrative as a result of having a creative and productive identity –an alternative and very personal form of self-expression. The use of purposeful language throughout indicates that the speaker felt able to take ownership of the project, because it is something to which he could apply his skills. He positions himself as useful, and this discursive act is supported by his actual seeking out wool and making cushion covers for the care home. The speaker recounts the positive consequences of his creative skill, particularly the admiring reactions he receives from others; from his inclusion of

these reactions it is evident that such affirmation is important to him. In terms of what this might indicate for dementia care, this gives further evidence to the benefit, emotionally and psychologically, of supporting and encouraging the expression of the creative identities of people with dementia diagnoses (Baines, 2007).

The analysis also pointed to the importance of paying attention to the narratives of people with diagnoses of dementia to identify interactions that foster disempowerment and objectification, which diminish *personhood* and 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 poems offered testimonies of *malignant social psychology*. The extract below clearly exemplifies the speaker’s inability to inhabit their preferred Self, due to contextual obstacles to their discursively and publically produced identities or *personae* (Harré & van Langenhove, 1992; 1999):

[...]

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)

In this poem, the speaker offers a bleak and painful reflection; with stark insight into how they are constructed as a consequence of their situation, itself resulting from their dementia diagnosis. As the narrative develops, the reasons behind this hopeless Self become clear; the speaker is not only aware of their situation, they articulate the unacceptability of their treatment and how this serves to extinguish their sense of personhood. Therefore, the disappearance of the Self and bleak future to which the speaker alludes, is not linked to the progress of the dementia, rather, it relates to the behaviour of those involved in their social life and care. It is clear from this extract that the speaker has insight into what is happening to them and yet, because of the social positioning of the person with dementia as one who is to be cared for, without much say in this care, they are powerless to do anything about it apart from this telling. This narrative is an example of first order positioning, whereby the speaker has been located within a particular category –that of helpless and worthless– which they are unable to renegotiate because it is the predominant positioning of people with dementia by those in charge and, thus, it continues to evolve without change.

The tendency for the person with dementia to be positioned as confused because of their diagnosis (McLean, 2007), leads to their speech acts and other forms of communication being taken as indicative of confusion by default. However, the analysis indicates that dementia services should begin to ascribe more value to what people with dementia diagnoses say if such ‘malignant’ experiences are to be addressed, minimised and, ideally, eradicated.

The individual in the world

These narratives are examples of speakers who attempt to understand themselves, their Self-constructs, and their experiences, in relation to others in their immediate environment and the wider social world. A person’s world manifests itself in social relationships, and this is equally true for the individual with dementia.

In line with previous research (e.g., Sabat, 2001; Sabat & Gladstone, 2010; Temple, Sabat & Kroger, 1999), this study provides evidence that various capacities can remain intact in people diagnosed with dementia. For instance, some narratives evidenced the capacity to feel concerned for the well being of others and take action to care of them, despite the diagnosis of dementia:

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.
- [...]
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)

Throughout this poem the speaker demonstrates social sensitivity, emotional intelligence and altruistic motivations. The speaker shows a desire to help Killick with his work and expresses a concern that the last time they met she was unable to provide what he needed, though she also emphasises that she had tried to be as helpful as possible; indicating that being considered as helpful by others is of importance to her. The speaker offers encouragement to Killick; she recognises what Killick's needs are (to produce a piece of writing) and she attempts to support him by reassuring him that he has achieved this well. The speaker expresses her hope that the poet will take away something useful from their meeting; showing her ability to look beyond the immediate situation (reflecting a future orientation), and to articulate her altruistic attitude of helping others.

Other common human aspects, such as the capacity for shame and embarrassment, for pride and maintaining dignity, and to manifest and experience selfhood, were also evident in the narratives. 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.

Some narratives demonstrated how people with a diagnosis of dementia look at their current contexts through personal life-long principles; by threading past and present experiences together, they skilfully bring continuity and coherence to the course of

their lives and their current circumstances. For example, the speaker in the poem below communicates that an important value is absent within her social world:

[...]

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

(*You Are Words*, p. 11)

This speaker reveals a discord between what she believes to be an essential principle, kindness, and this not being part of her present day-to-day interactions. This failure is even more striking when she pinpoints kindness as the single most important value, instrumental to the well-being of people experiencing dementia. The speaker uses the first-person indexical 'I', to place herself and her value system to illustrate that kindness should come naturally, irrelevant of who it is being expressed towards or from whom it comes; demonstrating an aware, morally and humanly intact *Self*. In the last line of the poem, the speaker furthers her argument of the intrinsic human capacity for kindness and effectively articulates the lack of continuity between the way she and others around her (i.e., people given a label of dementia) should be treated, and how she feels they are treated.

Several poems highlighted that the *personae* can persist, so long as it is validated and supported by others in the social world. The extract below points to a therapeutic benefit in being given a space to communicate to another who, by listening in an engaged manner, validates their story and, therefore, identity –since identity is socially constructed (Burr, 1995):

[...]

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)

One possible interpretation of this narrative is that the speaker has kept the door closed and has been holding back from sharing their stories and experiences until

now. Their words also suggest that for this speaker the process of talking about oneself is a tiring one, so much so that “for now” 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. By telling Killick to write “etc”, the speaker takes control of their own life story and indicates that there is more to tell, but perhaps on another occasion. Implicit in these words there is evidence of the speaker’s awareness of, and appreciation for the narrative process taking place, in some ways recognising the importance of documenting their story so that it is preserved for the future.

Finally, some narratives evidenced that social attitudes and structures 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. For instance, in the poem below, despite retaining capacities and communicating a clear sense of *Self*, the speaker’s *personae* has been changed as a result of the dementia diagnosis:

[...]

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)

As evidenced through this narrative, 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 define what a person can do, affects the Self by imposing concrete limitations with no accounting for individuality or current capabilities, thus, presenting a barrier to the successful manifestation of preferred identities. There is a sense of inevitability in this extract, which suggests a feeling of powerlessness as the speaker’s social status, that which had defined her, is redefined by societal forces. Experiencing a change (often reduction) in one’s status can compromise a person’s sense of continuity of personhood, which is fundamental to wellbeing (Kitwood & Bredin, 1992).

Implications

This study indicates that the words of people with dementia diagnoses can be richly explored through narrative analysis, despite the absence of some features identified by narrative researchers as valuable or necessary. Moreover, it highlights the empowerment of providing a space to self-narrate, as Killick does, to locate preferred and valued aspects at the centre of Self-constructs, and challenge prevailing understandings of dementia. Indeed, these narratives problematise the dominant biomedical construction of dementia as a gradual and inevitable loss of Self (Cohen & Eisdorfer, 1986; also Dempsey & Baago, 1998), which positions the person with dementia as helpless. The speakers in these poems undermine this understanding by displaying, for instance, reflection and self-awareness. Consequently, the issues that are raised within these narratives should inform the treatment of people with dementia in order to ensure that *personhood* is preserved throughout the course of the condition (Kitwood, 1997).

As such, this study has implications for dementia services and the systems in place to support people with dementia and their families and/or carers. At present, policy documents regarding dementia care (e.g., National Dementia Strategy, 2009), adopt a largely ‘top-down’, service-focused approach, as in the priority for dementia services to manage anticipated demand, in response to the prediction that there will be over one million people diagnosed with dementia by 2021 (Alzheimer’s Society, 2012); however, this approach reinforces the biomedical model of care and fails a purported ‘patient-centred care’. Given identity is performed socially through language and non-verbal interactions, relatives, friends and carers (paid and unpaid), professionals and services have a crucial responsibility in placing people labelled with dementia at the centre of their care, enabling and supporting personhood, improving the wellbeing of people with the diagnosis and, consequently, all relationships involved.

Critical Review

The study takes as its locus of analysis what is *present*: linguistic devices; acts of positioning; metaphor and juxtaposition. Thus, the standpoint of this research is, inevitably, a partial picture of a much broader whole. For example, focusing on the absent but implicit (White, 2003) in the narratives could have impacted upon the

interpretation of the data. Further, the tension between the proximal and distal implications of a speech act¹ is one that is readily acknowledged by narrative researchers (see Riessman, 1993) and not addressed here. Alternative methodologies would have provided another lens and yielded different results; for instance, thematic analysis would have also enabled valuable exploration of the data, arriving at patterns (or themes) within and across narratives. However, we were more interested in the nuances of these tellings.

The analysis was undertaken without significant biographical details on the speakers (e.g., age, ethnicity, marital status, sexuality or class), and such information could have had an impact on how the narratives were interpreted. Whilst the lack of details regarding the speakers may be seen as hindering the contextualisation of the poems, 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).

In meaning-making, qualitative approaches require in-depth data analysis, consequently narrowing the size of the sample that can be engaged with and limiting the generalisability of findings. However, from our epistemological position, all knowledge claims are uncertain and provisional, and connected to social and historical contexts; therefore, to the extent that particular narratives are identified, one must allow the possibility that these would also be available to other people diagnosed with dementia within our culture. Further, these 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.

Conclusion

Following the call for research approaches that continue to develop fuller understandings of people with diagnoses of dementia, this study has provided evidence that, first, the narratives of people with dementia are as valuable and revealing as any others; second, that narrative analysis can be appropriately used to examine the construction of dementia from the point of view of people with the diagnosis. In addition, by engaging with the narratives of people with labels of

dementia, this research recognises as central the voices that are all too often unrepresented and neglected.

The data source for this study was borne out of an interested listener providing one-to-one talking space; the richness of this data highlights this invaluable opportunity for people with dementia diagnoses to share their accounts. Further, the study demonstrates that personhood and meaningful experiences of people with these diagnoses can be represented narratively, which opens up possibilities for greater understandings of the personal significance of their experiences and of their identities –how these are affected by the dementia construct, interactions with others and wider contexts. This study has also pointed to the possibility of ‘opening up’ the narratives of those with a dementia diagnosis through the process of poetic re-transcription, which may provide a sympathetic textual platform for the use of metaphor, simile and expression of feeling that runs throughout the speakers’ narratives.

Finally, this study adds to evidence countering a biomedical model of dementia by demonstrating that dementia diagnoses do not equal loss of Self, nor loss of the full range of human values, skills, capabilities and needs. It is clear from this research that people with dementia labels not only have a conscious experience of self and other, but also of their social position, in terms of who they want to be versus who they are allowed to be. Consequently, the results provide further support to the growing body of literature that validates a whole-person approach to both research and practice in the field 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-context, whose experiences are inherently tied up with their Self-construct.

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¹ Meaning that there may be a tension between the immediate implications of a speech act on acting individuals and the broader social discourses that surround the speech act, which may not have space for all its possible and intended meanings (see Riessman, 1993; also Burr, 1995).