



The spirituality of people with dementia: a review of the research, a concept analysis and a consideration of its practical implications

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Abstract

Attempts to investigate and describe the distinctive spirituality of people with dementia suffer from a serious methodological difficulty in that, by the stage that dementia becomes the determining existential reality, communication is likely to be difficult or impossible. In this paper, the author uses a three stage process to elucidate this problem, its implications and constructive possibilities. First, a critical literature review is undertaken to evaluate the present state of research and explore its assumptions and methodologies. This is followed by a concept analysis to identify possible suggestions in the speculative literature. Finally, each of these solutions is examined in turn for its implications for the definitions and of and discourse on spirituality in dementia care.

Keywords

Dementia, Spirituality, Concept analysis, extended self, cognitive psychology

Introduction

Although the definitions of “spirituality” continue to multiply out of all number (Bregman, 2012) they tend to cluster around a few key concepts. Fairly high on the list is the notion that spirituality has to do with meaning-making (e.g. Gall, 2000) ; and that this process of meaning-making is a fundamental component of human nature. Thus (so the argument goes), “spiritual care” is close to the very heart of caring for another human being: it is an affirmation of their humanity at its core (e.g. Clarke, 2013)

This very claim for the centrality of spirituality and spiritual care renders the idea rather problematic in relation to people with dementia, because it rests on precisely those two concepts (meaning-making, and the nature of personhood) which the progress of dementia often seems to cast into question (Swinton, 2011 p.175). As dementia limits a person’s capacity to recall or to understand their environment in the conventionally accepted ways and to communicate their insights to others, it is possible to question whether and how meaning-making is taking place at all; and if not, whether there is recognisably a person towards whom care may be directed. As Julian Hughes aptly puts it,

So spirituality is part and parcel of what it is to be a person, qua human being in the world. Therefore, our models of dementia – person-centred, palliative, supportive – must be broad enough to encompass spirituality, not as an add-on, but as a fundamental feature. But this is to beg the question. It may be turned round, and we may say that if PWD [a person with dementia] no longer has spiritual needs, they are no longer a person (Hughes, 2011 p.205)

Thus, the question of the spirituality of people with dementia is not a theoretical indulgence or peripheral to the struggle for person-centred care. To arrive at conclusions about whether life continues to be “meaningful” for a person with late-stage dementia is to provide the groundwork

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for other clinical and practical decisions, not least those that relate to the continued provision of care and whether to offer therapeutic as opposed to merely palliative interventions for comorbidities.

To return to Hughes' point above, the assumptions underlying this paper are that somebody with dementia continues to be as much a person as somebody without; and that therefore we must conclude either that "spirituality" is irrelevant to the question of personhood, or that a person with dementia is as likely to have a living spirituality as anybody else. In order to warrant that assumption, it will be necessary in this paper to provide at least one of the following:

1. Empirical evidence that spirituality, understood as a process of meaning-making, remains an activity for people with late-stage dementia
2. A model of dementia which explains why we are justified in believing spirituality to be retained into late-stage dementia even if no evidence is available
3. A model of spirituality which can include people with dementia even if we may conclude that the process of active, conscious meaning-making is no longer taking place.

The plan of this study is therefore as follows. First, I will conduct a review of the available research literature on the spirituality of people with dementia. In an analysis of the results, I will argue that the gaps in the empirical data in fact reflect insoluble methodological and epistemological problems: at the very point where insight into the spirituality of people with dementia becomes most important and urgent, empirical approaches fail and the field is left open for speculatively-driven accounts. This will lead into a discussion of what may be understood as spirituality for a person with late-stage dementia, based upon more speculative "expert opinion" sources. Finally, I will turn the discussion back to consider prevailing understandings of spirituality itself, and whether our models need to be revised in the light of a prior commitment to defending the personhood, and so the spirituality, of people with dementia.

The empirical literature on the spirituality of people with dementia

The purpose of this review was to give an overview of the key themes and methodologies at work in research into the spirituality of people with dementia. Therefore, its purpose is to be a reliable and comprehensive survey: although systematic in design and execution, it does not claim to be an exhaustive inventory of every possibly-relevant contribution.

Four databases were used: Psycinfo, Proquest, Science Direct and JSTOR. In each case the search terms were (dement* OR_alzheimer*) AND spirit* and the search was narrowed to those where the terms appeared in the Title, Abstract or Keywords. This was to filter out items in which the words did not represent a main focus for study

Results were subjected to a two-stage sifting process for relevance and authority, firstly by title and then by analysis of abstract and contents. In general, the papers excluded at this stage were those in which spirituality was a minor issue; those focussing on spiritual care; and those focussing on the spirituality and spiritual needs of carers rather than PWD themselves. Also excluded were unpublished dissertations, editorial pieces and book reviews

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Finally, references and citations were followed up for sources that may have been missed as a result of the focus on four search engines. This was particularly useful in locating book-length treatments not necessarily references in the chosen databases.

The results are summarised in the Table below

[Table about here]

On detailed reading, the papers sorted naturally into the following groups according to their methodology and approach:

- Two Literature reviews (Beuscher & Beck, 2008; Keast, K., Leskovaar, & Brohm, 2010). Since this literature search is largely reproducing, extending and updating the results of these reviews, they were discarded after a search in their references for any items that had been missed in the database search.
- 13 concept papers and books by 7 authors (Everett, 1998; Killick, 2004, 2006; Lawrence, 2003, 2007; Post, 2000; Post, 2013; Shamy, 2003; Swinton, 2014; Vance, Moore, Farr, & Struzick, 2008; Vance, 2004a, 2004b; McFadden, Ingram, & Baldauf, 2001). Although these are not strictly speaking empirical studies, they represent a synthesis of “expert opinion” by practitioners in the field. They were therefore set aside from the analysis of empirical data, to be redeployed in the “discussion” section of this paper

The exclusion of these papers left 26 in the search:

- 8 anecdotal accounts of interventions or case studies, based upon participant observation: (Abramowitz, 1992; Desai & McFadden, 2013; Khouzam, Smith, & Bissett, 1994; McFadden et al., 2001; Stuckey, Post, Ollerton, FallCreek, & Whitehouse, 2002); four more (Killick, 2011; Otera, Horike, & Saito, 2013; Sacks, 1998; Wentroble, 1998) present case studies from their own experience.
- 5 autobiographical studies (Bryden, 2005, 2012; Bryden & MacKinlay, 2002; Davis & Davis, 1989; Snyder, 2003). These studies formed a natural group because, in each case, the findings are presented in an integrated literary form, a narrative which does not clearly separate the meanings imposed by the narrator from those which may have been inherent in the utterances or actions of the person at the time. Within this category, the details vary widely: four (Davis and Davis 1989; Bryden and MacKinlay 2002; Bryden 2005 & 2012; are autobiographical, albeit with assistance; whereas Snyder undertakes a review of autobiographical statements in the literature.
- 13 interview studies (Beuscher & Grando, 2009; Byrne & MacKinlay, 2012; Carr, Hicks-Moore, & Montgomery, 2011; Dalby, Sperlinger, & Boddington, 2012; Higgins, 2014; Katsuno, 2003; Mackinlay & Trevitt, 2010; MacKinlay, 2009; McGee, Carlson, & Myers, 2013; McGee & Myers, 2014; Phinney, 2011; Sullivan & Beard, 2014; Trevitt & MacKinlay, 2006;) Although sample size varied widely (from 6 in Dalby & Spelwood to 113 in MacKinlay and Trevitt 2010) the treatment was generally similar; a thematic analysis of the transcripts issuing in a summary account of the “spiritual” issues found to be important to people with dementia.
- 3 studies used a proxy for spirituality against an intervention or to correlate with other information. Thus Jolley et al. (2010) used the Royal Free Scale to assess the spirituality

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of a sample of people with dementia and their carers and came to two key conclusions: that people with dementia are as “spiritual” as their carers, and that they value practices that are associated with their declared beliefs. Kaufman, Anaki, Binns, & Freedman (2007) used a variety of scales to measure aspects of quality of life, including spirituality. They found that a slower rate of cognitive decline was associated with higher initial scores for spirituality. Walters (2007) tested the response of residents with mid-stage dementia to three different forms of worship

On this analysis, the available literature can be understood as falling on a scale of increasing reliability from observational studies and case studies which rely on the subjective account of a third party, through autobiographical accounts by people with dementia or those close to them, through qualitative interview-based studies which bring a critical and integrative analysis to the autobiographical material, and finally to those which attempt objectivity by the use of validated scales. However, each of these genres present its own difficulties and potential, so they resist being arranged according to a single scale of value. Taking each in turn:

1) The difficulties with case studies and anecdotal reports are apparent enough. The account of the reactions of the person with dementia and the interpretation of those reactions are combined in a single narrative in which meaning must be presumed to be rendered as much by the narrative structure and the priorities of the author as by the events themselves. As I will argue in more detail later in this paper, since we cannot know from the “inside” how a person with late-stage dementia experiences their spirituality or its meanings (or even if these categories can still be applied) it follows that such observational reports will to a large extent reflect the expectations of the observer. However, for all their limitations, these are the *only* reports which may give us an insight into the meaning of spirituality in late-stage dementia and so have a particular role to play.

2) On the face of it, first-person accounts by people with dementia should provide the most valuable insights into its relationship to spirituality. The primary difficulty here is that the construction of such accounts, even with the help of a collaborator or editor, requires a high level of cognitive and communicative ability. Thus as Davis himself says, he cannot know what will happen in the coming “uncommunicative silence”. He can only “pray that I will not fall over the edge into that dark chasm of total blackness either psychologically, emotionally, or spiritually” (Davis & Davis, 1989 p.120). His future feelings, responses and understanding are as opaque to him as to us – he is about to enter a dark tunnel.

3) The interview studies represent the largest group identified in this paper, and the advantages are clear. Such studies can lay claim to methodological and critical rigour, while still preserving the voice of the participants. However, in the present context, they like the previous group) suffer an insurmountable limitation in their reliance on the communicative ability of the participants themselves. By definition, this means that they are restricted to a study of spirituality in those who still have most of their communicative abilities intact.

But if there is anything distinctive about the spirituality of people with dementia, it is surely most salient at the stage where dementia becomes a dominant existential reality for the person concerned: when it is affecting not only their ability to remember, but to recognise, respond to and participate in the world in which they have always defined themselves. In short, the point at which a person with dementia loses the ability to communicate is likely to be closely related to the point at which it becomes useful and necessary to talk of a distinctive spirituality for people with dementia. The studies tail off around the point at which their real work begins.

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3 This insight is present in some of the findings of the interview studies themselves. Thus, for
4 example, reflecting on his research on mild to moderate dementia (Dalby et al., 2012), Dalby
5 (Dalby, 2011, p.68) draws out the theme of spirituality as 'staying intact' from interviews. This
6 is clearly a concern for the participants in his study, but becomes obsolete in later stage
7 dementia when the personal integrity is demonstrably not intact. On a slightly different note,
8 having extracted their themes from a large study of people with dementia in care homes,
9 Mackinlay and Trevitt (2010) point out that the themes they have identified are the same
10 themes that would be found in any group of older people. This indirectly supports the
11 conclusion that at this stage, "spirituality of dementia" is not a particularly useful term,
12 because dementia is not yet the dominant experience for the participants.
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15 4) The three studies which attempt to correlate observations against a validated scale turn out
16 to yield only disappointingly tangential results. Jolley et al. (2010) uses the Royal Free Scale to
17 measure participation in and esteem for religious activities, but the conclusion that people
18 with dementia broadly prefer to continue established activities tells us little or nothing about
19 the meanings attached to them. Kaufman, Anaki, Binns, & Freedman (2007) suggest that self-
20 rated spirituality may be associated with some form of protective effect, but this says nothing
21 about its content or its existential role for the persons involved. Finally, the study by Walters
22 (2007) compares three means of communicating religious ideas and so is of limited relevance.
23

24 This analysis of the literature is most revealing for what it says of the limitations of research
25 into the spirituality of people with dementia. Discounting the two studies based on the use of a
26 validated scale (which may be measuring a degree of spirituality on some previously decided
27 measure, but not its quality), the available empirical evidence is overwhelmingly dependent on
28 conscious, intentional meaning-making and communication by the person with dementia
29 themselves; and/or the interpretative activity of the observer or companion. By definition,
30 methodologies such as these can tell us little or nothing of the character of spirituality for
31 people who no longer coherently and intentionally communicate meaning in universally-
32 discernible ways. In this case, does it make sense to speak of the spirituality at all for people
33 with late-stage dementia at all, the people for whom dementia is now the encompassing
34 reality?
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39 **Spirituality and the options beyond linguistic communication: a concept analysis –**

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41 The practical problem posed by the forgoing analysis runs something like this: if our direct studies of
42 the spirituality of people with dementia will only take us to a certain point in the disease trajectory,
43 how may we understand their spirituality as extending beyond that point to the end of their life,
44 integral to their personhood regardless of any loss of other capacities and competencies?
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47 There seem to be five possible answers to this question, which I will explore in the discussion that
48 follows. As will become clear, I consider three of these to be broadly unsatisfactory, and two to have
49 rather more potential:
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- 51 1. *An ideological approach.* There is a group of studies which begin with a set of convictions
52 about the true status or nature of the person with dementia which rest upon deeply-held
53 principles which are not susceptible to revision in the light of empirical evidence. These may
54 be theological (e.g. Keck's belief that "God always remembers" in a way which guards the
55 individual's integrity and spiritual status(Keck, 1996)) but may reflect a broader belief in the
56 inviolability of what makes us human, such as Sack's discernment of Jimmie's "soul" at the
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act of taking communion, in his moving case study in *The Man Who Mistook His Wife For a Hat* (Sacks, 1998). The belief in a kind of “non-material soul that still exists intact underneath all the neurological losses of dementia” (Post, 2006, p.231) runs deep in western culture, and can still be drawn on as a possible explanation. But as I have pointed out elsewhere (Kevern, 2010) the difficulty with this approach is that it makes no space for “spirituality” as pertaining to human beings and their actions, and so leaves the concept with no purchase in the practical world.

2. *A palliative approach.* A second way to avoid the question of what spirituality might mean in late-stage dementia is to reduce spirituality to a form of palliative care which is valuable (and measurable) only in terms of patient comfort or distress. Thus the benefits claimed in some of the studies above e.g. bible therapy (Khouzam et al., 1994) and multisensory ministry (Walters, 2007) are expressed as reduction in agitation or an increase in attention and engagement. Cumulatively, they make a case for the value of certain religious practices, but the question is whether it is a case worth making? In therapeutic terms, the findings are to do with calming and palliation, which raises the question of whether this is what’s required; in terms of spirituality, the claim can only be that they work for some people as nursery rhymes or singing do for others. The oft-made claim among chaplains that “so-and-so suddenly joined in when I started saying the Lord’s Prayer” has no more intrinsic spiritual significance than if she had joined in the singing of a nursery rhyme; as critics such as Paley point out (Paley, 2008), this sort of finding only makes sense as spirituality if some theological or religious concepts have been “smuggled in”.
3. *A “romantic” approach.* I am using the term “romantic” in its more precise sense, as emphasizing the primacy of intuition over rational thought, and the interconnectedness of universal thoughts and values. This category unites two strands in the literature that, on the face of it, seem to diverge. In the first place, there is a tendency among some writers to validate the loss of cognition as itself contributing to a positive spiritual progress: as a form of living in the “here and now” (Swinton, 2011); and as escaping the malignant “hypercognition” of the current age (Post, 2000). Secondly, there are those (e.g. McFadden et al., 2001) who would want to claim that, by careful listening and attentive presence, it is possible for others to gather by intuition the meanings and intentions of a person with dementia long after their ability to communicate in formal terms has been lost. Both of these approaches are, in their own way, plausible and potentially useful. However, in both cases it is the individual observer or interlocutor who makes final decisions on the meaning(s) borne by the individual’s sounds or actions. To the extent that this approach relies upon the unvalidated claims and special gifts of a nominated “interpreter”, it must be treated with a healthy suspicion.
4. *The socially-extended self.* A more satisfactory approach may be to draw upon the strand in dementia studies that emphasises the way in which each individual self is established and maintained within a community of meaning.: what Radden and Fordyce (Radden & Fordyce, 2006, p.73) term, “active, collective authorship of the self-narrative” . Within this framework, spirituality and the activity of meaning-making might legitimately be taken to be a collective activity:

It is therefore vitally important that there are people around who can hold and keep alive those stories so that the person with dementia can maintain an identity, even though he or she may forget that identity. To the question, “Who am I?” we must answer: “I am the stories and memories that I have about myself, plus the stories

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3 and memories that you have about me, plus the stories and memories that others
4 have about me". For the person with dementia the answer becomes "I am the
5 stories and memories that I may hold for myself, plus the stories and memories that
6 you and others hold for me." These are the components which, together, enable the
7 person with dementia to remain a person, with an identity, a purpose and a
8 community (Goldsmith, 2011, p.172)
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12 5. *A cognitive-psychological approach.* Another way of reshaping, if not reframing, the
13 narrative regarding spirituality for people with dementia is by reference to something not
14 explicitly visible, but resistant to change in the spirituality of a PWD. Although direct
15 observation of the spirituality of a person with dementia may become difficult or impossible
16 beyond a certain point, inferences can be drawn from the wider body of evidence regarding
17 the persistence of "deep" capacities. The key construct here is that of procedural memory:
18 an ability to retain a learned response to certain stimuli long after conscious memory of the
19 meaning of the stimuli or the response has been lost. Thus, for example, Vance (Vance,
20 2004a, 2004b, 2005 Vance et al., 2008) understands spirituality "vertically" as imposing
21 some form of structure that persists through all the layers of a person's inner self and so is
22 recognisable even when many of those layers have been stripped away; and proposes a
23 Procedural and Experiential Religious Activity Therapy PERAT (Vance, 2005; Vance et al.,
24 2008) by way of a response. Similarly Abramowitz (1992) finds deep habits of prayer still
25 relevant for Jewish people with dementia, and speculates that this is due to the persistence
26 of habits and emotional connections retained below the level of conscious awareness.
27 Finally, John Swinton (2014) links the shaping of procedural memory to the acquisition of
28 habits of virtue by frequent repetition, as exemplified in many religious practices.
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Rethinking spirituality in the face of dementia

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34 As I indicated at the start of the previous section, for the reasons I outlined I consider the first three
35 options to be unsatisfactory answers to the question of how to conceptualise spirituality for people
36 with mid- to late-stage dementia. However, both of the alternative responses proposed "reframe"
37 spirituality in ways that challenge some of the commonly-held assumptions about its very nature.
38 This leads to a third, inductive stage in the argument that I am developing: if we hold to the
39 assumption that people with dementia retain a spirituality into the late stage of the condition, in
40 what ways will our understanding of spirituality need to be revised?
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43 One of the possible developments outlined above is to rediscover and lay more stress upon the
44 enduringly social character of spirituality, and the way in which its development and maintenance is
45 always at least partially dependent upon reinforcement and encouragement from others. In the case
46 of formal religious allegiance, this is self-evidently true, in that there are very few people who hold a
47 religion in social isolation, and the majority broadly follow the religion of those among whom they
48 grew up. But, albeit less obviously, and despite the popular assertion of spirituality as essentially
49 individualistic (Pesut, Fowler, Taylor, Reimer-Kirkham, & Sawatzky, 2008) it is demonstrably
50 historically, socially and economically conditioned (see e.g. Huss, 2014; Woodhead & Catto, 2013)
51 drawing on the available resources of a particular time and place. Thus, one possible dimension to
52 "spirituality" which is brought into relief by people with dementia is its shared, collective and social
53 character.
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56 The other dimension, which is brought out through the appeal to "procedural memory", is the
57 temporal persistence of spiritual responses and practices when they have been introduced early in
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3 life and frequently repeated. This insight stresses the character of spirituality as cumulative,
4 repetitious and to a large extent involuntary: the strongest and most persistent elements of a
5 personal spirituality may not be those that have been consciously chosen or held by personal
6 conviction, but may have built up almost by accident as the result of a multitude of small choices
7 and actions over years and decades. This understanding is very close to the classic definition of
8 virtue by Augustine of Hippo as 'a good habit consonant with our nature' (Augustine, 1989 section
9 25), and perhaps suggests that spiritual practices are best begun early, repeated often and changed
10 quite rarely if they are to develop the capacity to persist in the face of dementia.
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Conclusion

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14 The substance of this paper has, to a large extent, been an argument from silence. If we wish to
15 assert the persistence of the 'personhood' of somebody in late stage dementia; and if we take
16 spirituality to be an essential element of personhood; then we are committed to apprehending what
17 spirituality might mean in such circumstances. Since the review of the literature demonstrates the
18 limitation of direct empirical study to those with communicative capacity, it is necessary to fall back
19 on insights from social theory and cognitive psychology to justify an interpretation of some
20 phenomena as evidence of persistent spiritual activity. In the process, it becomes necessary to
21 challenge some prevailing assumptions about spirituality in order to make space for these new
22 insights. The practical lessons to be drawn from it are that the spirituality, and by extension the
23 personhood, of somebody in late-stage dementia cannot be separated from their embeddedness in
24 a particular social and historical milieu; and that the preservation of personhood thus rests on, as far
25 as possible, the preservation of history and context.
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28
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30 Spirituality meeting, London 1st November 2013
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Database (searched 11.2.14)	Initial number of hits	After review of titles	Combined hits after duplicates removed	Combined hits after review of abstracts and content	Total hits retained
JSTOR	6	6	57	28	42
Proquest	149	35		Citation/reference search additional	
Psycinfo	268	33		14	
ScienceDirect	40	6			

Table 1. Summary of literature search process