

Dementia and Spirituality:

The current state of research and its implications

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It goes without saying that, at present, dementia is the brain disorder with by far the highest public profile and raises the most widespread public concern. As one recent survey has it (Alzheimer's Research UK, 2011), dementia is now more feared in the population at large than cancer is, and this fear is against a backdrop of a rising prevalence. This rise in the prominence and fear of dementia represents a major change in the way in which we corporately and communally experience and construct our shared world.

Given this public concern, and given that the losses attendant on dementia (such as memory, communicative capacity and self-awareness) seem to strike at the very heart of who we are, you might expect there to be a thriving culture of research and reflection on the spiritual aspects of the condition. After all, most understandings of 'spirituality' entail some stress on the very questions of identity, dignity and meaning which appear to be eroded by dementia. And indeed, if you type DEMENT* and SPIRIT* into Google, you'll get something like 13700 hits. However, when you start to sift through them for the actual *evidence base* on the relationship between spirituality and dementia, you'll face some disappointment.

In this presentation, I will attempt to:

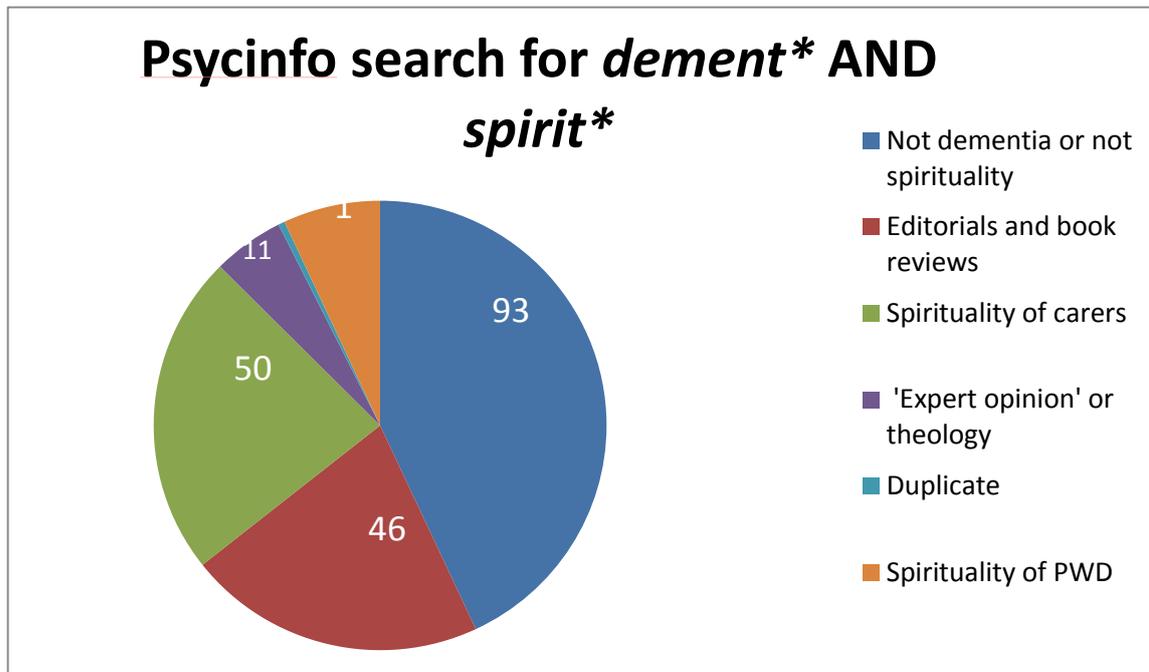
1. Gain an overview and analysis of what research is available
2. Discuss in detail what little work is applicable to mid- to late-stage dementia
3. Discuss the implications for both theory and clinical practice.

Overview of research

In contrast to the loose search on Google, a search on the Psycinfo database (26.9.13) using the terms Dement* and Spirit* gave just 216 hits, which broke down into the following categories when examined by title and abstract:

Studies in which either dementia or spirituality was not central	93
Editorials and book reviews	46
Research into the spirituality of carers	50

Research into the spirituality of PWD	15
'Expert Opinion' or theology	11
Duplicate	1



Chasing up citations yielded a further 13 sources, of which 3 were literature reviews. Finally, we may note that there are a few books that are overlooked in this analysis, and which may be claimed to provide empirical data. I have in mind Davis and Bryden (both autobiographical) and Sack's account of Jimmie in *The Man Who Mistook His Wife for a Hat*. That gives us a total of 31 primary sources for research into the spirituality of people with dementia (PWD).

Setting aside the first of these categories, the breakdown is already telling. The level of concern is shown by the number of editorials and book reviews, along with some conceptual papers. But the majority of studies have been conducted on carers, rather than PWD. This is hardly surprising, given both the ethical and procedural difficulties of studying PWD. A cynic may add that research to maintain resilience in carers (particularly informal carers) attracts funding because of the savings they represent to the public purse, whereas improvements in the QoL of PWD have less measurable benefits. Furthermore, as we will see, the available studies mostly depend upon interview data: thus, they are restricted to participants whose communicative abilities are still largely intact. For whatever reason, we may note that the actual research base on PWD is extraordinarily sparse.

Breaking down the research a little further it looks something like this:

Autobiography	3 (Bryden & MacKinlay 2003, Bryden 2005, Davis 1989)
Interview-based studies	14 (Beuscher & Grando 2009, Dalby et al. 2012, Gerritsen et al. 2010, Jolley et al. 2010, Katsuno 2003, MacKinlay E, 2003, MacKinlay 2009, MacKinlay & Trevitt 2010, McFadden et al. 2001, Phinney 2011, Snyder 2003, Stern 2005, Trevitt & MacKinlay 2004, 2006)
Therapies and reports of therapy	5 (Abramowitz 1993, Khouzam et al. 1994, Kirkland & McIlveen 1999, Vance 2005, Vance et al. 2008)
Case studies 1995)	3 (Webb 2001, Wentroble 1998; Sacks)
Intervention studies 2007)	3 (Lantz et al 1997 Smith 2008, Walters)
Literature reviews	3 (Beuscher & Beck 2008, Keast et al. 2010, Lindberg 2005)

The first thing to note, to nobody's surprise, is that the majority of studies (17/28, excluding literature reviews) are based upon interviews with or verbal reports from people with dementia (PWD). While this might be expected, it skews the picture in two distinct ways:

- 1) It makes a commitment (more on this later) to a view of spirituality as inextricably tied up with language, narrative and conversation. While this is a perfectly defensible position to take, it is not the only or necessarily most useful one, and deserves examination.
- 2) It necessarily restricts the conclusions to those with fairly intact communicative skills. Since these are progressively lost as dementia progresses, it restricts study to those in the early stages (some of the research is unfortunately quite vague about stages) and, by definition, to those whose experience of dementia is still not the overwhelming reality of their lives.

Given these two structural determinants, the convergence of findings and their content come as no surprise. It turns out that:

- 1) Participants found narrative framing (and in some cases re-framing) helped them to cope (Phinney 2011)

- 2) McFadden et al. 2001. 'Tragic optimism' could be maintained given a supportive environment. Personal spirituality was described as positively related to Quality of life (Gerritsen et al 2010, Katsuno 2003, Jolley et al. 2010)
- 3) Spirituality was understood under common themes, loosely those identified by Beuscher & Beck:
 - a. belief; (wisdom and memory MacKinlay 2009; Wisdom and insight MacKinlay and Trevitt 2010; Holding onto faith Beuscher & Grando 2009; Experience of faith Dalby et al 2012).
 - b. surrender/hope;(vulnerability & transcendence MacKinlay 2009; vulnerability & transcendence MacKinlay and Trevitt 2010; seeking reassurance and hope Beuscher & Grando 2009)
 - c. connections with Nature/God; (connectedness MacKinlay 2009; Need for relationship MacKinlay & Trevitt 2010; staying connected Beuscher & Grando 2009; spiritual connection & expression Dalby et al. 2012; Loneliness MacKinlay E, 2003)
 - d. practice such as prayer and church attendance; (spiritual/religious practices MacKinlay 2009; personal faith, prayer, connection to church, family support Beuscher & Grando 2009; prayer MacKinlay E, 2003)
 - e. Meaning-making (hope/fear MacKinlay 2009; hope and despair MacKinlay & Trevitt 2010; searching for meaning Dalby et al. (2012); fears, difficult times, MacKinlay E, 2003).
 - f. In addition, there was a theme around loss, suffering and change: (physical health issues;, war experiences; communication style of facilitator MacKinlay 2009; changes and losses in experience of self; staying intact; Dalby et al. 2012. difficult times, disempowerment MacKinlay E, 2003)

There is nothing particularly surprising about these findings. Indeed, one paper (MacKinlay & Trevitt 2010) points out that these are the same themes that would be found in any group of older people. This indirectly supports the conclusion that at this stage, 'spirituality of dementia' is not a particularly useful term, because dementia is not yet the dominant experience for the participants.

A much more salient, and clinically useful, study would be on PWD who have reached the point where they have difficulty with verbal communication. But herein lies the paradox, because by definition an interview-based study cannot be conducted beyond this point. This means that researchers have to choose between two courses of action: they can avoid the question of what spirituality is for PWD by reframing the question, or they can accept that their study is going to be driven and conditioned by their own prejudices and perspective as much as by any data they may interpret.

Research in mid- to late- stage dementia

It seems to me that there are two forms of writing on spirituality and dementia that effectively 'dodge the issue'. The first of these is what may be broadly termed 'theological' treatment – that is, studies which begin with an account of what it is to be human and/or a body of dogma which provides the framework for their discussion and which is reasonably resistant to any interference with empirical facts. Despite this rather cruel description, I am myself a theologian and have great respect for my own discipline: I just don't think it will provide any generalizable claims about spirituality for PWD. An example might be Oliver Sacks' case study of 'Jimmie' in *The Man Who Mistook His Wife For a Hat* (1995) whose soul, he suggests, is uniquely visible when he receives the eucharistic sacrament. Johnson (2007) continues to assert that meaningful, theologically-rich pastoral interactions may be held with PWD through 'implicit memory' in which the pastor supplies more of the meaning. Then there is John Killick's conviction that PWD who have words may intentionally generate (Killick 2008). I also point the reader to my own work and also, for example, that of Donald Keck.

A second way to 'dodge the issue' is to reduce spirituality to a form of palliative care which is valuable (and measurable) only in terms of patient comfort or distress, e.g. Bible therapy (Khouzam et al 1994); multisensory ministry (Walters 2007); (meditation Lantz et al. 1997). All the scant intervention studies take broadly this approach, demonstrating a reduction in agitation or increase in happiness. 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'. So, theory will not be dispensed with so easily, lest we want 'spirituality' to die the death of a thousand qualifications.

It seems, therefore, that we need to thread a path between pure theory and pure pragmatism. Looking at the remaining studies, I think there are three ways in which spirituality is conceived for persons in mid- or late-stage dementia which rely on a creative synthesis:

1. The 'hidden persistence' of spirituality. Another way of reshaping, if not reframing, the narrative regarding spirituality for people with dementia is by reference to something not explicitly visible but resistant to change in the spirituality of a PWD. Thus, for example, Vance understands spirituality 'vertically' as imposing some form of structure that persists through all the layers of a person's inner self and so is recognisable even when many of those layers have been stripped away. Hence, Vance's Procedural and Experiential Religious Activity Therapy PERAT (Vance 2005; Vance et al. 2008). Similarly Abramowitz (1993) finds deep habits of prayer still relevant for Jewish people with dementia

2. As an opportunity for growth. Clearly, change is taking place as dementia progresses and this is typically framed within a narrative of decline and loss. The case study/autobiography evidence is important here: there is a spiritual discipline to surrender which is implicit in the accounts of Bryden and MacKinlay (2003), Davis and Davis (1989) and Webb (2001) which see it as a positive spiritual growth as well as a pragmatic coping strategy. As with 'practice' generally, it is possible to imagine how the habits and disciplines of religious surrender may persist beyond the point of explicit speech.

3. Connectivity. This is stressed in all the interview studies and I want to treat it at further length here. I've been very strongly influenced by Tom Kitwood's approach to dementia as a socially-embedded and to an extent socially-constructed condition. In particular, I was influenced by the development of the theme by Hughes et al. in *Dementia: Mind, Meaning and the Person* (2006). One of the concepts developed there is that of 'active, collective authorship of the self-narrative' (Radden and Fordyce in Hughes et al. 2006, 73): *that our self-identity is originally constructed for us by our parents and we claim individual possession of it for a period of time; but throughout, and particularly with the onset of dementia, its maintenance and authorship relies upon the contribution of others.*

I think we can make a comparable move in relation to spirituality. As many religious traditions stress, it arises in the shared beliefs, practices and discourse of a community and is 'ours' only partially and temporarily. In that way, it might be more appropriate to understand it as a shared and corporate responsibility in which individual agency is not the deciding factor. The Protestant background from which I sprang is almost unique in finding this potentially problematic, implying as it does that the individual does not hold final responsibility for their spiritual status; unfortunately, this is the same background which informs the very individualistic approach to spirituality in Western discourse on health. But perhaps dementia provides a salutary limit-situation: if spirituality is an individual quality, then those in late-stage dementia cannot be said to have any. If we are to ascribe to them a spirituality, it is one we have helped to construct and maintain.

The clinical questions arising from the three strategies outlined above are as follows:

- **Is it possible to find a common spirituality without imposing an alien schema?**
- **Is your expectation for a PWD one of progressive spiritual decline, and is this self-fulfilling?**
- **Should 'spiritual care' be at the level of the community rather than the individual?**

There is no space here to discuss these at length, but I hope to make them the subject of further discussion at a later date.

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