

THE SPIRITUAL AND RELIGIOUS NEEDS OF PEOPLE WITH DEMENTIA

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INTRODUCTION



In England and Wales there are over 700,000 people living with dementia, a third of whom live in care homes. Notably two thirds of residents in care homes have dementia (Department of Health 2009). A study by Cohen–Mansfield et al (2006) found that the well-being of people with dementia living in care homes can be enhanced by the provision of person-centred care based on knowledge of their unique life story and the creation of positive relationships. For people with dementia, helping to maintain a link or reconnect with their religion as part of their provision of care has the potential to increase

their sense of well-being. This has been recognised in the National Service Framework for Older People (DOH 2001) and by NICE/SCIE (2006). Both documents stress the necessity of providing person-centred care that responds to the individual’s needs including those relating to spirituality and religion.

SPIRITUALITY

Spirituality is a term increasingly used in healthcare (Sloan et al 1999) although neither spirituality nor spiritual care is easy to define. McSherry (2006) notes that the word spirituality is perceived and used differently by individuals, it is complex and subjective and he suggests that creating a single definition may be difficult. This appears to be the case as there have been numerous attempts to define it. Swinton (2010) offers an alternative to attempting a single definition of spirituality. He instead suggests that, given the complexity of the subject, spirituality should be considered from various perspectives that take into account the diversity of human experience. Among those who have attempted a definition include:

Mackinlay (2001) who writes; “spirituality includes the need for ultimate meaning in each person, whether this is fulfilled through relationship with God or some sense of another, or whether some other sense of meaning becomes the guiding force within the individual’s life. Human spirituality also involves relationship with other people. Spirituality is part of every human being, it is what differentiates humans from other animal species.”

She continues by describing two components of spirituality, the generic and the specific. The generic part is central to all humans and is expressed by the search for meaning and purpose to life, whereas the specific part refers to the way each individual engages with the spiritual in his or her life. This can be through religion, relationships or anything that gives meaning to their life. Frankl (1964) states that this meaning must be specific and have purpose to the individual. Spirituality would appear to be something that is quite individual and may change over the life course as different things become important a person's life.

Speck (1988), writing from a cleric's point of view, notes that "A wider understanding of the word spiritual, as relating to the search for existential meaning within any given life experience, allows us to consider spiritual needs and issues in the absence of any clear practice of religion or faith, but this does not mean they are separated from each other."

Although religion appears to be an expression of spirituality, spirituality is not solely defined in the context of religion. Whilst religion cannot be separated from spirituality, Stallwood and Stoll (1975) note that spiritual needs are not purely associated with religion or belief in God but also a search for meaning and purpose in life. Importantly, Burnard (1988) warns against denying the spiritual needs of atheists and agnostics because they do not share a belief in a god or deity. It is clear that everyone has spiritual needs and this includes that those who do not have any religious affiliation.

Parsons (2001) takes the view that "On one level understanding spirituality involves finding out about the way in which someone has made sense of his or her life and identity; on the other it is about practising faith usually in a ritualised way with other people."

Following on from the difficulties in defining spirituality, spiritual needs have also been given much deliberation by many authors. Spiritual needs are identified by Moffit (1999) as being linked to religious beliefs and the need for religious ritual and also a desire to understand one's self. She elaborates that this includes seeking a deeper understanding of normal experiences, holding onto our sense of personal identity and contemplating the meaning of life. Moffit's definition, written for Methodist homes publications, implies a religious belief. Narayanasamy (2001) built on previous definitions by Higfield and Cason (1983) and identified nine spiritual needs including the expression of god or deity. He notes that the belief in a god may be an important dimension of spirituality but acknowledge that for some individuals their Supreme Being or deity may be their work or recreational activity. He suggests a flexible approach in which god or deity is defined by the individual.

RELIGION

Religion is perhaps somewhat easier to define than spirituality. Religion is associated with a faith in a God or gods and includes prayer, ritual and a particular way of life. Hicks (1999) describes religion as "a behavioural manifestation of an individual's spirituality and a framework from which he or she expresses that spirituality." The Cambridge dictionary online (2011) defines religion as 'the belief in and worship of a god or gods, or any such system of belief and worship'. MacKinlay (2001) notes that everyone we meet (within a particular society) knows what religion is, although the term does not mean the same to each person.

LITERATURE REVIEW

Despite a series of studies (see, for example, King et al 1995, Ross 1997 and Isaia et al 1999) showing that older people are reported to be a highly spiritual and religious group, the spiritual dimension, as an essential component of holistic care, is frequently overlooked. Notably, there has been little research into the area of religion and dementia. Personal accounts, however, of individuals with dementia such as Christine Bryden (2005) and Robert Davis (1989) shed light on the importance of spirituality and religion for them on their journey into dementia. Jolley et al (2010) found that in the early stages of dementia there was no obvious reduction of spiritual awareness amongst memory clinic patients when they were compared with those caring for them and the practices associated with their beliefs were very important to them. In addition, Katsuno (2003) found that religiosity had a positive association with perceived quality of life for people with early stage dementia. The participants used religion as a means of coping and to help them find meaning and purpose in their lives. Similarly, Snyder (2003) and Stuckey et al (2002) also found that religion can help people with early dementia cope with the impact of the disease on their lives. Trevitt and MacKinlay (2004) and MacKinlay (2009) explored issues of religiosity with care home residents with dementia and found that religious activities were particularly important to them. Also, studying care home residents, Walters (2007) found that a multisensory approach to ministry visits to the care home had a positive effect on the observed experience of people with moderate dementia. Several other interventions have been documented where people with more advanced dementia have participated in acts of worship (e.g. Goodall 1999, Kirkland & McIlveen 1999, Shamy 2003), which appeared to have been beneficial to them although none of these are evaluated from the direct perspective of the participants with dementia. Higgins et al (2004) report on a small pilot study interviewing people with dementia who had taken part in an act of worship and found this to be a positive experience. Recently the Alzheimer's Society (2010) collected the views of people with dementia, including some with more advanced dementia living in care homes, and found that the ability to practice faith or religion was one of the key quality of life indicators for them. Clearly there is a lack of knowledge on how religion impacts on the lives of those with more advanced dementia living in care homes. In particular the perspective of these individuals has not been sought regarding this aspect of their lives. While observational methods and anecdotal reports help to provide some understanding it is preferable to obtain their personal views. This will help those working in care homes and from church groups to support people with more advanced dementia living in care homes to remain connected to their religion. Ethical approval has recently been obtained to carry out a study in interviewing people with moderate to advanced dementia living in care homes and this will endeavour to understand the role of Christian religion for them.

DISCUSSION.

In addition to the benefits of religion described above there are many studies highlighting the clear immediate benefits of religion on health outcomes, see Koenig (2001), however we can only measure the benefits of religion here on earth. To those that have a religious faith and believe in an afterlife united with God, the potential eternal benefits outshine any that are gained here on earth. For this reason, it is particularly important that people with dementia are supported to remain connected to their faith group and in this way the future benefits for them may also be enhanced.

Bringing religion into the workplace, particularly in healthcare, is not encouraged, and this was highlighted by the case of the nurse, Caroline Petrie, who was suspended for offering to pray for a patient (BBC 2009). This may well have discouraged other nurses from offering prayer to those who indicate they would appreciate this support, for fear of a similar outcome. While there is concern regarding the possibility of proselytising, particularly in vulnerable patients such as those with dementia, healthcare professionals are guided by their own codes of conduct such as the NMC (2008) and are required to act in a professional manner.

And yet, the belief of Christianity is that spiritual care can help here and now and also make a true difference in eternity. We must not lightly ignore the spiritual needs of those who suffer dementia.(CMQ Augsut2011) (that article is attached below for info)

People with end stage dementia who lack capacity to decide on aspects of their care, such as taking part in a religious service or receiving Holy Communion, could have this decision made as part of a best interest process under the framework of the MCA (see CMQ August 2011). However, for those who are still able to express themselves verbally and particularly those who have a lifelong faith, we could ask them directly what they would like to help them remain connected to their faith. This seems a rather obvious course of action. Nevertheless, I suggest that in order to provide holistic person centred care that meets their needs, including those relating to religion and spirituality, this would be a good place to start.

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