DEMENTIA PALLIATIVE CARE NEEDS ASSESSMENT:

A FOCUS ON SPIRITUAL CARE

Stephen D M Smith

Abstract: Palliative and dementia care have a focus on holism and follow a person centred approach. Although these values could be described as core, they have arisen from differing perspectives of health and social care and as a result have different foci and approaches. This article describes a palliative care focus to assessing the needs of people with dementia and their carers, in particular their spiritual needs. People with dementia, carers and service providers participated in this assessment. The needs to know the individual, respect their beliefs, views and practices and adopt simple, practical approaches to spiritual care are highlighted.

Key words: Spiritual care, religious care, dementia, palliative care, person centred.

Introduction

The aim of this article is to present and discuss the findings of a needs assessment conducted in West Lothian during 2004. The investigation focused on the palliative care needs of people with dementia and their carers. As part of the data collection, needs specifically related to spiritual care were discussed with participants and it is this data that provides the focus for this article.

The needs assessment is the first phase of a three-year action research project funded by The Big Lottery Fund and managed by West Lothian Healthcare Division of NHS Lothian. The West Lothian Dementia / Palliative Care project has a steering group of ten members and links with Queen Margaret College University, Edinburgh and the University of Stirling for supervision in action research and dementia care respectively. The project co-ordinator, who collected the data, has been a nurse for 16 years, trained in General and Psychiatric Nursing with experience of working in palliative care with a national cancer charity and within the NHS.

Definitions

It is necessary to clarify what is meant by palliative care and dementia and how these definitions have been used in the context of this project.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual, (World Health Organization, 2002). Using the above definition this project is concerned with care given to people with dementia at any point after their diagnosis. It is not confined to terminal care at the end of a person's life, rather their overall experience and the care that is required to meet their physical, psychosocial and spiritual needs.

Dementia is the progressive loss of the powers of the brain. The most common cause is Alzheimer's disease. Other kinds of dementia are vascular dementias, alcohol related dementias, Lewy body dementia and Picks disease. What all these diseases have in

common is that they damage and kill brain cells, so that the brain cannot work as well as it should (Alzheimer Scotland, Action on Dementia).

Literature

Narayanasamy et al (2004) conducted a study to elicit the views of nurses regarding their role in addressing the spiritual needs of older people. Fifty two nurses from the East Midlands area participated by completing a critical incident questionnaire which examined a nursing situation. Nurses stated they were aware of spiritual needs for the following reasons; older people's religious background acted as a prompter, questions that were described as 'spiritually loaded' and the situation experienced, when a patient was given a diagnosis. The above situations triggered a nursing action, which was described as showing respect for religious beliefs and practices, respect for people's privacy and dignity, helping patients complete unfinished business, listening to concerns, comforting and giving reassurance.

Nurses provided evidence as to the effectiveness of their interventions and regarded the following as positive outcomes; patients providing gestures of gratitude, appearing peaceful and being in a relaxed state. Nurses also spoke about the satisfaction they gained from providing this form of care. It could be argued that apart from showing respect for religious beliefs and practices and helping to complete unfinished business, the other interventions are general in nature, not specifically concerned with spiritual care, although a part of it. In this article Narayanasamy et al (2004) discusses the concern that nurses equate spiritual needs with religious needs and this may leave unmet spiritual need for those patients who do not adopt overt religious practices.

Continuing with the issues of spiritual care and older adults Isaia et al, (1999) conducted research to determine the spiritual well being of 37 older adults living in the community, in a small semi-rural state in the south eastern United States of America. A spiritual well being scale by Paloutzian and Ellison, (Ellison, 1983) was used to determine participants perceived spiritual well being. The results of this research showed that the participants viewed themselves to be highly spiritual. Although this was a small study set in the united states the implication for professional carers is the need to be aware of spiritual needs of older people, particularly when their ability to independently meet these needs is diminished.

Spiritual care as part of palliative care has been acknowledged since the development of the hospice movement in the 1960's and the World Health Organisation included spiritual care in its original definition of palliative care in 1990. Much more recently Gordon et al (2004) reported on the development of competencies for spiritual care developed by a multidisciplinary group. Reflective practice sessions were used to utilize the competencies and improve spiritual and religious care practice within the hospice setting. This work was deliberately undertaken for professionals working within specialist palliative care but the author would suggest that they are relevant to professionals in other areas including for example health and social care. This practical approach may help carers identify 'real' actions, which relate to the provision of spiritual care.

It is appropriate to focus on literature regarding spiritual care and people with dementia. Bell and Troxel (2001) present anecdotal accounts of their experiences of providing spiritual care for people with dementia. They provide a variety of definitions of spirituality from people with differing backgrounds. One such definition by James Holloway and Sam Seicol states; 'spirituality is not what many think it is. Spirituality is to do with who we are and what life is about. It is not far away. It is very close to where we live. It has to do with our deepest longings, our sadness and joy, our loneliness and friendships, our fears and our times of trust, our beliefs and our disbeliefs. It has to do with the very essence of our being.'

The authors identified eight spiritual needs of people with dementia. They are as follows; to be connected, to be respected and appreciated, to love and be loved, to be known and accepted, to be compassionate, to give and to share, to be productive and successful, to still become and to have hope. Given the definition of dementia above there are real challenges, for example, in assisting the person with dementia to be successful. However, the authors emphasise the need for simplicity: to see a simple need and fulfil it is productive and successful.

Bell and Troxel (2001) also identified six ways to help meet spiritual needs. These are; value the person, celebrate the person's religious heritage, embrace simplicity, look to the creative arts, nourish your own spiritual life and give spiritual care throughout the illness. One example linked to the issue of looking to the creative arts relates to music. 'Music is almost the language of Alzheimers disease. Song lyrics, for example, remain intact much longer than a person's ability to converse. Dancing, rhythmic movement, playing a musical instrument, even simply tapping a beat are all valuable activities that touch the spirit'.

Lawrence (2003) acknowledges the need to 'tune into silence.' As a psychiatrist he describes the frustration and limitations of his professional input to the person with dementia. He describes contact as 'briefly acknowledging the persons presence, asking a few questions to test orientation and memory, and then talking about the person with their caregiver'. The need to take a more thorough history, incorporating information about the whole individual from the beginning of the assessment is a way forward. Adopting a holistic approach, including spiritual care, can help others to tune in at the right level and offer a potential pathway of connection.

Shamy E (1993) provides insights into spiritual care for people with dementia through her role as Methodist minister for people with dementia in Christchurch, New Zealand. Following a Christian tradition she offers practical ways of providing religious care. She describes the need to keep the faith memory alive by ongoing routine acts such as prayers, saying grace and using known bible readings. Using symbols such as rosary beads, flowers and a hand held cross can be useful triggers. She describes concern regarding faith communities not keeping links with those in their parish and positive links from the past therefore being lost.

There is much to consider in relation to the provision of spiritual care and people with dementia. The literature briefly described above focuses on the need to know, respect and acknowledge the individual and to be aware that spirituality is a component of everyone's lives.

Methods

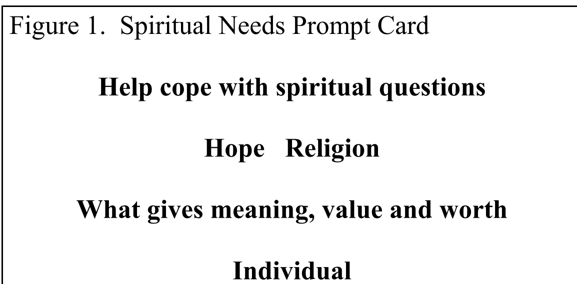
The project co-ordinator conducted a combination of semi-structured interviews and focus groups with people with dementia, carers of people with dementia and service providers.

Recruitment required time and sensitivity to the varying needs of people with dementia and their carers. Ethics permission was granted by the Multi-Centre Research Ethics Committee for Scotland.

In total there were 96 participants, (8 people with dementia, 25 carers and 63 service providers).

Service providers who took part represented a variety of services in West Lothian from social care, the private sector, charitable and voluntary organisations and health care providers.

Figure 1. Spiritual Needs Prompt Card



During the semi structured interview people with dementia and carers were asked to describe their experiences from the onset of their problems. Service providers were asked to describe their service and involvement with people with dementia and carers. All participants were then asked to describe palliative care needs. To facilitate this, prompt cards were used to initiate discussion of the main elements of palliative care. The spiritual needs prompt card is shown in Figure 1. There are numerous definitions of spirituality available in literature, but a definition by Swinton (2001) was used as the basis for this spiritual care element of the needs assessment; 'That which gives meaning, purpose, hope and value to people's lives. This is part of a wide concept which may include but is not defined by religious faith and culture.' The project co-ordinator introduced the prompt card by stating that spiritual needs can involve religious beliefs and activity but can also involve other aspects of life, which give meaning, value and hope to a person. It was highlighted that spiritual needs are individual. At each interview a

'real' example was given of a man who had a tremendous love of the outside and found peace and contentment when out in a garden. A spiritual need for him was being out in the open, close to nature, with a sense of freedom. This example was given to present spiritual needs in an inclusive manner, relevant to those who do and do not have religious expression as part of their spiritual life.

Reports compiled following the completion of interviews and focus groups were returned to the participants and reviewed by them, the final content was agreed and then anonymised. All reports were then independently analysed by the project co-ordinator and a member of the project steering group. This participative approach to data collection attempted to provide robust data that represented the experiences and views of those who took part.

Results of needs assessment

People with dementia and carers

There were five general themes that emerged, these included;

- Continuing with religious activity
- No spiritual needs
- Take it or leave it
- Connectedness to family
- Spiritual outlets

The following are comments from participant interviews related to the above themes.

Continuing with religious activity
She attends a church service once a month, which is organised for elderly people and she is picked up for this. This is something she looks forward to and takes great benefit from. The church visitor calls every Sunday. M was an organist in the church and has lots of connections. It is important that she knows people who visit. She also has other church friends who take her to mass on a Sunday. She benefits from a good church community.
Take it or leave it
Really in terms of religious / church activity she can take it or leave it. The church knew she had a problem and the minister did visit. She is really a quiet person who likes to keep herself to herself. She went to church and the women's guild, its hard to know if she misses that.
No spiritual needs
If able to think clearly my wife would have the same view as myself. There is not a need for her to receive spiritual input. She is not now aware of what is going on. 'I don't really have spiritual needs that I can think of'. Spiritual care, to be honest I think this is null and void due to the stage that she is at currently. Contn…

To be honest I gave up spirituality a long time ago after my experiences in the war. What I think is important is treating people fairly and honestly.

Connectedness to family

She got her value and worth by being close to me and the people she knew and loved. She was lost when we weren't together.

Interestingly my own family have become supportive recently. My brother and sister are very concerned and considerate, they phone and we have a good chat. I think that is really important for me, to have supportive family and good friends who are available to talk with.

In terms of spiritual needs family are the most important thing. We have three children, two sons and a daughter and four grandchildren, we have regular contact with family and this is very important to both of us.

Spiritual outlets

For me this is where poetry comes in, for XX it is her walks outside and her grandchildren.

XX has always had dogs and a real love of animals. He would love to have a dog of his own but this is just not possible and is a real loss for him.

What gives value and meaning to him is his cigarettes.

Service providers

The discussion from service providers focused on the issues of providing spiritual care, who should do it, what it would involve and their experiences.

Don't get involved

A number of service providers identified that this is not an area they would get involved in or would consider having a responsibility to address.

Spiritual care: the realm of people who have ongoing involvement

People with more ongoing involvement and contact with people who have dementia and carers are more likely to deal with the why questions and have a need to address the spiritual elements of their care.

Often the nursing auxiliaries are involved in this care and provide a supportive role…trained nurses can be more pressured in the time they have, less accessible to carers and have less contact with the person with dementia.

Need to understand previous beliefs and know the person

Religion is important for some people of this generation and this again is an individual issue. There is a need to understand the persons' previous beliefs.

Maintaining hope is important and trying to understand the individual's situation.

Contn…

The essential thing is to know who they are and work at that. When trying to establish meaning, following a client centred approach and to be led by the client is the most important thing.
What activities did participating services provide / suggest to meet spiritual needs?
Referral to the chaplain, pat a dog service, developing a net of support to help cope with the emotional and practical elements of the disease, working on a one to one basis, art classes, life experiences group, music, not imposing belief, respecting the vulnerability of people with dementia, assessment based on the individual, draw on positive skills and attributes of the person, church services, liasing with families, working on life stories, identify usual habits and practices and communicate these to relevant people, access to garden and flowers, providing a quiet space, maintaining family roles as far as possible, opportunity to take communion, pastoral visits and dancing.

Discussion

The results of the needs assessment are varied and wide-ranging. It appeared easier for people with dementia and carers to discuss religion and its associated issues rather than the broader term spiritual care. Those service providers who had a specific dementia or palliative care role were understandably more comfortable discussing spiritual needs and care. However the examples provided by services, of activities undertaken to meet spiritual needs, are broad and appear to reflect a wide view of spiritual care not restricted to religion or religious practice.

Some service providers were clear that they did not see their role as a provider of spiritual care. This view may be understood in that a number of those interviewed provided generic services not specific to dementia or palliative care. However it raises a question of who actually has responsibilities of providing spiritual care when people with dementia and carers encounter a variety of services and professionals. Do we think someone else is doing it? Are their key moments when spiritual needs arise and who can provide help at these times? From the results of this needs assessment it would suggest that those people with ongoing care responsibilities were identified, as being in the best position to meet spiritual needs.

Some carers and people with dementia identified that they had no spiritual or religious needs. It is the researchers opinion that this genuinely represented their views and it related to lifetime experiences, their belief system and view of the world. The difficulty of the participants' ongoing situation also needs to be considered when reviewing responses. This challenges the widely held professional view of the need to provide holistic care, involving physical, psychosocial and spiritual elements. It is possible however that what provides meaning, hope and value for people with dementia and their carers can be identified in practice and through involvement and may not emerge under 'labels' of spiritual or religious care. In contrast to this however, participants identified activities related to the more broad themes of spirituality for example writing poetry, demonstrating an individual approach and understanding of this issue and a degree of comfort with the terminology.

Conclusion

It is impossible for those of us who have not directly experienced the effects of dementia to understand the multiple losses which overwhelm the person. The need to connect with people, things, the world, the past, deeply held views and beliefs seem to be paramount. Trying to determine what gives a person hope, meaning and worth is one way of making that connection. Our collective challenge can be expressed in the comment, 'He feels worthless; he is always putting himself down. We are constantly saying to him you are still you despite your problems. He needs such a lot of reassurance'.

This needs assessment paints a picture of spiritual issues from the perspectives of people with dementia, carers and service providers. The need to directly explore these issues and address the inevitable questions this type of work raises is a necessary part of the development and understanding of the spiritual care we aim to give.

Stephen Smith is Co-ordinator Dementia/Palliative Care Project, West Lothian Healthcare Division, NHS Lothian

References

ALZHEIMER SCOTLAND, Action on Dementia What is dementia? Information leaflet

BELL V TROXEL D (2001) Spirituality and the person with dementia- a view from the field Alzheimers's Care Quarterly 2 (2) 31-45

ELLISON C W (1983) Spiritual well being: conceptualisation and measurement Journal of Psychology and Theology 11 330-340

GORDON T MITCHELL D (2004) A competency model for the assessment and delivery of spiritual care Palliative Medicine 18 646-651

ISAIA D PARKER V MURROW E (1999) Spiritual well being among older adults Journal of Gerontological Nursing August 15-21

LAWRENCE R (2003) Aspects of spirituality in dementia care When clinicians tune into silence Dementia 2 (3) 393-402

NARAYANASAMY A CLISSETT P PARUMAL L THOMPSON D ANNASAMY S EDGE R (2004) Responses to the spiritual needs of older people Journal of Advanced Nursing 48 (1) 6-16

SHAMY E HARRISON A (1993) Spiritual needs of people with dementia Dementia Services Development Centre University of Stirling

SWINTON J (2001) Spirituality in mental health care: rediscovering a forgotten dimension Jessica Kingsley London

WORLD HEALTH ORGANIZATION (2002) National Cancer Control Programmes: Policies and Managerial Guidelines 2nd Ed Geneva