



'De-mystifying spiritual care'

An exploration of the spiritual care of
people living with dementia
in care homes

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Executive Summary

Simon Jaquet Consultancy Services Ltd

www.simonjaquet.com

Introduction

Since its inception in 2007 Faith in Older People (FIOP) has worked extensively with health and social care staff to fulfil its aim of 'developing a better understanding of the importance of the spiritual dimension to the well-being of older people'.

The Life Changes Trust commissioned a two- year project from a consortium of four organisations (Faith in Older People, University of Aberdeen, Simon Jaquet Consultancy Services Ltd, and Mowat Research). The project aimed to improve the quality of life of people living with dementia in care homes in Scotland - by increasing our understanding of the role of spirituality, faith, and religion in their lives, and by encouraging the provision of an environment that actively worked to lift the spirits of those with dementia and their relatives. For the purposes of this project, we used the definition of spiritual care used by the Purple Bicycle Project¹.

'Spiritual Care involves developing a genuine relationship between individuals. Within this there is an acknowledgement that the clinical picture of dementia is not all that can and should be known, and that human lives are mysterious. There is more to living well than simply caring for our bodily needs. Spiritual care acknowledges the presence and importance of such things as joy, hope, meaning and purpose as well as the reality of disease, suffering, disappointment and death. This means that spiritual care is much broader than any one faith or religion and is of relevance to everyone.'

Methodology

In undertaking the research, we employed a mixed methods approach, involving both quantitative and qualitative methods. In order to inform the research design, we carried out 12 scoping interviews with a range of key stakeholders, including Scottish Care, the Scottish Social Services Council, the Care Inspectorate, NHS Education for Scotland, Edinburgh Interfaith Association, Interfaith Scotland, Scottish Ahlul Bayt Society, and three care home managers.

The key elements of the methodology were:

- An online survey for care home managers was designed and managed. It was publicised by Scottish Care who emailed 646 members directly, as well as sharing it on social media. It was also publicised by the Care Inspectorate via their website. Follow up emails were sent by Scottish Care, FIOP and Simon Jaquet Consultancy Services Ltd. We received 92 returns representing 89 separate care homes.
- An interfaith seminar was held in partnership with Interfaith Scotland, in order to hear the views of several of the faith communities in Scotland on the interim findings from the survey.
- Telephone interviews were conducted with 11 care home managers - seven from the independent sector, two from the local authority sector, and two from the third sector. The interviews focused on: what they saw as the spiritual needs of residents living with dementia; what kind of spiritual care they offered, and how this might be different from spiritual care for residents who are not living with dementia; who was involved in spiritual care; and how spiritual care for people living with dementia could be improved.

¹ https://www.abdn.ac.uk/sdhp/documents/TPBP_Booklet_1.pdf

- Four case studies were conducted in four care homes (Stonehaven, Renfrew, Lanark, Glasgow) in order to explore what raises the spirits of the person living with dementia in the care home; and to identify how you find this out. Discussions were held with residents, family members and friends, and care home staff.
- In September 2017, we invited representatives of a range of national stakeholder groups and organisations to attend a seminar to hear the research findings and to discuss their implications for the policy and practice of work with people living with dementia.

Findings and conclusions

Understanding spiritual care

"Most people see spiritual care as religion, but it isn't. Some residents have religious views. For others, their needs are met if they take part in an activity such as smelling the flowers or seeing the sea." (care home manager)

"Meeting the spiritual needs of the person by listening to them and the people important to them about what and who is important to them giving them joy, happiness, peace, love, laughter whatever brings about the essence of the person and ensuring staff and friends relatives provide the opportunities for them to experience these on a regular basis." (care home manager)

Spiritual care is already being offered to people living with dementia in care homes. There are many practical examples of care addressing needs that go well beyond the physical realm. However, most staff would describe this as 'holistic', 'person centred' care, or care that addresses the mind, body, and spirit.

The term 'spiritual care' still tends to be associated with religious faith and practice. Currently there appears to be a disjuncture between what people in care homes term spiritual care (providing for explicitly faith related needs, such as regular services of worship), and the practice of care that engages residents at a deeper level. This tension was apparent in the online survey, with respondents generally stating that spiritual care was an important element of their work, and available to residents. But, when asked for examples of practice, it was 'religious' activity that was quoted.

There is a need to clarify (and secure widespread support for) the concept of spiritual care, ensuring that 'quality of care' translates into genuine 'quality of life'.

Delivering spiritual care

"Residents just love singing. We've got the choir group, the church services. There's certain residents who'll just sing hymns in the unit anyway! Impromptu sing-alongs happen pretty regularly...Even if someone's distressed, especially in the dementia unit, or agitated with regard to personal care, if you start singing and they join in, it's good at relieving any anxiety as to what's happening to them." (Activities coordinator)

"There was a man in one of the units, and he was a wee grumpy man. He'd never married, he'd been a loner all his life. He was in the dining room one day, and I can't even remember what was wrong with him, and I hugged him from behind. I don't know what possessed me, because I'd never hugged this man - ever - but he was in such a bad mood and I wanted to cheer him up. And you felt him just relax, and he actually said 'You don't know how long it has been since somebody has kind of ...' - just to feel loved, nurtured." (Dementia unit manager)

Most care homes, when asked to give practical examples of when they had provided understanding and support for the less tangible and 'higher' level needs of residents, were able to do so - especially those involved in the case studies. These ranged from small acts of kindness (such as a spontaneous hug) to more systematic approaches (developing small community choirs, running a 'Namaste' session).

There is a high degree of consensus about what lifts the spirits of residents in care homes. These include: music and singing; interaction with children and intergenerational activity; the presence of animals and pets; physical touch; contact with family members; enduring relationships with staff; access to religious or faith-related activity both in the care home and in the community.

Spiritual care draws people out of themselves, and into relationship with others and the world around them. It has implications for staff inter-personal skills, and community building.

Spiritual care for those living with advanced dementia

"The needs of people living with dementia aren't different but need to be approached differently. It's not what we deliver but how we deliver it is different." (care home manager)

"It's not different for a person living with dementia. You look at the whole picture and get to know them in a different way. You need to be more creative. You get to know the person, their family, people in faith communities." (care home manager)

The spiritual care of people living with dementia can continue right to the end of life. Despite an apparently reduced ability to communicate among many of those with advanced dementia, numerous examples were given of staff and family members being able to maintain communication and to address the higher-level needs of their loved one. At the same time, it is important to recognise the considerable practical and emotional challenges to doing this effectively.

Significantly, it is the 'how' rather than the 'what' which needs to change. A greater focus on 1:1 care in an environment that is safe and secure will become increasingly required for people living with dementia. As verbal communication diminishes, there will be a growing reliance on other non-verbal means. Music and singing has an important role to play here.

The potential role of faith communities

*"I would like to provide regular support from their chosen churches and would also like to be able to help them attend their own church and be in contact with the congregation and church activities."
(care home manager)*

"If people were prepared to visit and develop voluntary relationships with the residents like elders in the church. But it's sadly lacking - maybe because people feel uncomfortable with dementia." (care home manager)

There is potential for faith communities to play a significantly more active role in the lives of people living with dementia in care homes – both in the care home and in the local community. The current picture is mixed, with 75% of care homes having arrangements in place for the provision of religious services and pastoral support for individual residents. At the same time, many report that it is difficult to set up regular visits by the priest or minister, and some say it is hard to get people from the churches to visit.

The Church of Scotland has 1500 parishes, (and 1.7m members) and there are 873 care homes for older people in Scotland. Although neither network has an even distribution throughout the country, a rather crude numerical analysis would give us almost two churches for every care home. It would theoretically be possible for each care home to be 'adopted' by a church. This would give access to human capital (for example the members of the congregations as potential 'befrienders'), social capital (for example the ability to maintain links and relationships within local communities), and a measure of economic capital (with these links providing access, for example, to skills and employment opportunities).

Underpinning this, there would appear to be considerable scope for the training and development of volunteers from faith communities to become involved in the life of local care homes. This could offer mutual benefit - opportunities for faith communities to participate in local community activity, and increased capacity for the overall 'team' within the care home.

If the other churches and faith communities were to become involved, there would clearly be significant scales of economy.

In order to launch anything of this nature, there would be implications for awareness raising, training, and capacity building.

Non-Christian faith communities

Establishing links at local level between local faith groups and care homes - so that faith groups could advise care home on faith issues, and care homes could advise care homes on faith issues. [proposal from interfaith seminar]

There are very few examples of non-Christian faith communities taking part in the life of care homes in a structured way. This reflects a national demographic, with non-Christian religions engaging 2.5% of the Scottish population.

However, informal discussion with some of these communities during the qualitative fieldwork phase of the research gave some indications that groups (such as the Muslim and Sikh communities) are now facing up to the challenge of changing patterns of social behaviour in third generation 'immigrant' families. In short, there is some evidence that communities which would previously have provided care for the elders within the home setting, are now looking at alternative modes of care, including care homes.

it is worth exploring how these communities can contribute to the spiritual care of people living with dementia in care homes.

Training, capacity building, and sharing practice

"[We are about] enabling service users to 'live well' and 'die well'. Continued staff training in dementia and the spiritual care of a person with dementia. Engaging with local faith groups if appropriate. Finding ways of enabling people with dementia to speak about their own spiritual lives." (care home manager)

For any substantial change of practice to become rooted within a sector, there are always implications for the training of staff and for organisational capacity building. Evidence from the online survey and the qualitative discussions suggested that care homes would be open to appropriate training on how to address spiritual care issues. Only 3% of managers said that no training was required.

Key to any training will be establishing a clear and shared understanding of what is meant by 'spiritual care'. Also, the varied roles played by the different actors (residents themselves, family members and friends, staff, volunteers) could usefully be explored. Given the time constraints and pressure of work, it would be important to develop flexible learning opportunities that can fit round the working day, and be seen to have a relevance for day-to-day practice (rather than, for example, requiring college attendance),

We came across many examples of interesting and creative practice in the course of the research, ranging from small but effective ways of meeting an individual's spiritual care needs through to larger scale programmes. There would be value in creating ways of sharing practical approaches to spiritual care across the sector – especially through the use of ICT.

There is an important role for both residents and family members to play in the training process.

The current funding environment

"The biggest issue is time. Staff are stretched just completing the personal care tasks, eating, drinking etc. We try and include spiritual care within activities we provide however staff struggle with how to implement this." (care home manager)

Current pressure on care homes, due to reducing budgets and unfilled posts, means that any new initiative related to spiritual care will need to be sensitively introduced, if it is not to be regarded as yet another 'scheme' imposed from the outside - making unreasonable demands on staff time and energies.

Two factors may be helpful in this regard. Firstly, the starting point for supporting the further development of spiritual care is the reality that it is already happening in many settings. This would argue in favour of an 'appreciative inquiry' approach, where current strengths are recognised, celebrated, and built on. Secondly, the potential for the use of volunteers means that, with sensitive management, there is scope to involve a wider set of stakeholders in this work.