

## Article

# Nurses' Understanding of Spirituality and the Spirituality of Older People with Dementia in the Continuing Care Setting

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**Abstract:** This research paper was presented at the Third International Spirituality in Healthcare Conference 2017—‘Creating Space for Spirituality in Healthcare’ at Trinity College Dublin, The University of Dublin. 22 June 2017. The number of older people living with dementia in Ireland is rising. Dementia is prevalent among those residing in the continuing care setting. Nurses have a professional obligation to provide person centred, holistic care, to which spiritual care is a core element, yet often do not. As there are no guidelines in Ireland for spiritual care provision it is open to personal interpretation and application. This study was the first in Ireland to explore how spiritual care is understood by nurses in the context of older people living with dementia in a public, rural, continuing care setting. A qualitative descriptive design was utilized. Following purposive sampling, eight semi structured interviews were conducted in a rural Irish community hospital among registered nurses caring for older people living with dementia. A conceptual framework developed from the findings of a literature review, as well as this research study’s aim and objectives framed the interview schedule and data analysis. Data analysis utilized Newell and Burnard (2011) Thematic Content Analysis. Ethical approval was granted by the Health Service Executive (HSE) and the University of Dublin, Trinity College Dublin (TCD). Six key themes emerged from the study—1. *Understandings of Spirituality*, 2. *Assessing spiritual need*, 3. *Providing spiritual care*, 4. *The impact of spirituality on quality of life*, 5. *Barriers to spiritual care and how these are addressed*, and finally 6. *The needs of staff*. This paper presents and discusses the findings of the first theme ‘Understandings of Spirituality’ and its two sub-themes, 1. ‘The nurse’s own understanding of spirituality’ and 2. ‘The nurses’ understanding of spirituality and older people living with dementia.’ It is evident from the findings that there exists a variety of responses with regards to the nurses’ own understanding of the concept spirituality and spirituality for older people living with dementia. Participants placed emphasis on person-centred approaches to understanding and providing for the needs of care recipients’ in this area of care. Most participants acknowledged the positive impact of spiritual care on quality of life for older people living with dementia. Indications for practice suggest the need to develop suitable evidence based professional, person-centred frameworks, guidelines and educational standards for nurses which better equip them to understand spirituality and how this area of need can be properly assessed in partnership with the recipient of nursing practice in the continuing care setting to ensure comprehensive holistic, person-centred practice.

**Keywords:** spirituality; religion; dementia; nurse; long term/continuing care

## 1. Introduction

This research paper was presented at the Third International Spirituality in Healthcare Conference 2017—‘Creating Space for Spirituality in Healthcare’ at Trinity College Dublin, The University of Dublin. 22 June 2017.

It is estimated that the prevalence rate of people living with dementia worldwide is 44 million. In Ireland this estimate is 47,849, with those aged over 65 estimated at 43,783. The number of older people living with dementia in Ireland and internationally is rising (Pierce et al. 2014). Dementia is prevalent among those residing in the continuing care setting (Dementia Services Information and Development Centre DSIDC). Nurses have a professional ethical and legal obligation in Ireland to provide person centred, holistic care, which spiritual care is central too, yet often neglect to do so due to competency and confidence concerns (Keenan 2017a, 2017b, 2017c; NMBI 2014), as well as out of personal belief and decision-making. As no nursing guidelines exist in Ireland for spiritual care provision it is open to omission, interpretation and application.

This paper presents and discusses the findings of the first of six key themes ‘*Understandings of Spirituality*’ and its two sub-themes, 1. ‘*The nurse’s own understanding of spirituality*’ and 2. ‘*The nurses’ understanding of spirituality and older people living with dementia*’.

## 2. Literature Review

In carrying out a literature review the following professionally recognised databases were searched: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline and Psychinfo to uncover what is currently known and not known in this important area of nursing practice. The search terms utilized were ‘spirituality’, ‘religion’, ‘dementia’, ‘nurse’ and ‘long-term care’, as well as relevant variations of these. The literature was confined to peer-reviewed articles published in the English language between 2006 and 2017. The search initially yielded 304 results as follows: Cinahl: 111, PsychInfo: 129 and Medline: 64. However, following a detailed reading of the retrieved article titles, abstracts and content there was a dearth of literature on nurses’ attitudes and perceptions of spiritual care and spirituality in relation to people living with dementia in the continuing care environment. In saying that three themes were identified in the literature as relevant to the focus of this study namely, the concepts of *spirituality* and *spiritual care*; and *Spirituality and people living with dementia*.

The topic of spirituality is not new in health literature and is often discussed. However, while many definitions exist, no consensus has emerged. Some definitions are considered vague and many are open to individual interpretation (Timmins et al. 2016). However, Sessanna et al. (2007), in their conceptual analysis of *Spirituality*, identified four common traits among many of the definitions, namely, 1. A religious system of beliefs and values, 2. That which gives meaning, purpose and connection to others, 3. A non-religious set of beliefs and 4. A transcendental phenomenon. These common traits have guided this investigation. Equally there is no consensus regarding the concept *spiritual care* (Kevern 2015). Currently its primarily understanding is perceived as being left to chance, or to the individual preferences and experiences of healthcare staff (Health Information and Quality Authority HIQA). Although Daly and McCarthy (2014) and Keenan (2017a, 2017b, 2017c) do argue that it has a person-centred dimension.

The importance of responding effectively to the care recipient’s holistic (including spiritual) needs as central to the nurse’s role is well established. (Higgins 2014; Keenan 2017a, 2017b; NMBI 2014). For example, within Ireland, the nurse has a legal obligation to support the spiritual needs of care recipients’ (NMBI 2014). While the volume of legislative and policy obligations for nurses increases, guidance in spirituality is still lacking (Attard et al. 2014; Ross et al. 2014; Timmins et al. 2016). Traditionally, papers on spirituality have focused primarily on end of life care (Timmins et al. 2017) and are mainly descriptive in nature. More recently there has been a small increase in the volume of peer reviewed research papers published in this area and across a wider range of clinical settings, (e.g., Timmins and Kelly 2008; Timmins et al. 2017; Keenan and MacDermott 2016; Patel et al. 2017;

Pike 2017). These papers highlight that the needs of recipients of nursing service can vary depending on care setting and individual need.

Cleary and Doody (2017) emphasise the importance of knowing the person living with dementia when providing support. Keenan (2017a, 2017b) stress's the person-centred aspects to understanding and delivering spiritual care, if quality nursing is to be practiced. It is recognised that defining spirituality is challenging. McSherry and Draper (1998) and Timmins et al. (2016) argue that spirituality is always evolving and therefore should not be a 'catchall' concept.

While religion, the ritual manifestations of spiritual belief, is not exclusive to some peoples' spirituality, many older people link the two together (Power 2006) and religion becomes more important for many people as they age (Carr et al. 2011; Hayden 2011; Holloway et al. 2011).

A Systematic Review of spirituality and religion in older people living with dementia, by Agli et al. (2015), found that spiritual and religious practice slow cognitive decline. Higgins (2014), in a qualitative study among residents of a UK care home living with advanced dementia, found that religion played an important role in maintaining an individual's identity.

While spirituality and religion may be significant for many older people living with dementia, how nurses understand these concepts and support this area of need is less well understood. This study's review of the literature, like Daly and McCarthy (2014), found a dearth of evidence on considering the spiritual care of older people living with dementia. This outcome provided further justification for carrying out further research in this area (Kirwan 2017).

### 3. Aim and Objectives

The primary aim of this study was to explore how nurses understand spirituality and meet the spiritual needs of older people living with dementia in an Irish, rural public sector continuing care setting. The purpose was to enhance professional nursing knowledge in this area with a view to improving quality, person-centred, holistic nursing practice.

### 4. Methodology

*Research Design:* A qualitative descriptive research approach was utilized. This provided participants with the opportunity to express their knowledge and talk about their nursing experience. This also provided the researchers with an opportunity to gain a deeper understanding of how the spiritual needs of older people living with dementia are understood, or not, by nurses and how this study's finding may be comparable to other nurses in similar situations. Although the authors recognise that to gain a true insight it is essential that nurses ask the care recipient. Furthermore, in an Irish context this research will act as a stepping stone to building a picture of if or how nurses focus on and provide spiritual care to people living with dementia.

*Ethical Considerations:* Ethical Approval was granted by TCD and the HSE.

*Setting:* The research study was undertaken in a public Irish healthcare organisation for older people living with dementia. The interviews were conducted in a private room in the nurse's place of employment.

*Recruitment and Participants:* Purposive sampling was used to recruit participants. Participation was open to all nurses who were from one continuing care provider, provided they were registered with the Irish Nursing and Midwifery Board (NMBI) and who have worked a minimum of two years in continuing care settings with older people living with dementia. This timeframe was chosen to ensure the study was open to a large number of nurses. Nurses who did not meet this criteria and Agency nurses were excluded. The minimum of two years' experience and non-agency nurses was chosen to ensure nurses participating in the study would have gained sufficient experience and knowledge of people living with dementia to enable them to speak confidently on this cohort. Other healthcare professionals were also excluded from the study as the research focus was on nurses' perspective.

The Director of Nursing appointed a gatekeeper whose role was to identify eligible participants and control access to them, uphold the integrity of the study and maintain confidentiality, advertise

the study and distribute information packs consisting of participant information leaflets, participant consent forms and letters inviting nurses to participate in the study. Initially twelve nurses who met the criteria expressed an interest via telephone in participating in the study. However, due to a myriad of factors, for example illness or not being available due to clinical practice demands, only eight nurses subsequently chose to participate in the interview process.

The demographic details of participants were as follows: All participants were female, with various years of nursing experience ranging from 2.5 to 20 years. With regards to education, three participants were educated to certificate level and the remaining five were educated to degree level. Their age range varied. Participants were aged between 25 and 60 years. Three were aged 25 to 35 years of age; four were aged 36–45 years of age and one was 55 years plus.

*Data Collection:* Semi-structured interviews were conducted using an interview schedule informed by the literature review and the study aims. This allowed the researcher to gather the required data, and enabled the participant the freedom to disclose what they felt necessary. The specific questions on the interview schedule, which relate to the findings presented in this paper were: *‘What is your understanding of spirituality?’* and *‘What is understanding of spirituality and people living with dementia?’* Each interview lasted approximately one hour. Interview data was recorded using a sound-recording device, and transcribed verbatim by the researcher. Participants provided written consent to the interview process prior to the interview, and again verbally on the day of the interview, a minimum of one week later. Data was safely stored in line with the Irish statutory requirements of the Data Protection Act (Amendment Act) ([Government of Ireland 2003](#)).

### *Data Analysis*

Data analysis, converging large volumes of data into smaller manageable pieces, was undertaken utilizing [Newell and Burnard \(2011\)](#) thematic content analysis, which allowed themes to be constructed from the rich data following extensive, in-depth reading and re-reading. The process was as follows—Stage One—Note making on interviews using a reflective diary noting personal interview techniques and demeanor of research participants. To become familiar with the data, it was read over and over and incorporated with listening and reviewing the reflective diary to gain deeper knowledge and familiarity with the transcripts. Stage Two—In order to identify general themes, each transcript was printed, each sentence on a new line, double spacing and wide margins to facilitate note making. Stage Three—Open coding of data obtained in all interviews involved highlighting and grouping relevant words and phrases which were then titled codes. In Stage Four—Higher order codes were created grouping similar phrases and expressions, the purpose being to reduce the number of codes. The higher order codes emerged as major findings of the study. An example of open coding to higher order codes was as follows—the higher order code of *spirituality is individual* came as a result of grouping, for example, the following words and phrases from the transcripts—*‘It’s individual’*, *‘Where someone gets their comfort’* and *‘it how you find peace ...’* Stage Five—By constant reviewing and updating the higher codes were matched with the transcripts. Stage Six. Presentation of findings: Finally, the six themes arrived at were: Understandings of Spirituality, assessing spiritual need, providing spiritual care, the impact of spirituality on quality of life, barriers to spiritual care and how they are addressed, and finally the needs of staff. This paper will now proceed to outline and discuss the findings from the first theme: *‘Understanding of Spirituality’* and its two sub-themes, 1. *‘The nurse’s own understanding of spirituality’* and 2. *‘The nurses’ understanding of spirituality and older people living with dementia.’*

## 5. Findings

### *Theme: 'Understandings of Spirituality'*

#### *Sub-Theme One: Nurses Understanding of Spirituality*

All participants recognized the presence of spirituality and described it as being personal and private for themselves and many others:

*'It's individual'. (Participant 7)*

The collective/congregational nature of spirituality for many people was also identified. The majority of participants (n. 7) linked spirituality with their religious practice. A number illustrated this with reference to their own religion, in this case Roman Catholicism. Examples included, participating in Holy Mass, praying, reading the Bible, reciting the Rosary and Adoration of the Blessed Sacrament:

*'Prayers are important.' (Participant 5)*

Participants spoke of spirituality providing meaning to life. Examples included deriving meaning from their religion, other people or routines. It also provided an inner peace, which created a sense of calm and provided comfort:

*'It's how you find peace in your soul, what gives you peace in your heart.' (Participant 2)*

*'Where someone gets their comfort.' (Participant 1)*

The awareness of spirituality was perceived as heightened at times of personal distress.

*'We all seem to call on spirituality when in times of distress. (Participant 1)*

#### *Sub-Theme Two: Nurses Understanding of Spirituality for Older People Living with Dementia*

Nurses varied in their understanding of spirituality for older people living with dementia. Two participants expressed clear views on the importance of spirituality for this cohort, while two other participants claimed the opposite for those living with end stage dementia:

*'It's the exact same. (Older) People with Dementia are no different to anyone else'. (Participant 8)*

*'I think the end stage of dementia . . . they are not into the spiritual . . . '. (Participant 3)*

Half of participants (n. 4) stated that older people usually believe in a Supreme Being:

*'Old people, they believe in God.' (Participant 3)*

All participants (n. 8) provided examples of how spirituality was important to older people living with dementia. The link of religion with spirituality was identified by all participants as especially important to older people in Ireland. Care recipients' spirituality was best understood through having knowledge of the individual's religion and religious and spiritual practices. For most of the recipients of care in this study practices, included Bible Reading, praying, singing, reciting the Holy Rosary, Adoration of the Blessed Sacrament, actively participating in Mass and attending Confession:

*'A lot of residents take comfort when a Priest comes and gives them anointing or a blessing or Holy Communion.' (Participant 1)*

Spirituality was perceived as both individual and collective, with participants gaining spiritual meaning from their religious beliefs and practices, personal attitudes, relationships, animals, music and nature. As well as giving meaning, spirituality was observed as providing inner peace, comfort and a sense of purpose in their lives.

However, some participants acknowledged their professional struggles in ascertaining what the personal meaning and purpose for individuals were.

*'You need to be so observant, mindful of the person. It might be just for moments when you can recognize and facilitate.'* (Participant 8)

Other meaningful moments included, for example:

*'One Lady, ... when she has the sun in her face ... it gives her great peace.'*

Providing space for, listening to and observing patient spirituality and respecting relationships were also seen as ways of enhancing the nurses' understanding. Participants, in particular, found life story, reminiscence and validation to discover what is meaningful for the recipient of care very useful.

*'Just to be present, to listen to them, give them time.'* (Participant 4)

Spirituality was also seen as a means for older people to be able to cope with their lives and was perceived as particularly important at times of distress.

*'Where someone gets their comfort.'* (Participant 1)

While Roman Catholicism was the faith expressed by all participants in this study, there was respect given to older people of other faiths, and no faith, and how care recipients chose to manifest this, or not, through emphasis on various rites, rituals and practices.

*'We respect their religion.'* (Participant 3)

## 6. Discussion

In this study, the nurses' personal understanding of the concept *spirituality* varies little from that presented within the health literature. Spirituality is described as a broad, ill-defined concept with various understandings among nurses (McSherry and Draper 1998; Timmins and McSherry 2012; Scott 2016). The lack of an agreed definition is seen by Sessanna et al. (2007) and Carr et al. (2011) as a reason why nurses are unable to address the care recipients' spiritual needs. This is despite it being an expectation of care recipients' and families (The Spiritual Care Association 2017), supported by a number of national and international health policies (Romeiro et al. 2017; Egan et al. 2011) as well as a professional and legal obligation in many jurisdictions (e.g., NMBI 2014). Health professionals have a duty to enhance care recipients' spiritual safety by effectively managing their needs in this area of holistic care and by responding appropriately to spiritual vulnerability and spiritual risk (Keenan 2017a, 2017b).

The existence, within health literature, of no one, dominant definition and/or the absence of practice guidelines may on the surface present challenges for nurses. However, unless the nursing professional seeks knowledge of the various faiths, as well as acknowledge and facilitate the personal dimensions of spirituality and its manifestation by individual recipients of care then, one may argue that the philosophy of person-centred nursing and the holistic ethos of quality approaches to individualized care will be in jeopardy (Keenan 2017c). Secondly, utilizing the absence of an agreed definition of spirituality and/or nursing guidelines as explanations for not addressing this core holistic domain or addressing it inadequately raises serious ethical (Keenan 2017a) and legal concerns. In fact, the absence of a consensus on spirituality's meaning, while also challenging for some academics and theologians, may actually be beneficial for both the health professional and the recipient of support within a multi-cultural, multi-belief health care setting. Nursing frameworks and guidelines on spirituality need to incorporate such realities, and an approach which is person-centred may be less restrictive if an ubiquitous definition is not always applied.

Participants in our study expressed freely and with confidence their beliefs and understandings of spirituality and religion. This was similar to those participants researched in, for example, Keenan and MacDermott (2016). They found that 80% of the interviewees, i.e., nurses who had cared for an intellectually disabled child who had died, confidently made reference to God and stated that spirituality, as a core competency, plays a central role in their professional practice. It was evident that:



*'Spirituality was not simply a reactive strategy in a time of need, but one of deep meaning and value to the nurses and was (confidently) embedded within their holistic nursing care.'*  
(Keenan and MacDermott 2016, p. 4)

Furthermore, (Keenan and MacDermott 2016) demonstrated that the spiritual awareness and spiritual care of self, colleagues and recipients of service are at the heart of competent and confident nursing practice. This is in stark contrast to a direct quote from a New Zealand participant in Egan et al. (2011, p. 13),

*'People are too scared to show any religious or spiritual learning. It is frowned upon. Religion is also unpopular, not in vogue. You are thought of as weird. You have to be careful to express or show spirituality, which is a sad reflection on society.'*

Therefore, it should be acknowledged that many nurses lack competence and/or confidence in this area of practice because of the cultural norms and pressures at the societal, organisational and peer level, such as dominant attitudinal expressions.

Participants in our study identified religion as being particularly important for Irish older people living with dementia, because of the care recipient's strong beliefs and practises. They also identified the role of culture and the predominance of the Roman Catholic Church as supporting and enhancing such activities. These findings are supported by Daly and McCarthy (2014), but are not unique to older people in Ireland (Power 2006). For example, Ødbehr et al. (2014) qualitative study, using focus groups, found that religion was meaningful to Norwegian residents as a form of spiritual expression. According to Carr et al. (2011) religious beliefs become more important as people age.

Participants in our study placed much emphasis on the individual's understanding and manifestation of spirituality/religion, while at the same time recognising the collective/congregation dimension for many older people. The person-centred aspect of spirituality is also recognised within the literature (Keenan 2017a, 2017b) and it is acknowledged that any attempt to define and understand the concept must contain this element (Power 2006; Daly and McCarthy 2014). The person-centred approaches to care in this area was also demonstrated by the nurses' acknowledgement and facilitation of care for older people of differing spiritual beliefs and practices and those with no spiritual beliefs or practices.

Furthermore, this study highlighted some ways, not evident in the health literature, in which the nurse may enhance their understanding of the person living with dementia's spiritual needs, and therefore avoid disrespecting the individual. Examples from participants include, attentive listening to the participant's spiritual perspective, close observation and recording of what provides spiritual inner peace and comfort to the person, providing space for, respecting and enabling spirituality in care recipients. Particularly useful in this nursing quest was the use of life story, reminiscence and validation to discover what is spiritually meaningful for the recipient of care.

A minority of participants in this study questioned the relevance of spirituality for this care recipient group. Their views are also debated in the literature. Theological existential writing questions the meaning and significance of memory loss in dementia. Bryden (2005) and Swinton (2014) pose the question, *'If people loss their memory do they forget who they are?'* Kevern (2015) systematic review of the literature on this area concluded that people living with dementia are reliant on the reinforcement and encouragement of others to support their spiritual needs. According to Goodall (2009) people living with dementia are dependent on others to support their sense of identity, belonging and spiritual well-being as the disease progresses. Killick (2004) states that spirituality and the facilitation of spiritual moments for people living with dementia is linked to maintaining identity. Maintaining identity is a central need for people living with dementia and as dementia progresses and people lose their awareness, it is the gestures, habits and responses that are meaningful (Swinton 2014). Recognition and facilitation of residents to reach spiritual moments promotes a sense of personhood.

Finally, what makes this study further unique is the Irish and Irish rural setting. The findings and conclusions drawn may assist nurse policy makers, developing guidelines on spirituality,

to acknowledge that much of the nursing research on this important holistic domain, though non-Irish, may have important insights for nursing practice within our own cultural context. Secondly, the effective use of life story, reminiscence and validation were viewed as providing avenues into understanding in person-centred ways the spiritual needs of people living with dementia.

## 7. Limitations

As this qualitative research was of a small-scale, the findings and the conclusions drawn from them may not be generalized. Secondly, they are also context-dependent in terms of being undertaken in one country: Ireland, within a rural catchment area and within one Public Health Service, as opposed to a Private establishment. Thirdly, all participants were female.

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**Conflicts of Interest:** The authors declare no conflict of interest.

## Abbreviations

The following abbreviations are used in this manuscript:

DSIDC	Dementia Services and Information and Development Centre
HSE	Health Service Executive
NMBI	Nursing and Midwifery Board of Ireland/Bord Altranais agus Cnáimhseachais na hÉireann
SIG	Spirituality Interest Group, Trinity College Dublin
TCD	Trinity College Dublin, University of Dublin
UK	United Kingdom of Great Britain and Northern Ireland

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