**Searching for life meaning: Spiritual discourses in dementia leadership using interpretative phenomenological analysis**

**Abstract**

**Background**

Dementia is a significant threat to modern-day health and social care, especially given a rapidly expanding and ageing population. Provision of effective and quality care for people living with dementia and their families is testing health and social care systems that are already financially stretched, with staff shortages and high turnover, while being subjected to higher levels of regulation and scrutiny.

**Aim**

Explore the ways in which health and social care professionals understood notions of spirituality in relation to dementia care.

**Methods**

A qualitative phenomenological investigation was undertaken involving a group of 17 health and social care professionals who had completed a Dementia Leadership Programme (DLP). Individuals were invited to participate in a semi-structured interview. Participants were presented with a dementia-based scenario (DBS) detailing a hypothetical patient living with dementia, with their family in crisis.

Interpretative phenomenological analysis (IPA) was utilised to ascertain idiographic, phenomenological insights into each healthcare professional’s notion of quality care and addressing higher-level goals for the hypothetical person living with dementia.

**Results**

Spirituality was presented as a major theme in the way participants strived to provide person-centred care. Spirituality was expressed through ensuring the patient remained central to all care provision and care management and by addressing spiritual aspects of care within the initial assessment, providing holistic care and support for their family. Person-centred care was considered essential to operationalise priorities of maintaining care at home through innovative and adaptive care, thus promoting patient happiness and quality of life.

**Conclusion**

In conclusion, participants acknowledged that the challenges associated with providing ‘truly’ holistic and person-centred care can be overcome by focusing specifically upon the personal narrative, biography and story of the individual living with dementia searching through their life meaning and discourse to gain understanding and insight into the uniqueness of the person.

**Keywords** *Dementia, Spirituality, Person and family centred care, leadership, Education, Interpretative Phenomenological Analysis*

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**Introduction**

One of the greatest threats that modern society and the health and social care sectors face is caring for an ever expanding and ageing population (Office for National Statistics [ONS] 2012). In the United Kingdom (UK) it is estimated, “By 2035 … the number of people aged 85 and over will be almost 2.5 times larger than in 2010, reaching 3.5 million and accounting for 5 per cent of the total UK population” (ONS 2012: 4). The World Health Organisation (WHO) (2012: 2) states, “The total number of people with dementia is projected to almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.” These epidemiological projections have recently been challenged due to them being based on historical data that does not take in to account the changes in life expectancy, living conditions, and health profiles (Wu et al. 2015).

Whilst dementia is not specifically a disease of old age both the prevalence and incidence of the disease increase dramatically in older age groups. The Alzheimer’s Society (2014a: 45) indicates, “Older people are most at risk for dementia. Hence the largest increases in the number of people with dementia would occur in the oldest age group”.

Dementia is an umbrella term describing a variety of symptoms that may include loss of memory and difficulty in learning new information, thinking, and problem solving (Colman 2006). The Alzheimer’s Society (2014b) estimates there are over 100 different types of dementia with Alzheimer’s disease accounting for approximately 62 per cent of dementia diagnoses, followed by 17 per cent vascular dementia diagnoses, with other types of dementia being of mixed aetiology or rarer causes. The aetiology of dementia is highly complex and currently attracts investigation into genetics, neurochemistry, neuroanatomy, and links with other long-term conditions such as hypertension, heart disease and diabetes (Alzheimer’s Society 2014b). Despite multidisciplinary efforts to determine the causes and prospective treatments of the various forms of dementia, the prospect of a curative or preventative treatment remains elusive.

While statistics illustrate the prevalence and incidence of dementia these do nothing to portray the physical, psychological, social or spiritual impact of dementia for the person living with this condition or upon their family and carers. Furthermore, while there is a burgeoning of literature associated with spirituality and dementia, primarily from theological (see Kevern 2009; Swinton 2012), and religious perspectives (see MacKinlay and Trevitt 2010; Higgins 2013, 2014), there is a paucity of empirical research detailing how to prepare health and social care professionals to attend to this dimension of people’s lives (Doherty 2006).

**Background**

There is a notable lack of evidence addressing the educational preparedness of health and social care professionals to meet the spiritual needs of people living with dementia and their carers. This is despite a growing literature base surrounding dementia education generally (see Tsaroucha et al. 2011; Smythe et al. 2014).

This article reports the findings from a qualitative evaluation of a Dementia Leadership Programme (DLP) focusing specifically on the spiritual aspects of dementia care that were identified during the interviews and analytical phases.

**Dementia as a spiritual experience**

The following quotation highlights the symbiotic relationship between spirituality and the person living with dementia.

“I connect at the deeper level of spirituality, so I treasure your visit as a ‘now’ experience in which I have connected spirit to spirit. I need you to affirm my identity and walk alongside me. I may not be able to affirm you, to remember who you are or wherever you visited me. But you have brought spiritual connection to me, you have allowed the divine to work through you. This can happen across cultures and languages, and is a very meaningful depth of communication, one that perhaps we should all strive for.” (Bryden 2005: 110-111).

This quotes highlights the complexity but also the beautiful simplicity of the lived experience of a person (Christine Bryden) living with dementia. The present moment, or the ‘now’ experience, can be considered the only moment there exists in which to live (Kabat-Zinn 2009), and in the case of Christine Bryden, when meeting with another person, is portrayed as a spiritual experience where there is a simple but profound connection which transcends boundaries of dementia and suffering. The implications of integrating this “spiritual connection” (Bryden 2005: 111) in a context of care provision for people with dementia is profound.

All person-centred care must be holistic in nature that is caring for the bio-psycho-social-spiritual aspects of the person. To neglect any of these dimensions will undoubtedly lead to a violation of the person’s dignity.

Bryden (2005) articulates and confirms that spirituality is a multifaceted, multidimensional phenomenon that comprises of transcendent, existential, relational, dimensions. Similar attributes connectedness, transcendence and meaning in life were documented by Weathers et al. (2015) in their evolutionary concept analysis. These attributes of spirituality have significance and relevance to people living with dementia and their carers especially when providing non-pharmacology approaches.

**Non-pharmacological approaches**

Efforts in health and social care practice have orientated to finding ways of managing the progressive decline in physical and psychological well-being associated with dementia. In the past this has comprised using a range of antipsychotic medications to ‘manage’ the various behavioural and psychological symptoms in dementia, for example, agitation, aggression, wandering, shouting, repeated questioning, sleep disturbance, depression, and psychosis. Use of antipsychotics in dementia is now becoming less desirable, with national policy now aiming to significantly reduce the use of antipsychotic drugs for people with dementia; receiving antipsychotic medication only when absolutely required (Department of Health [DH] 2009). Non-pharmacological management of behavioural and psychological symptoms in dementia, requiring curricula for the development of appropriate skills for carers of people with dementia, is becoming a priority in supporting this strategy (DH 2009).

Despite the move towards non-pharmacological management of behavioural and psychological symptoms in dementia there remains a lack of consensus over what these interventions may comprise in practice, along with the lack of standardisation of providing interventions whilst accounting for individual differences (National Institute for Health and Clinical Excellence [NICE]/Social Care Institute for Excellence [SCIE] 2006). Although there are some guidelines available for non-pharmacological interventions (Alzheimer’s Society 2005), there is mixed evidence as to the efficacy of non-pharmacological interventions, which comprise but are not limited to: behavioural therapy, reality orientation, validation therapy, reminiscence therapy, along with art, music, activity, complementary, aroma, and bright-light therapies (Douglas, James and Ballard 2004). NICE/SCIE (2006) found no substantial evidence that standardised approaches, for example, validation therapy, cognitive stimulation, and reminiscence therapy reduces behavioural challenges in people living with dementia. Furthermore, there is lack of evidence that other non-pharmacological interventions, for example, music-based approaches, multi-sensory stimulation, aromatherapy, and bright-light therapy are effective (NICE/SCIE 2006). Despite this, a meta-analysis has demonstrated that non-pharmacological interventions such as skills training and education for caregivers, enabling management of behavioural and psychological symptoms, enhancing communication and problem solving, along with activity planning and environmental redesign, appears effective (Brodaty and Arasaratnam 2012).

**Personhood and person-centred Care**

Personhood is currently well-operationalised in dementia care, at least theoretically, through person-centred frameworks. Although there have been concerns that the *language* of person-centred care is adopted but without any corresponding change in care (Baldwin and Capstick 2007), there is evidence that healthcare professionals orientate to person-centred attitudes rather than hope attitudes in dementia care (Kada, Nygaard, Mukesh and Geitung 2007). Person-centred attitudes are oriented to aspects of care such as ensuring people living with dementia are treated with dignity and respect and have stimulating, enjoyable activities. While hope attitudes refer to issues connected to attitudes towards the condition. For example negative hope attitudes may lead to less social engagement, purposeful activity and poorer physical care interventions for people living with (Lintern 2001).

There remains a distinct challenge of achieving person-centred care within an acute care environment, where there are many missed opportunities for healthcare professionals to connect with the person with dementia (Clissett et al. 2013). Person-centred frameworks may help to reduce the number of missed opportunities for health and social care professionals to connect with the person living with dementia, through developing awareness of applying person-centred care in practice. A popular example includes the VIPS Framework (Brooker 2006). This framework that has been used primarily in care homes and not the acute sector asserts four major elements, which are outlined in Table 1.

Although person-centred frameworks, such as VIPS, clearly have much to offer in helping health and social care professionals to develop their awareness of person-centred care and, importantly, assessing the extent to which this is operationalised in practice, there is little reference to the concept of spirituality which is described so eloquently in the opening quote (Bryden 2005). The notion of personhood comprising transcendence and absolute value can be rather esoteric to interpret within a health and social context, but may be this should be referred to more explicitly within existing frameworks.

**Defining spirituality and spiritual care**

Spirituality has been defined as:

“…universal, deeply personal and individual; it goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all of humanity” (McSherry 2009 in McSherry and Smith 2012: 118).

This definition reinforces that spirituality is not dependent upon intellectual or cognitive functioning. This point is pertinent when addressing spirituality within the context of caring for people living with dementia who may have experienced a decline in cognitive functioning and intellectual ability. A further contemporary definition is the one provided by Weathers et al. (2015: 15):

“Spirituality is a way of being in the world in which a person feels a sense of connectedness to self, others, and/or a higher power or nature; a sense of meaning in life; and transcendence beyond self, everyday living, and suffering.”

A potential problem when applying this definition within the context of living with dementia is the implication that the individual may need to cognitively process or be introspective in order to make sense of their life, relationships and connectedness. It could be argued that within the context of people living with dementia, connections, meaning in life and sense of transcendence are preserved through the interactions and spiritual care provided by others, family, friends and carers.

Spiritual care is recognised, along with aspects of physical health, undetected pain, side effects of medication, psychosocial factors, and physical environmental factors, as a significant aspect of assessment for people living with dementia, particularly when there is challenging behaviour (NICE/SCIE 2006). Despite this importance, along with the recognition that spiritual care forms a significant aspect of holistic nursing (Ennis and Kazer 2013), and that people with early-stage Alzheimer’s disease seek existential interpretations for the cause and meaning of their suffering (Beuscher and Beck 2008), there remains limited evidence addressing how health and social care professionals operationalise spirituality in practice when caring for people with dementia.

**Aims**

The aims of this phase of the study were:

1. Explore the ways in which health and social care professionals understood notions of spirituality in relation to dementia care.
2. Evaluate how their completion of a Dementia Leadership Programme impacted on their ability to lead changes in dementia care, orientated to non-pharmacological management of behavioural and psychological symptoms.

**Method**

The Dementia Leadership Programme (DLP) involved collaboration between the Independent Sector as the administrator, and a Higher Education Institute (HEI) as provider. The DLP had been commissioned by a primary care trust/local authority.

**Participants**

A total of 30 health and social care professionals commenced the DLP that had been delivered over a 10-month period by the HEI. The programme consisted of lectures and seminars addressing diverse aspects of dementia care. At the time of conducting the evaluation, only 24 were eligible to take part in the evaluation since they had attended and completed all elements of DLP. A total of 17 participants from the independent/private sector, local authority, National Health Service (NHS) acute and mental health services, and domiciliary care participated (Table 2).

**Data collection**

Ethical approval was obtained from the Faculty Research Ethics Committee. Participants (in pairs from the same organisation) underwent a face-to-face interview lasting approximately one hour. Interviews were audio recorded using a digital recorder and conducted by two of the investigators, followed by independent transcription. Informed consent was gained prior to conducting the interviews. Participants were reminded that they would remain anonymous and all information stored securely. The interview comprised of three elements: review of hypothetical dementia based scenario, constructive review of the DLP, and feedback on action planning.

The focus of this paper was analysis of the participants comments and feedback on how they would address the personal, religious and spiritual issues arising in the hypothetical, but realistic, dementia-based scenario (DBS see Box 1) (McSherry 2006; DH 2011).

The DBS had been validated in previous work (DH 2011) and was chosen specifically for use in this study because of the realistic way it illustrates the complexity of dementia and the challenges posed of the person’s family, friends, carers, and health and social care professionals. The DBS also alludes to notions of spirituality, relationships, connectedness, transcendence, and existentialism. Therefore, the DBS would test the problem solving, decision-making process of the participants, exploring their knowledge of holistic and person-centred care, and identifying the non-pharmacological interventions they may utilise. As such, it was anticipated that the DBS would stimulate further in-depth discussion of spirituality pertaining to dementia care and leadership generally.

**Data analysis**

Given the complex nature of inquiry, examining how health and social care professionals consider spirituality in relation to dementia care and leadership, it was felt that a purely qualitative and exploratory methodology was considered most appropriate. Interpretative phenomenological analysis (IPA) (Smith 1995, 1996) was utilised as the method of data analysis, given IPA is specialised on determining underlying meaning according to direct experience: the first-person perspective (Larkin 2012). Analysis comprised a detailed systematic analysis of participants’ transcripts, interpreting this in the context of the DBS (Figure 1). Tomkins and Eatough (2010) suggest that IPA is focused on the analysis of individual interviews, rather than focus groups. Because of the structure of the DLP two individuals working as single unit we conducted the interviews in a pair. To do otherwise would have gone against the philosophy of the DLP, which was for the two colleagues to work collaboratively as a team.

**Findings**

IPA led to the development of 49 themes arising from the discussion of the DBS. The following were related either directly or indirectly to the concept of spirituality perceptions of spirituality, maintaining a person-centred approach, assessment of spiritual needs and ambiguity surrounding the assessment of spiritual needs.

**Perceptions of spirituality**

Participants appeared to have a very broad understanding of the concept of spirituality that included both intrinsic (inner peace, inner-self) and extrinsic discourses (religion, environment) aspects. The importance of the intrinsic aspect of spirituality is reflected in the following transcripts:

*“[…] looking at what her beliefs, her spiritual beliefs are and then we could support her with that. For that inner sort of peace that she might get from that.”* (Int. 1, L. 6).

*“So she's got her inner spirituality, so who knows what someone’s inner spirituality really is, even her husband and daughter do yeah. […] It's kind of how she expresses that, how we can help her to express it again.”* (Int. 7, L. 34, 35).

These transcripts indicate that the participants were very much of the interior aspect of spirituality describing how this could be drawn upon to foster resilience and inner peace.

The exterior or community aspects of spirituality such as promoting or preserving formal religious practice were described in the following:

*“[…] it might be things like hymn singing that she might enjoy particularly because even if she hasn’t gone to church as a regular thing, the hymns from school are generally familiar, and in those days people did sing hymns in school so some of those hymns will still be familiar at some level […].”* (Int. 1, L. 7).

*“[…] the side about her religious beliefs would take you know some really detailed work perhaps with her family to find out how she did express that, what her choices were within her beliefs and whether we can incorporate that into you know her daily life now, so maybe some of her frustrations and her being withdrawn is because she... they perhaps, perhaps the family don’t realise that she can still use her religious beliefs to express some of her feelings and the way she is.”* (Int. 8, L. 18).

These transcripts indicate that the participants were aware of the need to handle religious aspect of care with sensitivity and professionally. They also demonstrate an awareness of how religious faith, beliefs and practices such as using liturgy, hymns, and the symbols and routines of religious practice may be one way of enabling the person living with to dementia to express feelings and emotions providing connection and continuity with the past and the present (Higgins 2013)

The importance of environment and the impact upon self-reflection are expressed in the following:

*“[…] I'd probably create or give her time or what was better for a little quiet place and find nice music […].”* (Int. 4, L. 104).

*“For someone whose you know creative, she's obviously got an eye for lines of colour the perspective and texture and that links into spirituality and being outside in the open spaces how do we know, it might have been mountains or seas or rivers or something that's particularly appealing and if we could find what moved her, what her attachment is then that gives us something to hold onto and work with I think.”* (Int. 7, L. 18).

These findings reveal that some participants were acutely aware of the need to engage in dialogue with the person exploring their relationship to the environment, creating opportunities for quiet time alone using the outdoors to maintain previous connections that had shaped identity and provided a rich meaning in life.

**Maintaining a person centred approach**

The most prominent expression of spirituality in relation to the DBS and leadership related to person and family-centred care those characteristic of the notion of personhood (Kitwood 1997). Maintaining a person-centred approach was critical in undertaking effective assessment of needs, reflecting guidance from NICE/SCIE (2006) on the importance of ascertaining a person’s individual biography, encompassing their religious beliefs and cultural or spiritual identity:

*“[…] the first thing we do is talk to Martha and get her opinions then we talk to the family and get their opinions as well […] I think once you’ve done those two things you can then formulate your plan more appropriately […] you can’t do anything until you know what the important things are to them […].”* (Int. 1, L. 17).

Person-centred care was also interpreted in the assessment of a person’s interests and what the person can still do, despite having dementia. This related closely to the notion of connection and meaning in life core attributes of spirituality:

*“[…] find out what [Martha’s] interests are […] how we can incorporate something […] we haven’t got the resources to do a lot of things, but we try our best to do what we can.”* (Int. 3, L. 9).

It was clear during the conversation and in the subsequent analysis that the participants did not believe, that because a person had developed dementia, the concept of spirituality was no longer relevant or in some way diminished or lost (Daly and Fahey-McCarthy 2014).

**Assessment of spiritual needs**

Determining what aspects are of importance to a person living with dementia is complex and requires considerable knowledge, experience, and sensitivity on the part of the health or social care professional. Some participants considered the challenges of undertaking a spiritual assessment, especially in the midst of a crisis situation:

*“[…] looking at [Martha’s] spirituality and things like that, I think that is actually in a way secondary to getting her feeling better about herself […] an infection or some physical thing that’s happening to her that’s making her like that [deterioration/challenging behaviour and so on] […] whilst it’s important, you can’t really have a discussion about her spirituality while she’s screaming and shouting and throwing things […].”* (Int. 7, L. 100).

Health and social care professionals need to carefully consider how the person living with dementia is orientated towards their condition, sensitively determining the most effective way forward, especially given the notion that spirituality can offer a sense of meaning in the midst of deterioration (Pargament 1997). Despite this, many participants were rather more pragmatically and practically orientated towards managing the challenges posed in the DBS and in leading changes in dementia leadership:

*“[…] if to Martha, if it’s the incontinence that’s upsetting her more than anything and the personal care involved in that […] getting some advice from the incontinence nurse […].”* (Int. 1, L. 17).

*“Our main goal is always going to be because of our role […] dealing with social care needs […] that always has to be our focus.”* (Int. 2, L. 2).

**Ambiguity surrounding the assessing spiritual needs**

There was also some ambiguity in how spiritual needs were assessed in practice, highlighting the complexity of operationalizing the concept of spirituality in health and social care:

*“[…] it also depends on the [assessment] because the question for me personally, the question asks, ‘what’s important in your life?’ is one all people always stop and look at me as if to say ‘what are you asking me?’ […].”* (Int. 2, L. 62).

Other participants considered that formalised assessment is all but one aspect of dementia care and leadership, with the notion that there has to be a ‘human’ encounter with the person living with dementia:

*“I think that has to be when you’ve met the person, because on a piece of paper it doesn’t tell you who somebody is […].”* (Int. 6, L. 48).

Other participants go further to explain that even after you have made an initial assessment of the person living with dementia you cannot be certain whether a care plan is going to be appropriate or effective:

*“[…] until you know [a person living with dementia], initially you have to just let the individual just be who they are so as you can gauge whether that plan is appropriate […].”* (Int. 8, L. 34).

The notion of “letting the individual just be who they are” reflects the essence of personhood: the uniqueness of being and the recognition of personal worth are in themselves a window into the consciousness of another person. This finding highlights that the participants approached the assessment and care planning aspect of their work with sensitivity and flexibility putting the needs of person living with dementia at the centre of all care.

Spirituality was an underlying theme, which was operationalized as enabling Martha to achieve her potential, regardless of the dementia, but with having a positive impact on the course of dementia;

*“I think that the aim is to support Martha and help her to achieve the highest level of happiness in herself that she can achieve. That way you’re going to have an effect on the [challenging] behaviours […] it does say [in the scenario] that she’s unable to do the activities that she used to do but she might be unable to do them at the level that she previous had, but I would be shocked to see that she couldn’t manage them at some level. Just because somebody has dementia doesn’t mean that they can’t do things at some level.”* (Int. 1, L. 3).

It would appear that happiness and spirituality could be synonymous here, which forms the fundamental aim of professional health and social care. As such, spirituality (or enabling the patient “to achieve the highest level of happiness”) reflects the notion that it is difficult to separate, for example, nursing and spirituality as two separate concepts: “spiritual nursing operationalizes spirituality” (Ennis and Kazer 2013: 106). Indeed, for many nurses the very notion of ‘providing’ spiritual care is something that is difficult to define in practice but remains a tacit and implicit aspect of nursing itself (Clarke 2013).

**Discussion**

The purpose of the DBS was to provide participants with a hypothetical but entirely realistic example and context where their skills as health and social care professionals in dementia care would be tested. The findings suggest that the use of the DBS was a useful method to gathering data and ascertaining the knowledge, skills of the participants’ especially in the area of spirituality and spiritual care.

Generally, it was found that participants seldom referred to their knowledge and experience of completing the Dementia Leadership Programme when addressing the DBS. Specifically, participants referred to or drew upon their own experiential knowledge and skills based on their existing clinical practice. It was found that participants were already acutely aware of the importance of spirituality recognising this as integral to person-centred care and family-centred care. Reassuringly, participants readily acknowledged and routinely addressed this dimension of care when meeting the diverse needs of people living with dementia. There was also realisation that this should include family and carers. Interestingly, given that the scenario presented information pertaining to someone in the early stages of dementia, participants did not identify or engage with the clues that Martha may have been seeking existential interpretations for the cause and meaning of her suffering (Beuscher and Beck 2008).

It was also found that participants made no explicit reference to pharmacological management. The findings indicated the importance of dialogue and communication promoting inner-peace by using a range of non-pharmacological intervention such as quiet time, outdoor space, which may positively impact on behavioural and psychological symptoms in people living with dementia. This combination of interventions, regardless of their scope, aim to keep the person living with dementia (and their family) at the centre of care and support. As outlined earlier, this refers to the notion of personhood (Kitwood 1997: 8), which comprises discourses of transcendence: “being-in-itself is scared, and that life is to be revered”; discourses of ethics: “that each person has absolute value”; and discourses of social psychology: that personhood is embedded within the fabric of one’s social group providing “integrity, continuity and stability” of the self. In all, personhood can be referred to as, “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being.” (Kitwood 1997: 8). Personhood implies “respect and trust” (Kitwood 1997: 8). The findings suggest that the participants preserved personhood by identifying the need to maintain connections and relationship with family and wider social networks using a range of caring interventions to achieve this.

The area of spiritual assessment is fraught with conceptual, organisational, practical and ethical challenges and dilemmas (McSherry and Ross 2010); remaining a contentious issue. It was clear that the participants seemed to be opposed against one-off or tick box approaches to assess spiritual needs. A more continuous and person-centred approach was recommended. There was a realisation that there is a hierarchy of needs that dictated the focus or priority of the assessment. Participants’ felt that was important to resolve any crisis or physiological needs before embarking on any in-depth biographical assessment. Participants were conscious that assessment should be undertaken in a timely manner. As Béphage (2009) asserts, the early identification of the individual’s spirituality and spiritual needs is crucial because this enables those providing care to develop care plans and set realistic goals. He also indicates that early assessment enables other aspects of care to be considered such as the caring environment that may enhances the patients’ wellbeing.

**Limitations**

The homogenous nature of the participant group who were all female and white. A more heterogeneous group in terms of gender and ethnicity may have provided different responses and set of experiences. The fact that only 17 out of the potential 24 eligible to participant took part may mean that the views and experiences captured are not representative of those who opted not to take part in the study.

**Conclusion**

Overall, the findings from this qualitative investigation provide some important insights into the attitudes and values of health and social professionals towards spirituality and the provision of spiritual care within the context of caring for people living with dementia. It would appear that despite attending a DLP, many of the health and social care professionals drew upon existing tacit knowledge and skills when assessing the spiritual needs of individuals. It was evident that the philosophy of person-centred care that is truly holistic and individualised was of paramount importance. Fundamentally those who participated in the investigation considered it necessary to review and search through the individual’s personal narrative, biography and history to identify the life meaning that had shaped their spirituality and personal identity. This was considered an integral part of person-centred and family-centred care, viewing this as positive resource that could be drawn upon to enhance the care and experience of people living with dementia and their carers.

**Conflict of interest**

No conflict of interest has been declared by the authors.

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Table 1

*Outline of the VIPS Framework (Brooker 2006; Care Fit for VIPS 2014)*

|  |  |  |
| --- | --- | --- |
| **Acronym** | **Element** | **Context** |
| V | Values | Unconditional values of honouring the person and human life. Emphasis on:   * Philosophical *vision* of valuing people. * Ensuring adequate *human resources* are available, caring for staff. * Creating and maintaining a positive culture of care through *management ethos*. * Ensuring adequate staff *training and practice development*. * Ensuring the *service environment* is designed and adapted for people with dementia. * Conducting on-going *quality assurance* ensuring improvements can be made where possible. |
| I | Individualism | Care oriented to the person, recognising the uniqueness of personhood. Emphasis on:   * *Individual care and support*, adapting care to meet individual needs. * *Recognising and responding to change*. * Preserving *personal possessions* to trigger memories. * Honouring *individual preferences* to promote personal empowerment. * Obtaining *life histories* to provide person-centred care and affirm personal self-worth through effective communication. * Promoting *activity and occupation* to provide life meaning. |
| P | Perspective | Exercising empathy through recognition of individual experience. Emphasis on:   * Effective *communication* through active listening and attentive body language. * The individual’s perspective through exercising *empathy and* (allowing) *acceptable risk*. * Adapting and promoting the *physical environment* to ensure adequate stimulation and safety. * Detecting *physical health needs* to prevent exacerbations of physical illness, impacting on dementia. * Understanding *challenging behaviour as* (a form of) *communication*. * Protecting individual rights to respect and dignity through *advocacy*. |
| S | Social | Promoting an environment, which supports individuals socially. Emphasis on:   * *Inclusion* of individuals to be part of activities and conversations. * Demonstrating *respect* and *warmth* for a person, honouring personal beliefs and life experiences with sincerity. * Providing *validation* of the person according to their life experiences. * *Enabling* the person to maintain control over their daily living, developing partnerships in care. * Helping people to integrate to be *part of the community*, maintaining normality. * Caring for *partners, families, friends, and relatives* to provide understanding and enable coping. |
| \* Outcomes for each element of the framework italicised. | | |

|  |
| --- |
| *Box 1*  *Hypothetical dementia-based scenario*  (McSherry 2006: 89-90) |
| Martha is 63 years old and has become increasingly confused, forgetful and very withdrawn. Her husband was very concerned and encouraged her to see her GP. A CT scan was preformed which diagnosed vascular and organic changes and a diagnosis of vascular dementia was made. Until her retirement at 60 she had been a highly successful business woman leading a very active and fulfilling life. Her final position before retirement was director of a large international company.  Martha is married to Tom they have three children and four grandchildren. Throughout her life Martha has had a strong belief and faith in a God but this has not been expressed formally through a religious institution. In her spare time Martha had enjoyed a range of activities such as travel, painting and regular cross‐country runs in the country. Martha liked to spend time on her own reflecting and keeping in touch with the creative aspects of her personality.  The progression of the disease meant that Martha was very much aware of the deteriorative nature of the illness and the result that this might have upon her life. As the disease progressed she was unable to maintain her interests and activities. She became more withdrawn and isolated within her own inner world. Familiar faces and locations lost their meaning. Martha’s modesty and privacy were lost as she began to display inappropriate behaviours and she became increasingly incontinent. Her entire personality changed, resulting in aggressive outbursts, shouting verbal abuse at her family and on several occasions household objects were thrown around the room.  Martha had become the complete opposite to everything in which she believed and her husband and family did not recognise the woman whom they had known and loved. The family was worried that has Martha’s condition deteriorated and she required more intense care, they would be unable to meet her needs towards the end of her life. They were especially concerned about meeting her religious and spiritual beliefs in the light of her abrupt and dramatic change in personality.  The diagnosis of dementia is challenging for all those involved. Martha’s husband and family were angry and described feelings of denial and loss often associated with bereavement despite Martha still being present. |

Table 2

*Overview of Participants*

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Gender** | | | **Role** | | **Sector \*** | | | | | |
| **Male** | **Female** | | **Manager** | **Specialist** | **D** | **H** | | **LA** | **R** | **N** |
| 0 | 17 | | 10 | 7 | 1 | 6 | | 4 | 4 | 2 |
| **Ethnicity** | | | | | **Employment \*\*** | | | | | |
| **White British** | | **Other** | | | **FT** | | **PT** | | | |
| 17 | | 0 | | | 13 | | 4 | | | |
| \* (D) Domiciliary (H) Health (LA) Local Authority, (R) Residential (N) Nursing  \*\* (FT) Full-Time, (PT) Part-time  Age range 35 – 63 – Average age 48.7 years | | | | | | | | | | |

Figure 1

*IPA as a 7-stage process*