

Spirituality and spiritual engagement as perceived by palliative care clients and caregivers

AUTHORS

Ms Joy Penman

MN, MSc (Pharm), RN, PhD candidate
Lecturer, Nursing and Rural Health Unit, Centre of Regional Engagement, University of South Australia, Whyalla Campus, Nicolson Avenue, Whyalla Norrie, Whyalla, South Australia.
Joy.Penman@unisa.edu.au

Associate Professor Mary Oliver

RN, PhD
Associate Dean Teaching and Learning, Centre of Regional Engagement, University of South Australia, Whyalla Campus, Nicolson Avenue, Whyalla Norrie, Whyalla, South Australia.
Mary.Oliver@unisa.edu.au

Dr Ann Harrington

RN, PhD
Senior lecturer, School of Nursing and Midwifery, Flinders University, Adelaide, South Australia.
Ann.Harrington@flinders.edu.au

Acknowledgement

We wish to acknowledge the assistance of the participants who provided us with noteworthy stories without which this study would not have been possible.

KEY WORDS

spirituality, engagement, hermeneutic phenomenology, end of life issues, palliative care, nursing

ABSTRACT

Objective

The purpose of this study was to examine the lived experience of spirituality and spiritual engagement as perceived by palliative care clients and their caregivers.

Design

A qualitative hermeneutic phenomenological approach was used based on van Manen's methodological structure of human science research to answer the research questions. Following ethics approval, fourteen home-based in-depth interviews were conducted with four palliative care clients and ten palliative care caregivers. Van Manen's 'holistic' and 'selective' approaches were used to identify the main themes in this study.

Setting

The participants of this study were recruited from people across rural communities of South Australia who had received or were receiving palliative care and their caregivers.

Findings

Seven main themes emerged from the data. These were categorised under two headings: spirituality and spiritual engagement. Spirituality was associated with 'God', 'coping', 'religion' and 'relationships with others', while spiritual engagement was associated with 'maintaining relationships', 'love' and 'participating in religious practices'.

Conclusion

This phenomenological inquiry set out to understand the lived experience of spirituality and engaging in spiritual matters for clients living with life-limiting conditions and their caregivers. In the process, the study identified the many benefits that may be derived from engaging in spirituality. The findings have relevance to clients and caregivers because they may wish to seek opportunities to discuss spiritual matters with health professionals and for health professionals, who will be better prepared for such conversations.

INTRODUCTION

The concept of 'spirituality' has various connotations. Its meaning has evolved slowly and even now there is no agreed definition (Carroll 2001; Hermann 2001; Coles 2000; McSherry 1998). At the time of a significant life crisis, spirituality becomes more poignant and confronting to the individual and family. Palliative clients and their caregivers report conflicting times of loss of faith and despair and at other times of growth and even inner peace (Byrne 2002). As spirituality has a wide range of interpretations, the delivery of spiritual care can be equally challenging. There is difficulty in defining what constitutes spiritual care and how to bridge the gap between theory and practice of spiritual care (Wright 2002; Cornette 1997). Health professionals are inadequately prepared to provide spiritual care (MacLeod et al 2003; Bertero 2002). Consequently, spiritual issues, more often than not, are overlooked and unresolved (Dom 1999).

This research focuses on the everyday experience of clients and caregivers experiencing life-limiting conditions who are engaging in spiritual matters. However, before the engagement in spiritual matters is explicated, it is important to clarify first the research participants' understanding of the experience of spirituality. The emphasis of this paper is on the lived experience of how participants attribute meaning to spirituality and spiritual matters in coping with life-limiting conditions.

LITERATURE REVIEW

The root meaning of spirituality in Latin, Hebrew or Greek translates to *spiritus*, *ruach* and *pneuma*, respectively, which means breath or wind (Barnhart 1988; Smith 1988; Dickinson 1975). The spirit gives life to the person, signifying that spirituality is central in all aspects of a person's life (Dombeck 1995). The 'spirit' and 'spirituality' may be understood from different perspectives such as religious, cultural and philosophical traditions (Fry 2000). While spirituality and religion are intertwined, they are not synonymous (Sheldon 2000; Dyson et al 1997). Spirituality is much broader than religion (Mueller et al 2001; Taylor and Ferszt 1990). Religion is an organised

system of beliefs and worship (Emblen 1992). Spirituality is about the meaning of life (MacKinlay 2004), connectedness to humanity (Hassed 2002), relationships (Reed 1992) and harmony with the universe (Carroll 2001). The difficulties in defining spirituality have curtailed the assessment of spiritual needs (Dyson et al 1997), hindered the provision of spiritual care (Greasley et al 2001) and impeded progress in this area (Ross 1994).

Studies suggest that there is a positive correlation between spirituality and/or religious commitment and health outcomes (Koenig et al 2001; Mueller et al 2001). The real and potential benefits of spiritual involvement have been reported by Wink (2006), Albaugh (2003), Baldacchino and Draper (2001) and Fisher (2000). However, some studies report also that religious involvement and spirituality have negative health outcomes (Kinney et al 2002; Hermann 2001; Satterly 2001; King et al 1999).

Some contend that the association of spirituality with health is unknown (Sloan et al 1999). Nevertheless, there appears to be a widespread agreement that human beings are spiritual and may need help in their predicaments, especially at the end stages of life (Wright 2002). Studies on the spirituality of people with life-limiting conditions have been reported by Tanyi and Werner (2008), Siegel and Schrimshaw (2002) and Fryback (1993), who suggest that spirituality is important in interdisciplinary health care. Since spirituality has a wide range of interpretations, the delivery of spiritual care can be equally diverse. This difficulty in defining spirituality, what constitutes spiritual care and how to bridge the gap between theoretical insights and daily practice in offering spiritual care (Soothill et al 2001; Cornette 1997) warrants attention. While studies incorporating spirituality in health practice have been reported in the literature (Harrington 2006; Tanyi et al 2006; Hockey 2002; Cobb and Robson 1998), gaps are evident and the most important for health professionals is what and how to provide spiritual care and support. Hence, the overarching question of this research is, 'What is the lived experience of spirituality and engagement of spiritual matters of palliative care clients and caregivers?'

METHODOLOGY

Using van Manen's (1997) theoretical framework of hermeneutic phenomenology, a fuller and deeper understanding of the nature and essence of lived experiences of palliative care clients and caregivers was gained in this study (Munhall 2007). In analysing the data, a dynamic interplay of several research activities was undertaken as described by van Manen. This involved: turning to a phenomenon; investigating experience as we live it; reflecting on the essential themes; describing the phenomenon through the art of writing and rewriting; maintaining a strong relation with the text; and 'balancing the research context by considering parts and whole' of the research process (van Manen 1997, pp. 31-32). The researcher paid attention and commitment to the topic under study by actively exploring the lived experience of spirituality and spiritual engagement in its entirety and by asking what it is that constitutes the nature of this lived experience. In applying language and thoughtfulness to the research phenomenon under examination, the researcher was fully 'animated' by the phenomenon of the lived experience of spirituality and spiritual engagement. By constantly gauging the 'overall design of the text against the significance that the parts played in the total textual structure' (van Manen 1997, pp. 34), the researcher was better informed of the phenomena being studied.

The research participants in this study consisted of four palliative care clients and ten palliative care caregivers. Participants selected for this study had been diagnosed with a life-limiting condition, or were caring for, or had cared for a loved one with a life-limiting condition. Following the gaining of institutional ethics approval, participants were recruited into the study through various palliative care services and self-referral. Informed consent was obtained from the participants to conduct in-depth interviews in their homes.

The in-depth interviews commenced with brief introductions about the study. The introduction included a recognition of the sensitivity of the topic

and the assurance that the interview could be terminated at any time should the participant feel uncomfortable. The focusing questions were: 'Tell me about your experience of spirituality,' and 'What was it like to engage in spiritual matters with your loved one?' During conversation, other prompts were used such as, 'What happened?', 'How did it feel?' and 'What did it mean for you?' The interview was concluded after summarising important points, seeking confirmation of accuracy and thanking participants for their time and cooperation. With the permission of the participants, interviews were digitally recorded.

The interviews, which were conducted in 2005 to 2006 and averaged 1.5 hours, were transcribed verbatim. Six interviews, conducted in languages other than English, were first translated into English before transcription. The researcher's fluency in several languages and the use of professional interpreters enabled her to capture unequivocally the true meanings of the participants' stories. The researcher verified meanings of words and phrases during the course of the interviews and followed these up as appropriate.

The characteristics of the fourteen participants interviewed, classified as client, caregiver, or ex-caregiver, are summarised in Table 1. The palliative care clients interviewed were managing their conditions from the home as were the caregivers. Previous caregivers had cared for their loved ones both in home and in-patient settings. Bereaved caregivers revealed that it had been two to seven years since the death of their loved ones.

In this research, the 'holistic' and 'selective' approaches in isolating themes were employed as illustrated by van Manen (1997, p. 94). In the former, the researcher examined the interview text as a whole and endeavoured to grasp its basic meaning. In the latter, the researcher read the text several times, asked what statements and phrases stood out as revealing and highlighted these to represent the themes of the experience of spirituality and spiritual engagement.

Table 1: Characteristics of participants

Participant (Male/Female)	Age	Palliative care client /caregiver	Place of birth	Religious denomination
Barbara (F)	77	Client	Europe	Catholic
Diana (F)	59	Client	Asia	Catholic
Frederick (M)	48	Client	Australia	Protestant
Nathan (M)	58	Client	Australia	Protestant
Catherine (F)	34	Caregiver	Asia	Catholic
Eleazar (M)	70	Caregiver	Australia	Catholic
Gina (F)	50	Caregiver	Europe	Catholic
Maria (F)	50s	Caregiver	Australia	Protestant
Ana (F)	61	Ex-caregiver	Asia	Catholic
Hilary (F)	70	Ex-caregiver	Asia	Catholic
Isabelle (F)	60	Ex-caregiver	Asia	Catholic
Jonathan (M)	57	Ex-caregiver	Asia	Protestant
Kelly (F)	62	Ex-caregiver	Asia	Catholic
Leah (F)	68	Ex-caregiver	Australia	Protestant

Pseudonyms were used

Trustworthiness was ensured by maintaining credibility of the research, the accuracy of the research process and the authority of the researcher on the subject while conducting the study (O'Mahony 2001; Sandelowski 1993; Guba and Lincoln 1989). Credibility was ensured by validating the interview interpretations with participants. Auditability was achieved by presenting a research procedure that was clear and logical, while neutrality was achieved by remaining neutral while reporting the study findings and by undertaking personal reflection in order to draw out and make explicit pre-understandings about spirituality.

FINDINGS

Within the experience of a life-limiting condition, seven main themes were identified. Four themes related to spirituality, namely: 'God', 'coping', 'religion' and 'relationships with others'. Three themes embodied spiritual engagement, namely: 'maintaining relationships', 'love' and 'participating in religious practices'. It was found that the fundamental experience of spirituality and spiritual engagement for palliative care clients was no different from that of the caregivers.

First, the themes relating to spirituality are discussed.

Theme 1: spirituality refers to 'God'. The most common description ascribed to the experience of spirituality was belief in 'God'. In the following extract, Frederick, a client, talks about relating to the God dimension. He said, 'Spirituality is believing that there is a living God that is concerned about your happiness every moment of your life. If I didn't have faith in God I think it will be very difficult to cope with this situation.'

Theme 2: spirituality is described as coping. Nearly all clients and caregivers had a reasoned response why spirituality took centre stage in times of crisis. In this study, it was revealed that spirituality gave them power, strength, courage, purpose and encouragement in spite of their situations. Many found spirituality to be helpful in their 'coping'. Frederick stated, 'My faith helps me cope ... It takes the pressure off, removes fears about family and makes life easy.' Hilary, a caregiver, stated, 'My spirituality helped me cope during the time my husband was sick and during the time of his death ... I did not feel so sad and abandoned.'

Theme 3: spirituality embodies religion. Commitment to religion was manifested in several ways including professed affiliation to a religious organisation, awareness of religious beliefs and involvement with religious workers. Diana, a client, revealed, 'I am a good Catholic and I practise my beliefs as best as I could. I am an active member of the local church, where I am a special minister for Holy Communion and for the elderly and sick. This is my pride and joy.'

Theme 4: spirituality is associated with 'relationships with others'. The following extract shows how a caregiver attributed spirituality to interpersonal relationships. Jonathan said that spirituality for him was about thinking and caring about others. He continued, 'Some would say the giving of oneself to others, to be of benefit or service to others. ... It is the spiritual conviction that is going to be the greatest motivator to look after your kin ...'

In the following section, the three main themes relating to the experience of spiritual engagement are discussed.

Theme 1: spiritual engagement is illustrated by 'maintaining relationships'. In referring to 'maintaining relationships', participants spoke about being intimate, showing concern, being present, rendering service to others and giving attention and support. Diana reflected, 'I think engaging in spiritual matters refer to the intimate times like when a friend would accompany me to the doctor, sleep with me in the hospital, or cook for me. ... I appreciated another friend who gives me hand and back massages ... We embraced, cried and prayed together.'

Theme 2: spiritual engagement describes love. The relationships were premised on 'love'. To love is to manifest a sense of selflessness and feeling for others. Isabelle was also a caregiver who described and reflected on the experience and stated, 'Spirituality for me is showing my love by being here caring for my husband every day ... It means giving him my undivided attention as he was sick. Spirituality is showing my love by being with him every day because he didn't want to be left alone. ... It means being comforting and long-suffering on behalf of others.'

Theme 3: spiritual engagement embodies participating in religious practices such as praying. Praying was generally understood to mean talking to God. There were different experiences of prayer and yet it was perceived to be 'powerful', 'uplifting' and 'helpful'. Hilary, a caregiver, intimated about her husband's situation, 'He had no religion but I believe in church. When I was with him all night long, I kept praying and praying [to the Lord] to help him. ... We had priests, nuns, pastors, even from other religions praying for him. This was helping him spiritually because he knows somebody is praying for him and this helps me also.'

DISCUSSION

Through reflection and being immersed in the study, the researcher came to the realisation that her personal understanding of spirituality was related

to transcendence. Her experience in engaging in spiritual matters was closely linked to the physical aspects of care delivered in her capacity as a nurse. Undertaking personal reflection was important to recognise overtly pre-understandings and preconceived notions about spirituality and spiritual expressions.

The study presented diverse understandings of spirituality similar to those described by Hassed (2002) and Reed (1992) but dissimilar to those earlier described by Barnhart (1988), Smith (1988) and Dickinson (1975). With the reality of death looming, spirituality became a priority for some participants and their view became focused on their present situation. For some, spirituality became central in their lives (Dombeck 1995). Woodruff (2004) and Fry (2000) contends that people's understanding of spirituality is influenced by many factors, including life experiences and various religious and cultural beliefs and practices.

In this study, it was found that many participants did not distinguish between spirituality and religion. The two concepts were found to be closely linked but they were not the same, as illustrated by Sheldon (2000) and Dyson, Cobb and Forman (1997). This finding may be attributed to factors such as age and cultural background. The majority of the participants were elderly and were immigrants from countries where religion played a dominant role in the people's lives. It was found that 'God' was the prime motivator of spirituality for the participants and 'religion' enriched participants' spirituality. Both sentiments revealed how the participants experienced spirituality as found in Christianity. This finding could be attributed to the fact that all participants affiliated themselves with Judaeo-Christian denominations, although not all were actively practising their faith. Of importance to this study was ethnicity, which might explain how some participants framed and expressed spiritual experience through culture. Many of the participants were from countries where Christianity is largely practised. This is interesting, considering its application in a multicultural and multifaith society like Australia.

Spirituality propelled people into positive actions. As such, it provided many real and potential benefits and was valuable for those engaged in it. This conclusion is supported by others such as Wink (2006), Baldacchino and Draper (2001) and Fisher (2000). The findings of this study are supported by Albaugh's (2003) phenomenologic study on spirituality and life-threatening illness which highlighted the comfort, strength and 'blessings' derived from spiritual involvement. In another study, Siegel and Schrimshaw (2002) reported that participants enumerated a variety of benefits, such as gaining strength, empowerment, control, social support, a sense of belonging and spiritual support through a personal relationship with God.

The participants in this study demonstrated the direct links between spiritual engagement and love by enumerating how love was manifested, including mundane activities such as visiting, having coffee, massaging, gift-giving and embracing. In addition, a deeper relationship that involved 'sharing intimate times' and 'understanding vulnerabilities' was mentioned. Time was an opportunity to show love and spending quality undistracted time was necessary for participants. Such sentiments have been similarly reported by Fryback (1993), who stated that people with advanced illness associated health with belief in a higher power that gave them the ability to love.

Engaging in spiritual issues will continue to be an important element for some people at the end of their lives. For this reason, health professionals should learn to tap into this valuable resource. This study raises health professionals' awareness of clients' and caregivers' capacity to articulate and express spirituality. This is important because spirituality can help them cope during this crucial time.

Health professionals, including nurses, can assist both clients and caregivers in maintaining personal relationships and religious practices, help identify spiritual meanings, look beyond present circumstances and help improve the quality of life. This may involve creating environments that value relationships, even amongst strangers and addressing unique spiritual needs. Consider

Harrington's (2006, p. 181) exposition on the role of altruistic love in which health professionals spiritually connect with patients 'sacrificially'. Displaying caring behaviours is a way of incorporating spirituality into professional practice (Tanyi et al 2006).

The limitations of the study relate to the nature of phenomenological descriptions and non-return of transcripts to participants because of personal circumstances. There is no single phenomenological account that could embody the full complexity of spirituality and spiritual engagement.

CONCLUDING REFLECTIONS

In this phenomenological inquiry, the researcher set out to understand the lived experience of spirituality and engaging in spiritual matters for clients living with life-limiting conditions and their caregivers. In the process, the study identified the many benefits that may be derived from engaging in spirituality. The findings have relevance to clients and caregivers because they may wish to seek opportunities to discuss spiritual matters with health professionals. Palliative care workers also may find the implications applicable as they may be inspired to undertake personal and professional reflection and draw on this inquiry to find their own ways of assisting clients and caregivers.

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