

Methodological and ethical challenges while conducting qualitative research on spirituality and end of life in a Muslim context: A guide to novice researchers

Nasreen Lalani, Assistant Professor, Purdue University, West Lafayette, Indiana, USA.

Gulnar Ali, Consultant in Spirituality and Existential Care, New School of Psychotherapy and Counselling, London, UK

Email: lalani@purdue.edu

Abstract

Spirituality could be understood as a personal belief, relation with sacred, divine experience, a sense of purpose and meaning towards life, authenticity and connectedness. It is a continually evolving, highly complex, contextual, subjective, and sensitive construct. A continuous development is seen around understanding about spirituality and spiritual concepts, such as spiritual experiences, spiritual pain and spiritual distress, especially among patients and families at the end of life care. The concepts, values, attitudes, and beliefs around spirituality, spiritual needs and expressions vary among different individuals, cultures, and religions. There is a dearth of literature around spirituality, especially among Muslim patients and families at the end of life. The complexities around the concept of spirituality in the literature raise several ethical and methodological concerns for a novice researcher while planning and conducting a study on spirituality during end-of-life care in a hospice setting, especially among a Muslim population. This paper aims to share some of the methodological and ethical challenges that can be faced by qualitative researchers while conducting research around spirituality and end-of-life care in an Islamic/Muslim context. Major challenges include defining the term spirituality, spirituality and culture, communication, power relations, language and translation, recruitment and selection of the participants, emotional distress, and reflexivity and reciprocity. Having an in-depth understanding of these challenges can guide researchers to address these issues adequately in their spirituality research in a Muslim context.

Key words

End-of-life care

Ethical challenges

Muslim traditions of thought

Qualitative research

Spirituality

Key points: NEEDED

1. Approaching the notion of spirituality from transcultural perspectives.
2. Exploring language as an agency to approach spiritual care needs at the end of life care.
3. Using reflexivity as a tool for availability and vulnerability in the research context.

CPD reflective questions: NEEDED

1. What is the significance of spirituality at the end of life care in a Muslim context?
2. How spiritual care needs could be understood from Muslim traditions of thought?
3. What are some of the ethical and methodological challenges a researcher might face while conducting spirituality research in a palliative care setting?

Introduction

Spirituality is a deep and mysterious concept that influences human thought and behavior formation towards life (Swinton, 2012). Spirituality could be understood as a personal belief, a relation with sacred, divine experience, a sense of purpose and meaning towards life, authenticity and connectedness (Ali, 2017). In the past two decades, spirituality has received special attention in the end-of-life and palliative care literature. End-of-life care supports spirituality and the spiritual dimensions of care, as it can ease suffering and brings peace, comfort and strength to the patients and their families (Deal, 2011; Worldwide Hospice Palliative Care Alliance (WHPCA), 2014). There has been a continuous development around understanding spirituality and spiritual concepts, such as spiritual experiences, spiritual pain, spiritual distress among patients and families at the end-of-life care in the recent research literature (Fitch and Bartlett, 2019). The notion of spirituality has been identified as essential to be dealt with in health care, especially while approaching the spiritual care needs of patients and their families (Wattis et al, 2019). Lack of spiritual care competency could lead to professional ambiguity, anxiety, role confusion with chaplains and fear among health care professionals; while understanding and approaching spiritual care needs of service users can promote patient care (Ali, 2017). The concepts, values, attitudes, and beliefs around spirituality, spiritual needs and expressions vary among different individuals, cultures and religions (Sessanna et al, 2007; Speck, 2016). Recent literature describes spirituality as a broader concept than religion and the term 'spirituality' is understood more from the humanistic dimensions and values (Cohen et al, 2012). For some individuals and communities, spirituality is still experienced and expressed in terms of religious values, faith and belief (Cohen et al, 2012) and there seems to be little distinction between the processes of religion and spirituality, especially among the majority of people professing a monotheistic religion (Hwang et al, 2011). The constant debate and plurality around the definitions and concepts of spirituality pose difficulties for researchers to examine and interpret the phenomena in their true essence (Moberg, 2010; Pattison, 2013). Such complexities pose several methodological and ethical challenges for a novice researcher studying the concept of spirituality, especially during end-of-life care among patients and families (Berry, 2005; Berry et al, 2011). A researcher's own paradigm and personal philosophical considerations can influence the way spirituality is addressed or studied (Sessanna et al, 2011). Subsequently, it is important that researchers should have a

conceptual clarity for the term 'spirituality', its various dimensions and its meaning in varying contexts (King and Koenig, 2009).

Significance of Muslim spiritual perspectives in palliative care

Islam is an esoteric religion and spirituality has a significant place in Islam. According to a Pew Research Center report (2017), there are an estimated 1.8 billion Muslims residing in different continents around the world and the figure is continuously rising, making Islam the world's second-largest religious tradition after Christianity. Islamic spirituality is seen as the presence of a relationship with Allah or God that shapes the individual's self-worth, sense of meaning, and connectedness with others and nature (Stephenson and Hebesly, 2018). Religious and spiritual values play an important role in defining how Muslim patients and families define their health and illness (Hasnain and Rana, 2010; Ramezani et al, 2014). Most literature around spirituality is found within the context of the Judeo-Christian faith community (Sessanna et al, 2011) and little has been found from the Islamic context (Jafari et al, 2014), which makes it challenging for the researcher who wants to study spirituality in health and healing from a Muslim context. Careful planning and a deeper understanding of the concepts around spirituality and how to interpret spirituality among people from different contexts is therefore essential and should be given a high priority (Moberg, 2010; Pattison, 2013). Spirituality serves as an ethical foundation in making healthcare choices and decisions (Jafari et al, 2014). Professional codes of ethics and principles give limited clarity to address certain types of issues arising in the context of patient-provider interactions around spirituality at the end of life (Pesut, 2008). As a case in point, the ethical principle of autonomy varies for patients and families from different societies; for example, societies in which religion remains a communal force may not share the value of autonomy. For some patients and families, dependence on a higher power may be more important than independence in a spiritual person and for them seeking God's help or willingness is preferred when making their healthcare decisions and choices (Isaac et al, 2016). Such conflicts and misunderstanding around different spiritual constructs and values can introduce several methodological and ethical dilemmas for a novice researcher conducting a study around spirituality at the end of life (Moberg, 2010).

The following paper aims to shed light on various ethical and methodological challenges that can be faced by novice researchers while designing a qualitative study around spirituality at the end of life among Muslim patients and their families. Very few studies on spirituality have been done in Muslim populations, therefore this paper aims to fill those gaps in spirituality research at the end of life among Muslim patients and families. The challenges described in the paper also include personal experiences and reflections of the researchers using qualitative interviews to gather spiritual experiences of family caregivers caring for their dying family member in a hospice setting. Findings of our previous research have been published in another journal (Lalani et al, 2019).

Spirituality in a Muslim context

Under Muslim philosophy, the search for an ultimate reality or the divine may be pursued in various ways. The Islamic perspective allows a variety of interpretations and traditions within and outside of Muslim civilizations. Moreover, throughout various intellectual traditions of Islam, a major emphasis is placed on the notion of personal search and self-awareness to recognize the spiritual aspect of religious life (Esmail, 1998; Madelung and

Mayer, 2015). Muslim philosophy relates existential, cosmological and intellectual grounds shaping human intention and intuition. The concept of God is understood as an ultimate ideal and source of spirituality reflected in all aspects of human life, across all Muslim intellectual traditions (Esmail, 1998). Religious experiences such as striving to seek wisdom, self-consciousness and humility are multiple expressions of actualizing the highest human potential (Walker et al, 2016). Also, the notion of intellect and knowledge-seeking is associated with the concept of revelation, which is often rooted in a religious doctrine. Variety of religious expressions and diversity in health-seeking behaviors, may lead to ethical challenges, especially in palliative care. Esmail (1992; 1995; 1998) analyses the meaning and articulation of the sacred in its social context and distinguishes theological doctrine from religious experiences, and defines religion as a vision, which influences human intellect, imagination, perception, conviction, emotion and behavior. According to Esmail, religion appears both implicit and explicit in human life, defining cultural values, language development, intellectual progress, social interactions and symbolic interpretations in searching and encountering the sacred.

Islam says all humans are spiritual beings and it's only the spirit that is immortal. Care of the spirit and spiritual values is therefore given utmost importance among Muslims (Stephenson and Hebeshy, 2018). There is a concept of after life, of adherence to the religious values, beliefs, and practices that transcend the soul with God, Almighty Allah, and enable one to attain spiritual enlightenment (Hasnain and Rana, 2010). Muslims believe that life is always to be cherished and protected, illness and suffering are inevitable parts of life and the moment of death is fixed by Allah. During illness, Muslims are taught to seek Allah's help and maintain a closer relationship with God (Brown, 2000). Muslims believe religious and spiritual rituals and practices are integral to one's health and healing and are viewed as a source of strength and coping during the illness, especially during end of life, both among patients and caregivers (Lalani et al, 2018). Spiritual and religious practices such as rituals, belief systems, ideologies, and institutions are often ways to awaken, stimulate, nourish, and satisfy desires and drives that originate in the spiritual essence of people (Moberg, 2010; Balboni et al, 2015). Caregiving is seen as sacred in Muslim families, giving meaning to the causes of suffering during illness and especially at the end of life (Saleh and O'Neill, 2018; Lalani et al, 2019). Muslims believe altruistic values, selflessness, and service to others are spiritually enriching and enlightening and may result in achieving self-transcendence (Khan, 2017; Lalani et al, 2019).

Methodological and ethical challenges in spirituality research at the end of life

From an ontological standpoint, reality is experiential, shared and relative to the context, culture, moral values and beliefs of the people and their environment (Dahnke and Dreher, 2011). Spirituality is a subjective phenomenon and spiritual experiences can be enriching and unique. Spirituality is interrelated with the religious beliefs and values within an Islamic context. This paper highlights several methodological and ethical challenges that can be faced by novice researchers while conducting a qualitative spirituality research at the end of life. These include defining the term spirituality, spirituality and culture, communication, power relations, language and translation, recruitment and selection of the participants, emotional distress, and reflexivity and reciprocity. All these challenges are discussed in

detail, with some possible strategies for the researchers carrying out research in spirituality at the end of life within a Muslim context.

Defining the term 'spirituality'

Spirituality has been defined by several philosophers and researchers from diverse perspectives and philosophical dimensions in different disciplines. These multiple constructs and dimensions of spirituality adds to the complexity of how to approach this topic (Berry et al, 2011). For a novice researcher, the initial struggle often remains choosing a single most appropriate and relevant definition of spirituality for the study. Given the diverse perspectives of spirituality, some may choose to take a religious perspective, including the role of religious attendance, beliefs, practices, and rituals (Koenig et al, 2001), while others may like to view it from an existential and philosophical construct, such as meaning in life, connectedness, and transcendence. A constant debate and argument can be found in the literature around the existing polarized concepts of religion and spirituality, where religion has been reified into a fixed system of ideological commitments with or without dynamic personal elements, and spirituality is relegated to the personal dynamics and subjective experience of religion (Pargament, 2013). Multiple authors identify three broad approaches to understanding the meanings of spirituality and religion. The first approach views spirituality and religion as a single construct, in which spirituality and religion or religiosity are interchangeable. The second approach adopts a polarized approach, in which religiosity represents an institutional, formal, doctrinal expression, and spirituality represents a personal, subjective, inward, and unsystematic expression, whereas the third approach views religion and spirituality as mutually related constructs (Piedmont et al, 2009; Pargament, 2013; Pattison, 2013)

In the nursing as well as social work literature, spirituality is seen as a universal human experience, an essential dimension of human life (Ortiz et al, 2000). Spirituality as an ontologically existent phenomenon could also be understood as an innate drive in humans to have a connection with a deeper source of wisdom (Wattis et al, 2019). Given this universal dimension to spirituality, spirituality is understood in terms of: a relationship with a higher power; a loving and caring relationship with self and others (Sinclair et al, 2009); the search for existential meaning; the way a person relates to the ultimate conditions of existence; a transcendent dimension within human experience; and a subjective experience of the sacred (Zinnbauer and Pargament, 2005; Pargament and Saunders, 2007); an innate capacity and tendency to move towards connectedness and transcendence (Reed, 2008) and as a subjective relationship to larger and transcendental realities (Piedmont et al, 2009).

Puchalski (2013) asserts that spirituality is a highly subjective, and personal experience, whereas religion is more formalised and communal and can be one of many forms of spiritual expression. As a subjective or personal construct, spirituality must mean what it means to the individual within his or her own individual experience (Unruh et al, 2002). Spirituality is one's personal relation to the sacred or transcendent, a relation that then informs the other relationships and the meaning of one's own life, whereas religion refers to practices and beliefs related to a dogma system (Sinnott, 2001). Similarly, Pattison (2013) asserts that not all religious individuals relate to their religion in the same way and therefore, a researcher needs to maintain the respect and dignity of the individual's own perspectives of spirituality. Mahoney and Cano (2014) insist that there is a need to identify and untangle spiritual beliefs or practices pursued within or outside of organised religion

that influence the individual or family relationships. Certain aspects and experiences of spirituality are so individualistic and personal that they cannot be relegated or confined to just attendance to religious practices and beliefs or given the name of universal spirituality. People often describe religious and spiritual experiences as a mutual construct and are unable to separate these two constructs from their daily life experiences. Some people believe all life is spiritual or sacred and everything human enacts or mirrors spirituality: every thought, feeling and action reflects spirituality in some way or the other (Moberg, 2010). King et al (2013) further argue that in many religious traditions, certain experiences of faith or of a spiritual nature are believed to lie beyond what science can fully explain. Yet the scientific community often tries to interpret such experiences in forms of behavioural, cognitive, or social characteristics of a human, rather than interpreting those within the realms of spiritual behaviours and actions. There are certain personal experiences that extend beyond the empirical observation, such as experiences of awe, ecstasy, inner states of consciousness, creativity, love, mystical experiences, and purpose in life (Moberg, 2010). These are the core and personal experiences within the spiritual dimensions of a person's life experiences and therefore need to be addressed, as they can influence the physical, psychological and social health of the person (Simpson et al, 2007).

Due to the very subjective nature of the spirituality, a single definition may not fit all people in different circumstances. Some authors suggest that it's the author's decision to choose the definition of spirituality based on his/her own belief systems, experiences and comfort level with the terminology (Berry et al, 2005), while others state that while choosing or interpreting the definition of spirituality, the researcher must interact with the definitions held by the research subjects (Moberg, 2010). Existing multiple definitions and perspectives around spirituality make it difficult and challenging for the researcher to decide on a single definition of spirituality. It is noteworthy that researchers using a qualitative approach may find that the chosen definition of spirituality takes a new shape based on the experiences shared by the participants during the analytical phases of research. The fact that the meaning of spirituality often lies within the experiences of the participants needs to be valued and preferred.

Spirituality and culture

Literature supports that spirituality is highly contextual and influenced by cultural values and interpretations (Sessanna et al, 2007; Speck, 2016). A clear understanding of the context and culture is essential for the researcher doing a qualitative research around spirituality. Spirituality and culture are often seen as a resource for meaning making. Speck (2016) states that during the illness trajectory, the patient or family go through several existential questions where they ask themselves 'why me?' or 'why now?', expressing a desire to find meaning, purpose or helpful coping strategies. Such kind of a search often leads the person to turn to their personal and cultural belief systems to find answers to these questions. To facilitate the communication on spiritual values and beliefs, it is helpful if the researcher has adequate knowledge of or familiarity with the cultural values and context. Multiple studies on spiritual experiences and beliefs among Muslim patients and families have found that spiritual responses were influenced by their personal, cultural or religious values (Rahimi et al, 2013). In both these studies, religion and spirituality were seen intertwined and religious ritual and ceremonies were important aspects of several spiritual dimensions such as hope, peace, internal strength and comfort. For Muslims, spirituality is a journey, a journey that enables a person's closeness or submission to a

divine, supreme being or God (Ghobary et al, 2013). Religious beliefs and practices are different forms of expression of spirituality (Koenig et al, 2001). Religious rituals and belief systems can be sources to awaken, stimulate, nourish and satisfy, desires and drives that originate in the spiritual essence of people (Moberg, 2010). Prayer, meditation, religious place attendance, performing religious rituals are forms of spiritual expression and can bring self-awareness and understanding towards one's own beliefs and values (Anandarajah, 2008). Various studies among Muslim patients and families have reported that religious practices such as prayers and other rituals and beliefs enabled individuals to create meaningful worldviews, reflect on their own spiritualities and find meanings for their own spiritual desires (Rahimi et al, 2013; Dedeli et al, 2015).

Communication challenges due to sensitivity of the topic

Discussions of spiritual experiences at the end of life are often sensitive and challenging both for the study participants and researcher. Maintaining sensitivity around these issues is therefore crucial at all stages of communication, such as while asking, listening, interpreting, and analysing those experiences (Boston and Mount, 2006). The authors argue that experiences of the participants may generate countertransference that might lead to risk of vulnerability. Participants while discussing their experiences may find the threat of their own mortality mirrored in their patient experience (Lee and Kristjanson, 2003; Boston and Mount, 2006). On the other hand, they might find in sharing those experiences an opportunity for reflective assessment of the personal emotions and such sharing might become a source for the provision of informal and formal opportunities for personal support (Tan et al, 2010).

Similarly, rights to participants' autonomy can influence communication among the researcher and research participants and is an important element to be considered from an ethical perspective of research. Individual autonomy is viewed and practised differently among Muslim families following collectivist societal values. In most Muslim families, healthcare decisions are taken by the whole family or usually the elder male person in the family (Khan, 2012; 2017). A researcher might face a situation during the consent process where an individual refuses consent or is not willing to provide any form of information before he/she seeks permission from the family. A researcher needs to be knowledgeable and respect such contextual values and should be willing to provide enough time for the participant to consult family before a negotiated, informed consent is signed. There is also a likelihood that a participant's experiences may vary during the illness trajectory and therefore, there is a need to determine when and at what stage of illness the data was collected. Interviews taken at a single point in time may pose a limitation in the process of analysis and this therefore needs to be explicitly mentioned (Kim and Given, 2008). The participant may not speak during the first interaction and might need some time to establish rapport with the researcher. Consequently, the researcher may plan to have multiple interactions with the participants during the course of the study (Adamson and Holloway, 2012). Thus, both communication and timing of the interactions needs to be well considered while studying in spirituality during end of life.

Power relations

In most qualitative studies, researchers and research participants are engaged and considered as equal partners in the process of knowledge generation. Power differential

and power shifting can also exist in any stage of the research, from the stage of research question development until the process of research dissemination (Enosh and Ben-Ari, 2016). Hence, a researcher needs to be careful about the power relations between the researcher and research participants. Building a good rapport and respect between researcher and participant is essential in qualitative studies. It is encouraged to enter participants' worlds with humility, rather than as an informed professional (Thorne, 2008). In many instances, the subjects may find it easier to give answers that are acceptable to the researcher and therefore, a data bias may be generated. Power struggles between researcher and participants might produce or hinder knowledge construction; therefore, a dialectic, egalitarian, and an empowered approach must be assumed to bridge the power differential gap between the researcher and the research participant (Enosh and Ben-Ari, 2016). The authors also suggest that both the researcher and research participant are assumed to bring their own expert knowledge, to share a mutual respect and knowledge gain and be empowered in the knowledge-generation process. Such an approach of reflexivity and reciprocity assists the researcher to acknowledge the power differential and promotes the exchange of knowledge in an empowering fashion while also promoting credibility, and trustworthiness in the study. (Kaufman, 2015; Enosh and Ben-Ari, 2016).

Language and translation

Language and translation pose a serious threat in conceptual and methodological aspects of the study. From the conceptual perspective, language is important in terms of dialogue between the researcher and the research subjects, and its interpretation (taking out the meanings) at the analysis stage (Van Nes et al, 2010). In qualitative research, language is the primary means by which a researcher comes to understand how the social world is interpreted, understood, experienced, produced, or constituted by an individual (Mason, 2002). Moberg (2010) asserts that the regional and global nuances in the meanings of words, the breadth of the vocabularies of research subjects, reading and writing skill levels, dialects, previous spiritual knowledge and experiences all influence data collection related to spirituality. Moreover, the varying educational and cultural background, religious traditions and lifestyle patterns all affect the data within a study. Therefore, it is advised that all such possibilities should be seriously considered during all the phases of research. From the methodological perspective, translation might pose several challenges. The researcher must anticipate translation challenges, as translation might introduce biases in the true interpretation or meaning around the concept during the data collection and analysis phases of the study (Santos et al, 2015; Vaismoradi et al, 2016). Translation during early phases of a study i.e. soon after data collection, allows a more interactive process of data analysis among researchers and translators and minimises the risk of misinterpretations of actual meaning during the analytical phase of the study (Santos et al, 2015).

Recruitment and selection of participants

Additionally, the selection of participants can also impose methodological concerns in the study. Where, whom, and how to select as study participants is an important element to be considered before any study of such nature. Age, gender, and socio-economic status all can influence the sample selection: people of different age, gender and social status express their spiritual experiences differently. Moberg (2010) argues that middle-aged and older

adults often have a broader spiritual experience than the younger population, as they tend to have prolonged exposure to life situations. On the contrary, a researcher also needs to be careful if all research subjects are within a narrow age range, as they may differ greatly in spiritual alertness and maturity. Additionally, space, comfort level, and readiness of the participants could be of additional concern to the researcher, from the recruitment phase until the data collection phase during the research (Sivell et al, 2015; Peter, 2015). Participants should be provided with enough time so that they feel comfortable in sharing their personal spiritual experiences with the researcher. Moreover, it is advised that timings of the interview should be kept flexible and participants be given choices to choose the time that is suitable for them to talk about their experiences. Having such a flexible approach would allow for increased participation and gathering enriched data in the study.

Emotional distress

Both the researcher and participants can go through emotional distress while discussing end-of-life issues (Kumar and Cavallaro, 2018). A good rapport, showing respect and maintaining the dignity of the participants need to be maintained throughout the study (Adamson and Holloway, 2012; Peter, 2015; Sivell et al, 2015). Participants need privacy and a comfortable space for interviewing and should be allowed the opportunity to stop or discontinue the conversation, whenever they wish during the interview. Listening to the participants' painful stories and their experiences of grief and loss can be challenging. Kumar and Cavallaro (2018) suggest various strategies for self-care among researchers. These strategies include taking short breaks during interview schedules, maintaining reflexive journals, regular debriefing, and ventilating self-feelings with the study supervisor or colleagues. These strategies can be helpful to overcome emotional distress during the research (Kumar and Cavallaro, 2018).

Reflexivity and reciprocity

Reflexivity and vulnerability could be a challenge while interacting with terminally ill and palliative care patients (Berger, 2015). Especially in qualitative studies, one of the challenges for the researcher is to refrain from imposing his/her own values, and beliefs on the client's belief systems (Adamson and Holloway, 2012; Unruh et al, 2002). Literature also supports the fact that no knowledge is value-neutral (Dahnke and Dreher, 2011) and the description provided by the participants is therefore always influenced by the perceptions, inclinations, sensitivities and sensibilities of the describer (Sandelowski, 2010). To overcome such challenges, a process of continuous reflexivity using regular logs, journaling and field notes should be maintained to minimize bias as well as to maintain the credibility and trustworthiness of the given study (Berger, 2015).

Conclusion

Spirituality is a subjective and complex phenomenon; spiritual experiences are unique and vary among different individuals in different contexts. Spirituality and spiritual care have a special significance in an Islamic context of health. A great deal of diversity exists around spiritual values and beliefs in health generally, and at the end of life care specifically. As a researcher, it is critical to acknowledge several ethical and methodological challenges while studying unique human experiences of meaning making and connectedness especially at the end of life care. Various strategies and tools discussed in the paper will guide the

researchers to address these challenges adequately in their spirituality research in a Muslim context.

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