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RESEARCH ARTICLE

Centrality of spirituality/religion in the culture of palliative care service in Indonesia: An ethnographic study

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Abstract

Experiencing life-threatening illness could impact on an individual's spirituality or religious beliefs. In this paper, we report on a study which explored cultural elements that influence the provision of palliative care for people with cancer. A contemporary ethnographic approach was adopted. Observations and interviews were undertaken over 3 months with 48 participants, including palliative care staff, patients, and their families. An ethnographic data analysis framework was adopted to assist in the analysis of data at item, pattern, and structural levels. Religion was identified as central to everyday life, with all participants reporting being affiliated to particular religions and performing their religious practices in their daily lives. Patients' relatives acknowledged and addressed patients' needs for these practices. Staff provided spiritual care for the patients and their relatives in the form of religious discussion and conducting prayers together. An understanding that religious and spiritual practices are integral cultural elements and of fundamental importance to the holistic health of their patients is necessary if health-care professionals are to support patients and their families in end-of-life care.

KEYWORDS

ethnography, Indonesia, palliative care, religion, religious belief, spirituality

1 | INTRODUCTION

In palliative care, a holistic approach is essential so that the palliative care health-care team can attend to the multidimensional needs of patients and their families. The World Health Organization (2010, p. 1) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". Experiencing life-threatening illness could impact on an individual's spirituality and religious belief. Spirituality and religion might help patients to cope by renewing hope, finding meaning and purpose, and adjusting to insoluble problems (Ferrell & Munevar, 2012). Alternatively, the impact might be negative, with experiences including anger with God and loss of belief (Byrne, 2007; Puchalski *et al.*, 2009). The delivery of spiritual care to patients is an important consideration, as it is associated with better quality of life at the end of life (Balboni *et al.*, 2010). However, its provision is often not integrated into palliative care due to lack of training, time constraints, and lack of vocabulary surrounding spiritual issues among health-care professionals (Abbas & Dein, 2011).

1.1 | Palliative care in Indonesia

Indonesia is a multi-religious country in South–East Asia that consists of approximately 17 000 islands, and has a population of more than 237 million. According to 2010 census data, approximately 87.6% of the nation's residents are Muslim, 6.96% are Christian, 2.91% are Catholic, and the rest are Hindu, Kong Hu Cu (Confucianism), and Buddhist (Statistic Indonesia [Badan Pusat Statistik/BPS], 2010).

The provision of palliative care in Indonesia commenced in the 1990s when palliative care services were established in several public hospitals (Al-Shahri, 2002; Soebadi & Tejawinata, 1996). There has been some progress in this area, such as an increasing number of organizations that provide palliative care services and the provision of guidelines for palliative care for cancer (Ministry of Health, 2013). Rochmawati, Wiechula, and Cameron (2016) identified that most

formal palliative care services are available only in the big cities of the major islands. The available literature on palliative care in Indonesia has focused on the development of palliative care services; however, to date, none have explored the cultural elements of the provision of care, particularly in relation to spirituality or religion.

In this paper, we report on one aspect of findings from a larger ethnographic study that was conducted in two palliative care units in central Indonesia within a period of 3 months. The overall purpose of the study was to explore how palliative care is being provided in two facilities in Indonesia and the cultural elements that influence the provision of care. In the present study, we aim to report findings in relation to spirituality/religious aspects of palliative care provision.

1.2 | Literature review: Spirituality/religiosity in palliative care

Spirituality refers to a connection with a larger reality that gives one's life meaning, and is experienced through religious practices or other paths (Peteet & Balboni, 2013). Candy *et al.* (2012) define religion as a system of practices and beliefs that are designed to facilitate closeness to the sacred being (i.e. God, higher power). Although there has been growing separation of the concepts of spirituality and religion in recent literature (Edwards, Pang, Shiu, & Chan, 2010), they are, however, often interrelated and used interchangeably (Bauer-Wu, Barrett, & Yeager, 2007; Hill, Pargament, & Hood Jr., 2000; Taylor & Brander, 2013).

Spirituality and religion are crucial aspects of comprehensive palliative care, as the aim of palliative care is to maintain wholeness of patients and families while integrating the physical, psychological, and spiritual care of patients and families. There has been increasing literature related to the health-care professionals' perceptions of spiritual care, spiritual care delivery and its barriers, and the effects of spiritual care in palliative care settings in Western countries. For example, Ronaldson, Hayes, Aggar, Green, and Carey (2012) compared spiritual care perceptions among palliative care and acute care registered nurses (RN) in Sydney, Australia, and found that palliative RN had stronger perspectives of spiritual care and their practices of spiritual care were more developed. Other studies have shown spiritual care was delivered to patients in various forms, such as the use of chaplains or spiritual counsellors and worship facilitation (Balboni *et al.*, 2011; Candy *et al.*, 2012; Kwiatkowski, Arnold, & Barnard, 2011). Other forms of spiritual care practice include meditation, tai chi, and yoga (Taylor, 2005). Evidence from several systematic reviews and meta analyses have shown benefits from spiritual care delivery to include better quality of life, less aggressive care at end-of-life care (Balboni *et al.*, 2010), increased spiritual well-being, and a decrease in depression and anxiety (Oh & Kim, 2014).

While there is extensive Western literature on spirituality/religion in palliative care, the literature from Indonesia is limited. Only four studies could be identified related to spirituality/religion in the general care setting, three studies explored perceptions and attitudes of health-care professionals toward spirituality (Herlianita, Yen, Chen, Fetzer, & Lin, 2017; Lucchetti *et al.*, 2016; Ramakrishnan *et al.*, 2014), and one study measured spirituality in patients with coronary heart disease (Ginting, Naring, Kwakkenbos, & Becker, 2015). These studies do not provide a picture of spirituality/religious factors in play in the palliative care context. An understanding of spirituality/religion in palliative care in Indonesia will potentially improve the delivery of spiritual care for patients with palliative care needs and their families in this setting.

2 | METHODS

A contemporary ethnography is an adaptation and reinterpretation of ethnography to meet research needs that are different in term of aims, scope, resources, and time (de Laine, 1997; Picken, 2009; Speziale & Carpenter, 2007). It is typically conducted in small elements of society, where it is used to capture a specific topic in relatively shorter-term field visits (Knoblauch, 2005). Knoblauch (2005) stated that the shorter period in the cultural setting is possible because researchers can have prior knowledge of the culture, such as the language and etiquette of groups. In addition, the shorter period in the cultural sites is typically compensated for by the intensive use of audiovisual technologies of data collection and data analysis (Knoblauch, 2005).

In the present study, we adopted contemporary ethnography due to its ability to capture specific issues within a given context (Cruz & Higginbottom, 2013). In this instance, it was the provision of care and cultural elements that influence palliative care services in two service units in Indonesia. Based on the tenets of contemporary ethnography, the present study included field observations, questionnaires, informal discussions, interviews, and the collection of relevant documents to enable understanding of the studied cultural groups. It should be noted that ethnographic research aims to provide descriptions and interpretations of a cultural or social group. When using this approach, an ethnographer should observe, understand, and report, rather than judge behaviors, values, and interactions of the cultural groups studied (Fetterman, 2010).

2.1 | Sample

For this ethnography, we committed to see, hear, and understand the realities, as lived by members of this cultural field. The settings of the study were a palliative care unit based in an acute care hospital and a palliative care unit that was based in a non-profit organization. The participants in the present study included a palliative care team (n = 6), patients (n = 21), and their relatives (n = 21), with all the participants involved in the observations. All of the patients were living with advanced stages of cancer, and most were being cared for at home by family members. Observation was focused on care and interactions between patients, relatives, and health professionals. Semistructured interviews were conducted with the palliative care staff.

2.2 | Data collection

Fieldwork was done on an average of 35 h per week over a period of 3 months during 2014 to collect cultural data from numerous sources. The data were derived from observations, semistructured interviews, and the collection of relevant documents by the primary author. The observations focused on all care provision situations in

TABLE 1 Summary of pattern analysis

Pattern	Item	Exemplar quotation and field notes
Patients' and relatives' spiritual/religious practices	• Availability of holy book and prayer • Playing religious music • Performing religious practice • Inviting chaplains to the home	'Every afternoon I recite the Quran near my husband's ear. I prefer to recite by myself other than playing the recordings' (patient's relative)
Palliative care team's spiritual/religious practices	• Praying together • Performing religious practices	'Let us pray that we have a smooth day during the home visit, and all of the patients are in comfort' (Nurse)
Spiritual/religious assistance from patients and relatives	• Assisting palliative care staff to undertake religious obligation • Providing appropriate facilities	'You can pray in this room and these are the prayer cloth and mat' (Patient's relative)
Religious acknowledgment and encouragement	• Being respectful of others' religions • Praying together	'Do you want to prayer together with us?' (*Physician*)

the daily routines of palliative care staff, which included communication among staff, and with patients and their relatives, interventions during care provision, and staff meetings. The researcher observed and recorded the interactions between staff and patient/relatives without interrupting the interactions. Field notes were written immediately after the observations. Expanded accounts consisting of observed details, together with a reflexive account, were systematically transcribed in a Microsoft Word document immediately after each fieldwork episode. Of six palliative staff, only three semistructured interviews were conducted with the staff involved in palliative care provision. Of these interviews, in one interview more than one staff member was interviewed at the same time. Questions in these interviews included type of service being provided, criteria of patients to obtain palliative care, admission process, and process of palliative care delivery.

2.3 | Data analysis

Analysis was iterative; a data analysis framework from LeCompte and Schensul (2013) was adopted to assist in the analysis of data at item, pattern, and structural levels. The process of item-level analysis included selecting a sample of data, analyzing by giving meaning to all the basic items, and searching for possible terms for all the basic items that fit into a relationship. These steps were repeated for further data collected until all terms were identified. Following that, in the pattern-level analysis, all the identified terms were organized and examined for any relationships (Table 1). This included activities of comparing, contrasting, integrating, associating, and linking identified items to form a higher order of patterns (LeCompte & Schensul, 2013). Patterns consisted of groups of items that fit together, expressed a particular theme, or constituted a consistent and predictable set of behaviors (Bjorklund, 2006). A taxonomy was created to show the relationship between all the basic items. The structural level of analysis included reviewing items and patterns regularly to understand how they correlated and addressed the research questions (Barusch, Gringeri, & George, 2011). The element of spirituality and religiosity emerged in the structural level of the analysis.

2.4 | Rigor

We gave specific consideration to rigor and trustworthiness. Techniques to enhance rigor included conducting prolonged observations, independent recording, and transcribing of data by the primary author, and the use of data extracts to support developing themes. To ensure dependability of the present study, data were recorded immediately after each observation, and compared and contrasted with existing data when sorting and coding data into categories (Fetterman, 2010). Another strategy to ensure the dependability of this study was to document a decision trail, which included providing comprehensive and explicit notes in NVivo (Bergin, 2011; Bloor, Frankland, Thomas, & Robson, 2002; Houghton, Hunter, & Meskell, 2012).

2.5 | Ethical considerations

Approval was obtained from the University of Adelaide Human Research Ethics Committee (no. H2013-05), as well the research ethics committee internal to the study hospital (no. 004/KEPK/1/2014). The observations and interviews began with an introduction and explanations of the objectives of the study. The audio files, verbatim, and field notes were kept on a computer with password protection. Confidentiality was preserved through anonymization of the verbatim and field notes.

3 | RESULTS

Analysis revealed that spirituality/religious practices emerged as one of the cultural domains. This domain included four patterns: patients' and relatives' spiritual/religious practices, palliative care team's spiritual/religious practices, religious/spiritual assistance from patients and relatives, and spiritual/religious acknowledgment and encouragement.

3.1 | Patients' and relatives' spiritual/religious practices

In Indonesian culture, religion is very important in everyday life, and becomes increasingly important in times of illness. The demographic characteristic of patients and relatives, including age, sex, and religion, are presented in Table 2. As shown, all of the participants were affiliated with religion, and more than half of patients were Muslim. After observing and analyzing all of the activities of patients, relatives, and palliative care staff, patterns were identified (Table 1). For example, patients and relatives paid a significant amount of attention to religious practices. Most patients had holy books (Quran, Bible) in-

TABLE 2 Demographic characteristic of the participants

Demographic	*n* (%)
Patients	
Sex	
Female	14 (66.67%)
Male	7 (33.33%)
Age (years), range (minimum–maximum)	34–87
Religion	
Islam	12 (57.14%)
Christianity	5 (23.81%)
Catholicism	3 (14.29%)
Buddhism	1 (4.76%)
Type of cancer	
Bladder	1 (4.76%)
Breast	8 (38.1%)
Cervical	1 (4.76%)
Colon	1 (4.76%)
Lung	3 (14.29%)
Nasopharyngeal	2 (9.52%)
Ovarian	1 (4.76%)
Pancreatic	1 (4.76%)
Prostate	1 (4.76%)
Renal	1 (4.76%)
Thyroid	1 (4.76%)
Family caregiver	
Sex	
Female	7 (70.0%)
Male	3 (30.0%)
Age (years), range (minimum–maximum)	33–67
Religion	
Islam	5 (50.0%)
Catholicism	3 (30.0%)
Christianity	2 (20.0%)

their homes. In addition, there were also printed prayers (i.e. *Dua* in Islam, or verses from the Bible) attached to the walls close to many patients' beds. Family caregivers had done this to enable immobile patients to keep praying, as the patients could see and read the printed prayers more easily. Even when patients were unconscious, relatives played recordings of religious music (i.e. Quran recital, Christian songs) to comfort the patient.

Most patients tried to keep performing their religious practices until their end of life. For example, one patient expressed her wish to do the Hajj (an Islamic pilgrimage to Mecca, Saudi Arabia, which is a mandatory religious duty that must be carried out at least once in their lifetime for adult Muslims who are physically and financially capable) in the near future, despite her condition. The wish to perform religious practices was also demonstrated by many other patients:

> I still perform my five daily prayers (*salat*) by myself but sometimes my son helps me to do *wudhu* (ablution) before performing *salat*.

The family caregivers considered the performance of religious practices important for the patients. In addition to providing support and assistance themselves, they would often invite chaplains to the home. One patient's relative said:

> I helped my brother-in-law (the patient) to do the prayers and I invited a Buddhist monk to lead a prayer at home.

These examples illustrate the importance of supporting religious practices for these patients. This was assisted by all involved, including relatives, the community, and the palliative care team, with all providing support and encouragement.

3.2 | Palliative care team's spiritual and religious practices

The palliative care team conducted morning meetings for approximately 10–15 min each day. To begin the meeting, a member of team (different for each meeting) would take the lead beginning with prayers. The group prayer was for a smooth and blessed day as the team went about their work. Following that, the leader would ask everyone in the room to pray based on their own religion. The meeting then continued with updates, such as a new policy or meeting notes from management. At the end of the morning meeting, the leader led final prayers for activities in the day and for the health and welfare of the patients, relatives, and the palliative team members.

3.3 | Religious/spiritual assistance from the patients/relatives

The patients and their relatives also recognized the religious obligations required by the palliative care team. Efforts from the patients and their relatives to assist the palliative team in meeting these obligations were apparent. The assistance included not only allowing the palliative team to do religious obligations in their home but also providing the facilities to do so.

In the provision of the home visit service, the palliative team was out in the community between 9:00AM and 4:00 PM. Most of the palliative team, but not all, were Muslim. In Islam there is an obligation to do prayers (*salat*) five time per day, performed at specific times of day, and one of these prayers (*Salat Zuhr or the noon prayers*) has to be performed at midday. On many occasions, this would coincide with a home visit. It was observed that the patients and their relatives were happy to be able to assist the staff to undertake their religious obligations.

This also involved providing appropriate facilities. All the Muslims in the palliative team were female. When doing the five daily prayers, all the body is covered, and Indonesian Muslim women generally wear the *mukena* (prayer dress), a loose outfit which can be put on over clothes when performing *salat*. The patients' relatives understood this need and provided the *mukena* and a prayer mat to the palliative team members.

3.4 | Religious acknowledgment and encouragement

Generally, the practice of religion is encouraged in Indonesian daily life, regardless of religious affiliation. Being respectful of other religions is expected and was very obvious during the present study. This acknowledgment and encouragement of all religious affiliations

existed between all those involved. This was seen in team meetings and during the provision of home-based care. During home visits, when the patients and relatives had a similar religious affiliation with one of the palliative team, the palliative team usually asked to pray together. If one team member had a different religion, they might wait in another room. For example, when visiting the Christian or Catholic patients, the doctor who was Catholic prayed with them. The nurse who was Muslim waited in the living room, because in Islam, religious encouragement is by respecting rather than participating in other religious rituals. On other occasions, when visiting Muslim patients, the Muslim nurse prayed with the patient and relatives.

4 | DISCUSSION

Ethnography is a particular qualitative approach used to describe culture or subculture in a specific context (Oliffe, 2005). The results of this study provide further understanding of the centrality of spirituality and religion in the provision of palliative care. Religion and spirituality are important aspects of everyday life for many people, with two thirds of people in 18 countries stating that religion is important in their lives (Theodorou, 2015). There are several major religious orientations (e.g. Islam, Christianity, Catholicism, Buddhism, and Hinduism) in Indonesia. People in Indonesia generally perceive religion as a fundamental part of life, and this was reflected among the participants of the present study. Religious beliefs and practices are the way for the patients, the families, and the palliative staff to express their spirituality. Importantly, in addition to practicing their own religions, there was an encouragement to engage in spiritual/religious practices by the participants, regardless of their own religious affiliation, as observed in the present study.

As expected, most of the patients and the families were affiliated with various religions. It was also observed in this study that the palliative staff were equally willing to demonstrate their religious affiliation. A previous study demonstrated that more than half of physicians in the USA are affiliated with religions and influenced by their religious belief in medical practice (Curlin, Lantos, Roach, Sellergren, & Chin, 2005). This study suggests an even stronger role of religion, with all staff observed engaging in religious practices at work (e.g. prayer) and in home visits.

Patients tried the best they could to maintain their religious practices with support from their families. Other studies identified the importance of prayer among cancer patients with advanced disease and their relatives (Alcorn *et al.*, 2010; Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011). Religion was as important to the palliative care staff, who routinely prayed together in the morning meeting before doing their rounds for the day. During home visits, it was also observed that the Muslim palliative care staff would perform *salat* (Muslim prayer) at the appropriate time of the day. These findings parallel those of previous studies, which indicated that Indonesian physicians described themselves as very or moderately religious (Lucchetti *et al.*, 2016; Ramakrishnan *et al.*, 2014).

Hanson *et al.*'s (2008) study of the provision of spiritual care among patients with serious illness and their caregivers identified that families are the main spiritual care providers for seriously ill patients. In this study, palliative care staff also provided much spiritual/religious support to the patients. The palliative team also often reminded families to provide such support to the patients. The provision of spiritual/religious care from health-care practitioners is likely influenced by several factors: the spirituality/religiosity of clinicians and the clinician's understanding of spiritual/religious practices of the patients (Curlin *et al.*, 2005; Lucchetti *et al.*, 2016; Ramakrishnan *et al.*, 2014). This religious support by health professionals is contextual. A study of nurses in a secular country found that nurses saw themselves as non-religious, and that providing spiritual/religious care was not something they were likely to do (Kisvetrová, Klugar, & Kabelka, 2013).

In a number of studies, the use of a spiritual assessment tool to formally assess spiritual needs has been demonstrated (Ahmed *et al.*, 2004; Blaber, Jone, & Willis, 2015). This was not, however, identified in this current study. Moving from the assessment of spiritual needs and supporting the patients to maintain their religious practices to actually joining patients in prayer is somewhat contentious and quite culturally specific. In their study, Poole and Cook (2011) debated this issue within the context of psychiatric practice in the UK, suggesting that patient–practitioner prayer is considered a breach of professional boundaries. Balboni *et al.* (2011), in contrast, surveyed patients and practitioners in advanced cancer settings in the USA, and reported that the majority felt it was dependent on the appropriate circumstance. In this study, the practice of praying together, to some extent, depended on the religion of the palliative team members. Muslim staff would step out of the room when Christian prayers were conducted, but this was not seen as a lack of support.

An important aspect of the spiritual/religious practices in the present study was the reciprocal nature of these practices. The palliative team provided spiritual/religious care to the patients and the relatives; in return, the relatives facilitated the palliative team to perform spiritual/religious practice in their homes. For example, a family caregiver provided a room, a prayer carpet, and clothes so that the palliative team could perform *Dhuhr Salat* (one of the five compulsory prayers in Islam, which must be performed at noon). To date, there have been no studies indicating this type of reciprocity in the relationship between patients/relatives and health professionals with respect to the spirituality/religion dimension. This reciprocity could be an important influence in maintaining the relationship between staff and patients and relatives, as it represents a very tangible sign of mutual respect.

In this study, we have shown that the role of spirituality/religion during the provision of palliative care is a positive aspect. This was a significant element in the Indonesian palliative care service, and many different religions were represented among the participants. Regardless of whether the clinicians' and the patients'/relatives' religious affiliations were aligned, all were encouraged to express and participate in their usual religious practices. This provided patients with much comfort. It gave them a sense of normality, and the mutual respect for religion assisted in developing and maintaining strong relationships between all involved. In some secular jurisdictions, this level of religious involvement by practitioners is questioned, but in the Indonesian context, it appears culturally appropriate and is encouraged.

4.1 | Limitations

This study has a few limitations, including the use of only two settings for data collection and a small number of participants in the semistructured interviews. Because the study was conducted at one hospital-based and a non-profit organization-based palliative care service, the organizational culture could limit the transferability of the results. Although the limited number of semistructured interviews was balanced with observations, one should be careful to not generalize the study findings to larger populations, or into other healthcare systems or ethnic groups.

4.2 | Conclusion

There were many situations that demonstrated the importance of religion and spirituality for the patients/relatives and the palliative care team involved in this study. These included not only the acknowledgment and support by the palliative care team for the patients and their relatives' religious practices but also how religion and spirituality were central to the team's life and their practice. Spirituality/religiosity was so central to the daily life of the patients, their relatives, and the palliative care staff that it became a significant element in the palliative care provision. The participants in this study (the palliative team, the patients, and the relatives) were affiliated with particular religions. The patients and their relatives performed their religious practices (e.g. prayer, worship) in their daily life, including during palliative care home visits. It was also observed that the patients' relatives commonly acknowledged and addressed patients' needs for spiritual care. The palliative care staff also provided spiritual care to the patients (e.g. religious/spiritual discussion, praying together). In return, the patients and relatives acknowledged the religious needs of the staff. The findings of the present study could help the palliative care staff in delivering spiritual/religion care for both patients with palliative care needs and their relatives. It would also be useful to explore how the reciprocal spiritual/religious relationship influenced the well-being of patients with palliative care needs and their relatives. The findings of the present study could be useful in investigating the delivery of spiritual/religious care in in broader palliative care population.

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AUTHOR CONTRIBUTIONS

Study design: E.R., R.W., and K.C.

Data collection: E.R.

Data analysis: E.R., R.W., and K.C.

Manuscript writing and revisions for important intellectual content: E.R., R.W., and K.C.

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