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Abstract

End-of-life care is encumbered with many complex issues that can impede quality of life, especially in populations for which little is known. This study addresses spirituality and preferences for last days of life in persons born in Japan and living in eastern and south central Texas. Descriptive, qualitative methods were used for data collection and data analysis. Two major themes emerged for spirituality: Spirituality as Culture and Universality of Spirituality, and three major themes reflected preferences for the last days of life: Environmental Peace and Comfort, Interconnectedness, and Communication is Key. Nurses and health care providers can use this evidence to facilitate quality of life for these persons and their loved ones to achieve a peaceful and dignified death. K.

Keywords

Qualitative, End of Life, Spirituality, Cultural, Japanese

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Spirituality in the Last Days of Life in Persons Born in Japan

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End-of-life care is encumbered with many complex issues that can impede quality of life, especially in populations for which little is known. This study addresses spirituality and preferences for last days of life in persons born in Japan and living in eastern and south central Texas. Descriptive, qualitative methods were used for data collection and data analysis. Two major themes emerged for spirituality: Spirituality as Culture and Universality of Spirituality, and three major themes reflected preferences for the last days of life: Environmental Peace and Comfort, Interconnectedness, and Communication is Key. Nurses and health care providers can use this evidence to facilitate quality of life for these persons and their loved ones to achieve a peaceful and dignified death. Keywords: Qualitative, End of Life, Spirituality, Cultural, Japanese

The last days of life are often laden with complexities that can be mismanaged by even the best-intentioned health care providers, regardless of the cultural setting. End of life care preferences can be influenced by one's spirituality and/or religiosity, and spirituality itself is enmeshed with multiple beliefs and practices that can complicate facilitation of a peaceful death with dignity. Spirituality can be defined "...as the core or inner life of the person, sometimes called the soul or spirit" (Lanzetta, 2010, p. 21). Spirituality also reflects a person's consciousness of the "whole" self that "...responds to and is sustained by nonmaterial factors" (p. 21), and proceeds through transformations as the person lives through the transitions of life. Begley (2009) argues that a sense of spirituality may be essential for some, but not for everyone, especially in the contexts of ethical decision making and the way one accords others dignity and respect.

Spirituality is perceived in different ways (Lanzetta, 2010; Shores, 2010; Moritz et al., 2006; Hodge, 2005; Mattis, 2000), and is different from religion, though religiosity is often an avenue for expression of spirituality through integration of similar practices (Hodge, 2005). Mattis (2000) acknowledges the overlap between spirituality and religiosity but aligns spirituality with the Judeo-Christian belief of the spirit being the "ethereal force" of "life giving power" (p. 103) that breathes life into the person. When one considers the sometimes extreme diversity of beliefs and practices that exist in any one belief system of Christianity, such as Catholicism, or the Baptist faith, it is no surprise that such variations exist in other religions. Though many Asian-Americans do not claim any religious preference (Kosmin & Keysar, 2009), those who do so are either Christian or Buddhist or adherents to another Eastern non-Christian religion (Fugita & Fernandez, 2002; Kosmin & Keysar, 2009). Religious Studies Professor Richard Seager has noted that Buddhism is the fourth largest religion in the US and is practiced by approximately two-thirds of Asian immigrants (Lampman, 2006). This population is rapidly growing, with 11.9 million Asians living in the US in 2000 (United States Census Bureau, 2002). Further, Texas is one of three states in which over half of this population resides (Schwartz, 2002).

Hospice providers are many times awarded credit for being the "experts" in end of life care, but hospice utilization by Asians in the US is minimal, and its use actually decreased from 2007 to 2008 (NHPCO, 2009). One study found that Japanese-Americans had the

lowest utilization rate of all Asian subgroups (Ngo-Metzger, Phillips, & McCarthy, 2008), meaning that many spend their last days in an acute care or long term care facility with personnel who are not trained in caring for persons at end of life.

Evidence of spirituality in the last days of life for persons from Japan is very limited and is often integrated under more general categories of attitudes and beliefs about end-of-life-care. Shirahama and Inoue (2001) found that Buddhists living in a Japanese farming community preferred spiritual care that eliminated fear of dying and promoted peace by assuring dying persons that they could see their ancestors in the next life. This desire was different from the view of nurses and physicians in the same study, who perceived spiritual care as searching for one's life meaning and purpose. Spiritual distress as a symptom that may need addressing at the end of life was found by researchers to be used synonymously with "existential suffering" and was defined as hopelessness, being a burden on others, and lack of purpose in life (Morita, Tsunoda, Inoue, & Chihara, 2000).

According to Long (2003), one's religion and culture can influence the dying process. With the religious and spiritual diversity found in persons from Japan, there is a need to clarify the end of life care needs of this population. Though no formal statistics are available, the growth of this population has been observed in the East Texas region, both by health care providers and by individuals from Japan living in this area. This study therefore examined the attitudes toward and preferences for care in the last days of life for persons born in Japan and living in Texas. (The study was part of a larger study of end-of-life care for persons born in Asian countries.)

The principal investigator for this study has a strong interest in palliative and end-of-life care, is very active in teaching undergraduate and graduate qualitative research, and works weekly at a local inpatient hospice. An observation was made by the researcher and other hospice health care personnel that no Asians had ever been patients at this facility. A community person who was born in Japan and had lived in this community for about 10 years and was a member of the local Japanese Club endorsed this study following contact with the researcher. She and the researcher felt that this study could be beneficial to this population by gaining an in-depth understanding of what their needs and preferences were, and by "introducing" them to the hospice concept. Further, even though this local hospice setting may not be able to apply these findings in the near future, health care providers caring for this population in acute care facilities may be able to render more culturally-sensitive care at end of life.

Methods

Study Design, Sample and Setting

In order to gain an understanding of the attitudes and preferences for end-of-life care for persons from Japan, a descriptive qualitative approach was used, with individual participant interviews. Polit and Beck's (2008) description of this method as sometimes being "eclectic" (p. 237) is appropriate for this study due to the ethnographic and phenomenological undertones of this study. The eclectic nature gives the researcher the freedom to diversify data collection methods in order to obtain the richest description possible. For example, the interview guide was adjusted numerous times throughout the study based on information participants provided. The researcher re-visited earlier participants to query them about issues that arose with participants who were interviewed later in the study. The eclectic nature of this study captured an ethnographic perspective in that the researcher had an increased sensitivity to how participants were approached. For example, the male participants were approached with a slight bow, and no handshake unless offered first by the participant. Touching or hugs were not offered, but were returned if the participant initiated this. Ethnic-

specific snacks were available for participants during the interviews. Interview questions were presented in a way that could be understood by the participants. A phenomenological perspective was reflected in the study since participants were asked to recall previous or current experiences with death and dying, and probing was done during the interviews to obtain as rich a description as possible of these experiences and preferences for care.

The researcher used purposive sampling to recruit participants who were willing to be interviewed face to face. Inclusion criteria initially were that the person had to have been born in Japan and to have been a resident of the United States (US) for no more than ten years, and that if they did not understand and speak English, an interpreter could be available. The ten year limitation was an attempt to avoid the influence of acculturation to Western values and influences. As the study progressed, snowballing led to contacts from potential participants who had lived in the US for up to 25 years. After consulting with a local Japanese academician and a potential participant, the author learned that many individuals from Asian countries adhere to their Eastern values regardless of the time they have been in the US. The author was careful to clarify the values of individuals who had been in the US longer. Interviews took place in a location of the participant's choice, including places of employment, the researcher's office, community settings, and participants' homes.

Sampling was done until data saturation (Polit & Beck, 2008) was achieved. Recognition of data saturation occurred when no new information was discovered in the interviews. Fourteen persons were interviewed; they included nine females and five males, ranging in age from 30 to 64, with an average age of 44 years. Length of time in the US ranged from 2 to 39 years, with an average of 14 years. The participant who had been in the US the longest was very adamant about not being influenced by Western traditions and values, and served as the President of a local Japanese social organization. Four participants were of the Christian faith, six of a non-Christian faith, and four had no type of religious beliefs. All except one had a college degree, and their occupations included nursing, dental/medicine, public relations, oil and gas, and primary education. One person was a full time student enrolled in a health-related field.

Data Collection

Person to person, audio-taped interviews were the primary source of data except in the case of one participant who wanted to be interviewed by telephone. Interviews lasted from 35 to 125 minutes, and averaged about 80 minutes. The open ended interview guide consisted of two primary questions that dealt with how the person's religious and spiritual beliefs might affect the care the person wanted in the last days of life, and what was important overall to the person in the last days of life. The second question also was later expanded to include post death rituals. Relevant probes followed the primary questions. The author was the only data collector. Field notes were written immediately after each interview and included non-verbal communication and other relevant contextual information.

Ethical Considerations

The study was approved by the University's Institutional Review Board and all participants signed a written informed consent form after their understanding of the study was verified. Because of the sensitive nature of some of the questions, the author was careful to monitor the emotional responses of participants. Several became tearful during the interview and they were offered an opportunity to stop and take a break. All declined, but the author imposed a small break for one of the participants who seemed to have some difficulty

continuing. All participants were adamant about continuing the interview; four stated that it “helped” to talk about their particular situations.

Credibility

Trustworthiness of the findings of a qualitative study is revealed by the clarity of the procedures used in the study (Johnson & Waterfield, 2004). In this study, procedures were discussed with and endorsed by an internationally known nurse scholar who also served as an expert mentor for the study. Because meaning units may overlap, or be too broad or narrow (Graneheim & Lundman, 2004), details of the data analysis, including transcripts and decision making regarding initial coding, formulation of categories and themes, and coding and thematic decision making processes were shared with another experienced qualitative researcher who agreed with the author’s interpretations. The researcher discussed themes and underlying meanings with participants who expressed general agreement. Finally, given the cultural nature of this study, Meleis’ (1996) eight criteria for a culturally rigorous and ethical study were met: Contextuality, relevance, communication styles, awareness of identity and power differentials, disclosure, reciprocation, empowerment, and time. Contextuality dealt with the researcher’s knowledge of the culture’s lifestyles and how that knowledge contributed to the significance of this study. The researcher demonstrated the relevance of the research questions to the need of this particular population. Communication styles of the sample were a focus of the researcher to ensure accurate understanding of the data. Even though Meleis (1996) acknowledges that power differentials cannot be totally equal between the researcher and participant, the researcher strived to ensure as horizontal a relationship as possible. Disclosure dealt with the researcher’s attempts to establish trust with the participants in order to facilitate in-depth revelation of their stories. Reciprocation reflected achievement of mutual participant-researcher goals, and was met with mutual information gathering and incentives for participation. Empowerment through a consciousness-raising of both the researcher and participant concerning the topic was achieved by the researcher. Time flexibility was critical in that it took significant time on the part of the researcher to successfully meet the previous criteria.

Data Analysis

Transcripts were transcribed verbatim and analyzed using Krippendorff’s (2004) approach to content analysis. Krippendorff’s belief that data are meaningful to individuals other than the analyst is congruent with the purpose of this study to provide health care providers a more thorough understanding of how to meet the needs of persons from Japan at the end of life.

Krippendorff (2004) describes six components of data analysis: unitizing, sampling, coding, data reducing, drawing inferences about phenomena, and answering the research question. These steps are not necessarily linear and may reflect an iterative process, as this study did. All of these steps were applied in the clustering and thematic analysis of text through the use of dendograms for each of the major coded areas. Dendograms, described as a tree-like structure, are a type of decision making model used in the clustering and thematic process (Bernard & Ryan, 2010; Krippendorff, 2004).

The researcher initiated data analysis with a complete reading of the transcript to gain a sense of the context and emotions and the person being interviewed. She then used highlighters with a different color for major areas pertaining to spirituality, religiosity or preferences for aspects of care in the last days of life to begin the unitizing, coding and data reduction components. Sampled units of text were transferred to a table (initiating the

dendogram), in which levels of coding progressed toward abstraction into categories that were further reduced to themes in each of the major areas. During transcript analysis, some areas needed clarification and the researcher did this electronically with some of the participants. Each of the participants had been informed at the time of the interview that they would be emailed information about data analysis. Only one participant was experiencing significant health-related issues during the time of the interview, and the coding of her transcript was contextualized to reflect her thoughts about spirituality and end-of-life care. Table 1 depicts selected examples of the coding process for the theme of “Interconnectedness.”

Table 1: Supporting Data for the Theme of Interconnectedness

Textual Data	Sub-Categories	Category
<p>“...People can understand each other even if you don’t understand (their) languages...”</p> <p>“We can tell if you show it’s not just business...can see (caring) in nurse’s eyes”</p> <p>“... You can feel that people care about me or not care about me”</p> <p>“...Little simple things (are important)”</p> <p>“(show them) kindness”</p>	<p>Sincerity, genuineness</p> <p>Intuition</p> <p>The little things count</p> <p>Kindness, gentleness</p>	<p>Authentic Presence</p>
<p>“Feelings are very universal”</p> <p>“Do not change your care just because they are Japanese”</p> <p>“We don’t want to feel weird because we are different...(we are) not from Mars”</p> <p>For herself at EOL: “dignity...have lipstick on...comb hair...don’t want to be messy you know, dirty, ugly, old lady”</p> <p>Best thing a nurse can do: “love...I wanted them to treat (me) like a person, not like a patient”</p> <p>“...Hug and talk to them...tell them it’s a tough time but patient is also fighting and try to understand the situation...”</p> <p>Wants nurse to “...be like a friendship than just a nurse (to make her feel comfortable and to know someone cares), and “...loves God”</p>	<p>Avoidance of stereotyping</p> <p>Acknowledging traditions</p> <p>Dignity, respect</p> <p>Empathy</p> <p>Acceptance</p>	<p>Person vs. Patient</p>
<p>Wants prayer but “...depend on sincerity of person doing prayer...(prayer) bring(s) peace”</p> <p>Prayer is “unnecessary...(but is) appreciated (if offered)”</p> <p>“...would be different for my husband (a Catholic) than me (Buddhist) at EOL (regarding spiritual care)”</p> <p>“(Remember that) Japanese (are) not too open with strangers”</p> <p>“(Is the) Japanese way (to not want sympathy at EOL)”</p> <p>“...Incense...Buddha...in my room (for prayers)”</p> <p>“(As recently converted Christian, his father) would not want chaplain or other...just family”</p> <p>“Bible...kind of boring...(but)...lot of meaning...what Jesus is saying...” (wants Bible read to him during last days)</p>	<p>Prayer vs. non-prayer</p> <p>Acknowledging diversity</p> <p>Spiritual presence vs. none</p>	<p>Spiritual Caring</p>

Findings

Most of the questions asked followed scenarios presented to the participants concerning decision-making in the event of an end-of-life situation that involved themselves or their elders. Participants often described what their parents or grandparents would want if they were in the US. Table 2 shows all categories and themes for spirituality and preferences for care in the last days of life. Spirituality issues at the end-of-life were expressed in two major themes: Spirituality as Culture and Universality of Spirituality; responses to questions about care in the last days of life yielded three major themes: Environmental Peace and Comfort; Interconnectedness; and Communication is Key.

Table 2: Spirituality and Preferences for Care in Last Days of Life: Categories and Themes

Category	Theme
Predestination Diversity of religiosity Endurance and hard times Spiritual legacy	Spirituality as Culture
Spiritual caring has no boundaries God is one Absence of religion Supreme Being presence Non-tangible-ness of God Values	Universality of Spirituality
Avoidance of aloneness Solitude with family Presence of family and friends Preparation for death	Environmental Peace and Comfort
Authentic presence Person vs. patient Spiritual caring	Interconnectedness
Complete disclosure Breaking the language barrier Facilitating perceived full support Family as decision-makers Talking vs. no talking	Communication is Key

Spirituality as Culture

Spirituality as Culture reflected general beliefs and practices, mostly about Christianity, Buddhism and Shintoism. Many participants, including the Christians, felt that religion was either absent or played very little role in the lives of the Japanese people in general, but some with no religion felt that there was a “higher power”, though not identifiable, “out there.” For example, Participant E expressed her belief in a higher power

that was "...out of reach (and her ancestors) protect her..." In addition, this participant said that "once you die, you are Buddha...that's in my spirit."

Christianity was perceived to be rare among the Japanese, even those in the US, and all of the Christians expressed belief in a higher power. Buddhism and Shintoism were mostly dually practiced in the same home, with sad events associated with Buddhism, and happy events, such as a wedding, associated with Shintoism. "Every family has two religious beliefs... Shinto is we celebrate and use for happy occasions, and Buddhism is for the sad occasions....weddings often go to the Shinto shrine, and the funeral...go to temple or Buddhism" (Participant C). Participants who were Buddhists did not pray to Buddha as much as they prayed to deceased ancestors, either in their home with altars that had a Buddha and pictures of deceased relatives, or in temples. "My grandmother...she pray (to) pictures of (deceased) family...with Buddha at side of altar... (is) a temple in her home" (Participant A). Most of the Buddhist participants said that their elders adhered to these practices more than they did, and they would do so in the US, if they lived here. Prayers included both gratitude and special requests. One Buddhist practice was to purchase a token in the temple with a special prayer. Participant B described it like this: "...it's like (a token) you carry, like God is in there....they say a little God is in there...makes you feel like you're taken care of..." There was also a belief by Christian: and non-Christian participants that God planned challenging times for us so that good things could come and we would be better prepared for the next "tough" times. "(I) have to endure...hard times... (it is my) job..." (Participant L). While Buddhist participants did not feel that Buddha had control over their lives, Christians felt that God was in control.

Beliefs in afterlife also varied. These beliefs were positive among Christians, but very diverse among Buddhists and those with no beliefs, who for the most part were unsure. Participant F was a Mormon and expressed concern about her deceased mother who did not have a belief: "we believe in afterlife. We will be okay, we will be reunited with family...but my mother...no religion...she is somewhere I can't quite go." This same participant also believed in post mortem baptism: "We need to give her baptism (so) she would have a chance to accept the gospel...to achieve the celestial kingdom." Participant L who believed in "some kind of supreme being" stated: "(the) body is different than mind...body is not finished when you die...I guess...heaven...is something spiritual out there." Participant R stated "I think, once human being dies, that's it... (spirit) die with the body... (but) we can see spirit, for example book, or music, or something which he or she make." Four of the participants explained that after several days or weeks after death a person of the Buddhist faith may ascend, not into the heaven that Christians refer to, but into a "type of heaven" or place where their ancestors are. One Buddhist believed that that "heaven" was reserved for those "...with kind hearts and hell for evil people. =" (Participant D). Unlike Christianity where there can be last minute redemption, or "saving", there is no such belief in Buddhism, and Buddhist participants felt that a person must live most of his life in a good way in order to go the "the next lifetime" (Participant D) that is similar to heaven.

Spirituality: Universality of Spirituality

The sense that one should care for people without regard to religion or spirituality was quite evident throughout the interviews. Participant C, who was the only informant who was experiencing significant health-related issues at the time of the interview, had no religion but had spiritual beliefs: "... (there) is one God on this earth....called different names: Buddhist, Christ, Jesus or whatever...". Participant B agreed: "God is just one, and whatever you know God...that's your church." Other participants stressed the importance of family togetherness in Christianity, even if a family member was without religion or was Buddhist,

as was the case in some participant families. Several participants found similarities between Buddhism and Christianity; as Participant T said: "...the bottom line, all the religions is appreciation for what you are...thanking for what you do, what you have...and (that) appreciation is common for all religions...." The universality of spirituality theme reflected participant perceptions that spirituality has no borders and God is everywhere regardless of one's religion. A sense of the need for mutual respect for one's beliefs permeated participants' stories. Only one participant expressed non-belief in a higher power or afterlife.

For the most part, participants saw religion and spirituality as separate, and this was reflected in the themes.. Most of the participants had parents who, both here and in Japan, practice two simultaneous religions: Shinto and Buddhism. One participant stated he felt that there were Buddhist influences in Christianity due to similar practices of family gatherings to celebrate the deceased person's life just prior to or after a funeral. The stories reflected similar practices with regard to spiritual beliefs: some acknowledged a specific spiritual belief but did not overtly practice it while others did. Most of those who did not specify a religion stated they believed in a higher power, and characterized themselves as "spiritual." Conceptions of the existence of a person's soul or spirit as well as "what happens" after death was viewed differently by the non-Christian participants. Variability within the same spiritual belief, such as Buddhism, also existed regarding disposition of the spirit after death. Overall, beliefs about a higher power were very individualized and unique to family beliefs and traditions, including both Buddhism and Christianity.

Last Days of Life: Environmental Peace and Comfort

The researcher asked the participants two questions about care in the final days of life: "What are your most significant concerns when you think of the last few days of your life?", and "Tell me what we as nurses and doctors need to know to take better care of you in your last days of life." The first theme, Environmental Peace and Comfort, incorporated: avoidance of aloneness, solitude with family, presence of family and friend, and preparing for death. Being left alone was a common fear, as expressed by Participant A: "No one wants to die alone...", and by Participant L: "...it's not fear to die, it's just fear (that) I won't be with family." The presence of family and friends was very important to the great majority of participants, but several also noted the value of solitude with family and friends without health care provider intrusion. Having ethnic food in the room or smelling aromas would bring peace and comfort, they said, because of its familiarity, and ethnic food had the symbolic meaning of "oneness" of family. Preparing for death included appreciating cherished memories, affirmation that the family left behind would be "okay", and opportunities for expressing gratitude to family and friends., As Participant R indicated: "... I want to say thank you to my wife, and friends, last time." Another participant was very concerned about whether she would be able to tell her family "everything" while she could. The ability to say "good-bye" was also noted by many of the participants, and that was one of the reasons that home was a preferred place to die. The choice of place of death was predominantly the home, even after the homelike descriptions of inpatient hospice were explained. One participant stressed the importance of being able to see "nature"...with "...the birds singing a lot" (Participant Q). Several of the participants expressed a strong desire to be at home during the last days of life, but they were concerned also about caregiver burden.

Last Days of Life: Interconnectedness

The theme of Interconnectedness included: authentic presence, person vs. patient and spiritual caring. Participants were very vocal about the importance of gentle, unhurried kind

care that reflected sincerity and genuineness on the part of the nurse, and they expressed intuitive perceptions about this type of care. For example, Participant A said that "...Feelings are very universal and people can understand each other, even though you don't understand (their) languages...we can tell if you show it's not just business..."; another participant said "...you can tell whenever you see their eyes...you can feel that they really care about me or not care about me" (Participant B). One agnostic participant said that prayer was helpful in bringing peace and comfort only if the person saying the prayer was sincere. Participant E stated that "...I think maybe I just want to hear or feel you care for me...close attention...smile very important..." Empathic understanding was also important: "...tell them it's a tough time, but (the) patient is also fighting and try to understand the situation..." (Participant D). This participant wrapped up the feelings of others in emphasizing the importance of sincerity in caring for persons at the end of life.

Avoiding ethnic stereotyping and prejudice by treating the person as a human being rather than a patient was considered important by many participants. One person advised health care providers to watch and observe Japanese persons because they are reserved, but said "...do not change your care just because they are Japanese...just be you...(we) don't want (you) to feel weird because we are different...(we) do not want (a) wall between us, and...(we want to) feel welcome with a smile ...and not from Mars" (Participant B). Participant A had no religion when she first came to the US but she converted to Christianity after her children were enrolled in a local Christian daycare. She hinted at the importance of not assuming a particular religion based on ethnicity: "...not really Buddhist, just because I'm Japanese...(spiritual care is) just a universal thing; if someone show you that you're caring...it would help in anybody...(to know the health care provider is) here for you and...want you to feel better." Other statements reflected the importance of being recognized as a person with dignity through provision of hygiene in general and application of make-up for females. In addition, concerns about "tubes" and "diapers" and lack of privacy were expressed as interfering with one's dignity. Other statements that alluded to maintaining dignity and respect for the person dealt with avoiding the perception of burden. Many informants expressed concern about Japanese not expressing their needs because they did not want to be a financial or physical burden. Participant F stated that "...don't want to burden other people...that's how we are, we are raised to not to give any trouble to other people, to society..." The significance of acknowledging the dignity, the "humanness", and being respectful of persons was a strong message expressed by these participants, as well as being always mindful that one is caring for a human being, not a patient.

Spiritual caring was considered manifested by health care providers' acknowledgement of spiritual and religious diversity, recognition of traditions within those diverse religions, and recognition of spiritual presence. A Buddhist participant who visited the hospital Christian chapel when her daughter was very ill said: "I told you that you shouldn't call the priest by the bedside, (but) we visit there...and there is a sanctuary and I stay there and pray, I wasn't Christian... but really, really comfortable to be there and soothing...(it helped me) because I couldn't do anything..." (Participant D). This participant specified that she was praying to God, not her ancestors. Most of the participants emphasized the importance of acknowledging religious and spiritual diversities, and "...to not bring the priest (if they are still breathing) or read the Bible (if they are Buddhist)..." (Participant D). Another participant acknowledged how different it would be in the last days for her husband as a Catholic and for her as a Buddhist; she did not feel that her religion would bring any type of comfort or help to her in the last days, but the presence of family was essential. This participant and others were relatively open about prayer being offered to them by the nurse. They said that if prayer was offered to non-Christians and it was accepted, prayer should be of the "generic" form with prayer to a universal God. Participant S shared similar thoughts of

most of the other participants when she specified she would be uncomfortable about saying a prayer herself, but preferred the nurse to pray.

Buddhists typically do not pray before death, but they do so afterwards. Participant F stated that "...prayer before death is rude." She also stated that it may be considered rude for a health care provider to initiate the subject of religion since this is considered a private family matter. However, some participants said that their elderly Buddhist relatives would not mind if a health care provider prayed with them if the provider asked first. Participant J, a Christian, said that prayer would not help him, but knowing that care providers were praying for, and with his family would bring him peace because he knew it would be helpful to them. He also stated in his response to a nurse-offered prayer: "I won't say no, I will just let you do it...to be polite." Some said that offering a spiritual advisor, e.g., a Buddhist monk, chaplain or other, might be helpful, but it was very important to ask first. In some traditions, a Buddhist monk or priest is not asked to visit before a person dies or it could be "bad luck"; rather this person is traditionally called after death. Participant A, who was a converted Christian said how "scary" it would be if a pastoral person entered her room in "robes", but she added that if an explanation was provided first, she would be okay with this. Other potentially helpful practices would be to bring symbols of spirituality, such as the Bible, a Buddha statue, or for those with Buddhist beliefs, pictures of deceased ancestors. Having a spiritual advisor present did not appear to be important, even for the Christians, though one participant said she would only go to the Christian-based hospital, not the other two in her area because of the lack of spiritual care given there. When asked about truth telling concerning a life-limiting illness, Participant B stated "...if Christians, their faith will carry them through if they know...". Faith was acknowledged as a resource for coping with the stress of having to tell the truth about a life limiting condition to a loved one.

Last Days of Life: Communication Is Key

Participant B stated that "Communications is the key...make them feel more comfortable and not saying (things that make people) feel weird, nervous..." and like many of the others, she stressed the importance of communications between healthcare providers and families and the person who is at the end of life. Another participant was very emphatic about communication with the person's family if the person was unable to speak English, and noted that communications can affect emotions and fear. Communication was considered important not only for informational purposes, but to also help the dying person feel a sense of support. "I like people to talk to me. I don't want them to be, I don't know I don't want them to be feeling sorry for me. But I want them to be the same as living healthy people (despite the circumstances)." (Participant F). As both a family member and as a person at the end of life in the future, participants were adamant about the need for communications to reflect information and support, without overtones of pity.

Explanations were emphasized especially when participants were discussing options for pain management. Participant S said that explanations help the family to make decisions about pain management for the person unable to communicate; some families may not want their loved one to suffer for the sake of being conscious enough to be able to communicate with surviving family: "(This)...matters for the...surviving...family members (because) they will keep it in their mind for the rest of life." Participant D emphasized a major reason for communication: "...Because they need to know how long they live and how they want to live in the last portion of their life." In other words, the family would not be able to make decisions about the person's care without careful explanations by health care providers about suffering and the sedative effects of analgesics.

Participants' overwhelming preference for dying at home was logical when

considering their preferences for care in the last days of life. Some diversity was expressed, some wanting to have solitude with family and others wanting family and friends close by, and never wanting to be alone. Smelling culturally-specific aromas and seeing or tasting food was important, as well as hearing certain sounds, such as birds singing were important in the last days. Expressing gratitude to family members, saying “good bye”, assuring family will be taken care of in the future, and other final business were reflected in participants’ stories.

Participants wanted health care providers to be cognizant of the importance of genuineness and compassion when rendering dignified care in the last days of life. This included being acutely aware that patients are human beings with diverse and unique lifeworlds and experiences, thus reflecting varying preferences for spiritual care, all within a framework of unconditional acceptance. Participants expressed the critical importance of effective communications concerning care, meaning explanations must be thorough and clear so that both the patient and loved ones feel supportive and know what to expect. Participants B and E sum it up nicely: “my personal thoughts of end of life care...want to know that (the nurse) you’re loving your job, that you really care about being a nurse....have compassion and loving and caring...and just that communication, just let them know you care about them...” (B)“I think maybe I just want to hear or feel you care for me....close attention...more communication...” (E). The participants expressed how meaningful it would be for them to have care that reflects clear communications and genuineness.

Death and Post-Death

When participants were asked about preferences for care in the last days of life, perceptions of death and post death practices were often spontaneously discussed, and thus this became a regular interview guide question. Three themes emerged: Light vs. Dark, Respecting Death, and Unity After Death. The first theme describes reactions at the time of death as well as the first few days after death and is very spiritually based. Participants who were of the Christian faith discussed behavioral patterns that reflected a more peaceful, though sad acceptance of death, while Buddhists were different in their responses. . One Christian participant said, “...a lot of people think about death as really negative and scary, fear, darkness...but it’s more celebrate...more party...not about crying or sad...(in Japan) is very devastating, crying, and screaming...depends on where (the) dead person is...with God...” (Participant B). The Christian “calmness and acceptance” was a sharp contrast against the more demonstrative reactions of the Buddhists with “screaming” and crying.

Respecting Death was the second theme, and this was best reflected by Participant D, a Buddhist, who remarked about the importance of never referring to “the body” because the person in death is still a person. This theme incorporated care of the person immediately post death. Most of the participants expressed a desire for family to be alone with the deceased for a period of time. Appropriate hygienic care for the deceased person was also a common desire, and though it would be acceptable for nursing personnel to bathe and clothe the person, some participants preferred that the family be given the option to do this. “In Japanese custom, usually family members would clean the body, and would put the new clothes” (Participant T). Some participants expressed a desire for a white kimono to clothe the deceased person.

Unity After Death was a final theme, including traditions and practices post death; the implication was that the deceased person was never left alone and was in some way “with” survivors or with ancestors. Most of the Buddhists preferred the person to be transported either to a temple or to a home where the person could lie “in state” for family to be with 24 hours a day for three days. Participants talked about a variety of traditions after that, including chanting and a funeral procession to the crematory, where the Buddhist monk

would pray with family. Participant A describes special sounds heard at the funeral: “At the funeral we have chanting... drum sounds...special drums yeah, those supposed to take you to heaven...” One Buddhist practice was to have a small, private funeral at night to be followed by a much larger funeral the next day, then cremation. Cremation was the dominant choice for all of the Buddhists-- a practice of necessity in their home country with little burial space. Participant R described a “family cemetery” for the burial of ashes: kind of a grave. Cemetery. The size is four times of this room and three hundred, two hundred years ancestors body in the same place.

Some of the participants talked about family traditions after the cremation, including picking out larger pieces of bone with chopsticks along with some ashes to place into a container and bury in a common grave with other ancestors. One said, “We don’t burn to ash, we will have bones...we pick and bring to (the) grave site and bury (a) pot (with the bones) under (the) tombstone” (Participant E). Another participant said she wanted cremation so she could be buried with her deceased husband in the same grave. Some of the participants indicated that their ashes would be transported from their American home to their Japanese home for burial. One said that half would remain here to be buried with her American family, and the other half would go to Japan. One of the “Buddhist turned Christian” participants (Participant A) discussed drums that are “...supposed to take you to heaven.” Christians expressed their belief in heaven and joining their ancestors, and Buddhists mentioning their practices of praying to ancestors.

Responses regarding death and post death practices reflected the diverse religious and spiritual beliefs of the participants, with some blending of Buddhism and Christian beliefs and practices, but with a demand for respect for the deceased at all times. Calm versus more demonstrative responses to a death appeared to reflect a spiritual basis, with calmer responses reflecting stronger spiritual foundations. Post death rituals were varied and again reflected spiritual beliefs. For example, special family traditions, ceremonies and gatherings were held for those who had spiritual beliefs, and for those of the Buddhist faith, monks “supervised” the cemeteries. Participants discussed varied dispositions of the deceased person, such as cremation and burial, some desiring their ashes to be distributed in their native homeland and here in the US. One’s spirituality also affected spiritual practices of those “left behind.” For example, we can be at peace knowing that we will one day reunite with our loved one in heaven; we can pray to our ancestors; or, there is the unknown as to what will happen to a non-believer after death.

Discussion

Current information on the willingness of persons from Japan to discuss end of life care issues is conflicting. Bito et al. (2007) asserted that it is not a “taboo” subject as long as the situation is not currently life threatening, but Matsui (2007) noted that only 16% of the older adults in their study had discussed end of life care preferences with their family or physician. Participants in the current study were very willing to discuss their views, and even if they became tearful during the interviews, they were adamant about continuing with the interview.

Davis, Konishi, and Mitoh (2002) note that end-of-life care and values stem from Confucianism and Buddhism. They also differentiate between the linear Western view of death and the more circular (death-rebirth) Eastern views. Many of the participants in this study expressed circular beliefs. Smith-Stoner (2005) has pointed out that Tibetan Buddhism, a type of Mahayana Buddhist tradition practiced in Japan, is one of the fastest growing religions in the US, and also notes that spiritual beliefs and practices can vary in the same religion, and this fact needs to be recognized in end-of-life care settings. This diversity was

reflected in the participants in this study with diverse religiosity and post death traditions, along with a unified sense of caring and protection of the deceased. Varying beliefs in a higher power may reflect religious beliefs, such as Christianity, more than spirituality overall. This is consistent with Roemer's (2006) view that most Japanese ascribe to a set of beliefs that are associated with ritualistic practices, such as the purchase of a token from the temple as a symbol of prayer, a practice described by several of the participants in this study. Roemer also noted the importance of acknowledging the continuing practice of religious rites in the home, temple, shrine and in other settings. The presence of spirituality, however, may or may not include the ritualistic practices of a religion (Moritz et al., 2006).

In her review of the literature, Easom (2006) found that prayer is used as both a folk home remedy and as a spiritual practice. Thus, the desire for prayer and related spiritual symbols at the bedside may be preferences for care in the last days of life. However, the practitioner must be attuned to cultural differences before introducing prayer as an intervention. Use of prayer in the last days of life was considered constructive by most of the Christian participants in this study, but feelings were mixed among those who were Buddhists. Most of these participants felt that a visit by a Buddhist monk for prayer before death was undesirable, even harmful. Other researchers have agreed that Buddhist prayer after death is more acceptable (Sharts-Hopko, 1996). Few of the participants in this study saw prayer as a helpful action by health care providers. However, this was inconsistent across participants. Hirai, Morita and Kashiwagi (2003) have noted that existential suffering, a mental form of distress caused by awareness that one's existence on this earth is about to end (Liebersohn, 1999), is common among persons who are terminally ill. These researchers found that prayer was not as powerful an intervention as authentic listening and acceptance, both of which were reflected in the theme of Interconnectedness. Davis et al. (2002) emphasize the Japanese cultural value of maintaining an enduring sense of group/family belonging, which ties in with spiritual caring.

Contemporary Japanese are more concerned about harmonious relationships with those they interact with than about their relationship with a higher deity (Dolan & Worden, 1994). This was reflected in the theme of Spiritual Caring and Interconnectedness. However, those who were Christians appeared to more consistently desire prayer and spiritual leaders at the bedside in their last days. Participants in this study felt strongly about being treated as persons with dignity and respect, as was also found by Oguso (2004).

Limitations and Implications

Limitations of this study included acculturation, demographic and experiential issues. In terms of demographic issue, age ranges and experiences with death in their families were quite varied among the participants. While it would have been ideal to obtain first person preferences for care at end of life, some of the younger participants had not really considered this, but did express confidence about what they felt their older relatives would want. In terms of experiential issues, most participants had experienced a death in the family within the previous five years, but some participants had not experienced death at all. Further, even though they claimed to have original Japanese values, some participants had been here as long as 25 years, and it would be difficult to deny that some acculturation effects were present.

Implications of these findings include the need for health care practitioners to avoid stereotyping. As Participant C indicated, "Just because I am Japanese does not mean I do what typical Japanese do!" Health care providers must also recognize the importance of an authentic presence with the person who is dying, and convey an openness and unconditional acceptance. Just because a person is known to be Christian does not mean a chaplain visit

would be welcomed. Acknowledgement of diverse spiritual and religious beliefs and practices is essential, and we must ensure that individuals' unique care needs are effectively met.

Often there are no guidelines at all for practice with a particular cultural group, and those that do exist are based on little research and reflect the recommendations of the particular cultural group who live in that community. This study only touched on the diversity and depth of needs at the end of life for persons of Japanese descent living in the US. Thus, replication of the research is essential to add to the findings. In addition, more attention should be paid to culturally focused credibility criteria for this type of research. Researchers studying cultural behaviors should focus efforts on meeting criteria that are specific to culturally competent and ethical research.

The author of this article is passionate about rendering care at the end of life that reflects dignity, respect and honor. Knowing how that care is translated throughout different cultures is an ethical and moral responsibility of health care providers. It is hoped that health care practitioners apply these findings as guidelines for delivering care for the Japanese person who is dying and for their loved ones, so that a peaceful death with respect and dignity can be facilitated.

If we value so highly the dignity of life, how can we not also value the dignity of death?
-Yukio Mishimo

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