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Awareness of Dying and Conflict Resolution: Texas Asian Perspectives

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Abstract

Individuals in the end-of-life (EOL) period may not be fully aware of their prognosis or know they are facing a terminal illness. As Asian beliefs and cultural tendencies intersect with Western values, health care practitioners may find their assumptions about disclosing an EOL prognosis differs from patients and their family members. Disagreements among family members regarding the disclosure of EOL to their terminally ill loved one can result in conflict—making difficult and sensitive times more burdensome. Little scientific evidence is known about first generation Asians who live in the United States (US) regarding their practices with disclosing EOL and how they handle conflict resolution when a family member is terminally ill. The purposes of this descriptive qualitative study were to explore issues surrounding patient awareness of dying and explore approaches to conflict resolution in EOL situations for first generation Japanese, Chinese and Vietnamese persons living in the south central, south eastern and northeastern parts of Texas. Face-to-face audio-recorded interviews were conducted and transcribed verbatim. Thematic analysis elicited three awareness and three conflict resolution overarching themes across all ethnic groups. Health care practitioners must be cognizant that assumed acculturation does not always coincide with Western beliefs regarding disclosure of the prognosis at the EOL. In order to provide culturally and ethically sound EOL care for the patient and their loved ones, clinicians must be mindful of the need to sensitively assess their patient's beliefs and understand the importance of compassionate and diplomatic approaches for conflict resolution in Asian cultures.

Keywords

End of Life, Truth Telling, Disclosure, Conflict Resolution, Asian

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Awareness of Dying and Conflict Resolution: Texas Asian Perspectives

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Individuals in the end-of-life (EOL) period may not be fully aware of their prognosis or know they are facing a terminal illness. As Asian beliefs and cultural tendencies intersect with Western values, health care practitioners may find their assumptions about disclosing an EOL prognosis differs from patients and their family members. Disagreements among family members regarding the disclosure of EOL to their terminally ill loved one can result in conflict—making difficult and sensitive times more burdensome. Little scientific evidence is known about first generation Asians who live in the United States (US) regarding their practices with disclosing EOL and how they handle conflict resolution when a family member is terminally ill. The purposes of this descriptive qualitative study were to explore issues surrounding patient awareness of dying and explore approaches to conflict resolution in EOL situations for first generation Japanese, Chinese and Vietnamese persons living in the south central, south eastern and northeastern parts of Texas. Face-to-face audio-recorded interviews were conducted and transcribed verbatim. Thematic analysis elicited three awareness and three conflict resolution overarching themes across all ethnic groups. Health care practitioners must be cognizant that assumed acculturation does not always coincide with Western beliefs regarding disclosure of the prognosis at the EOL. In order to provide culturally and ethically sound EOL care for the patient and their loved ones, clinicians must be mindful of the need to sensitively assess their patient's beliefs and understand the importance of compassionate and diplomatic approaches for conflict resolution in Asian cultures. Keywords: End of Life, Truth Telling, Disclosure, Conflict Resolution, Asian

Communication between a patient and their family member(s) during end-of-life (EOL) is a complex process influenced by a myriad of physical, social, and cultural factors. Numerous authors have identified differences in EOL decision-making preferences related to cultural values, demographic characteristics, knowledge of EOL treatment options, level of acculturation, contextual factors, generational differences and family relationships (Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998; Kwak & Haley, 2005; Lee & Wu, 2002; Matsui, Braun, & Karel, 2008). Communication, or the lack thereof, may impact EOL decisions.

One aspect of communication includes full and factual disclosure of information to a patient at the EOL, which is viewed as a basic moral concept in Western society (Pergert &

Lutzen, 2012). Seminal work by Glaser and Strauss (1965) identified a central concept called an “awareness context,” defined as awareness of the patient’s fate by all involved parties, inclusive of the patient and family members. Building on Glaser and Strauss, scholars introduced terminology of disclosure, represented as provision of information to patients either in whole, in part, or not at all (Miyata, Tachimori, Takahashi, Saito, & Kai, 2004). Despite the Western bias that full disclosure is an ethical and sound practice, not all cultures subscribe to these same beliefs. In some cultures, withholding factual information from a dying patient is considered an admirable act (Pergert & Lutzen, 2012), one delivered with compassionate and beneficent motives. Informed consent, coupled with other Western ideals of autonomy and self-determination may not be congruent with some Asian beliefs (Tai, 2013). Health care practitioners may find their assumptions about disclosing an EOL prognosis differs from patients and their family members (Zolkefli, 2018). The rights of the patients to be fully informed of their life-limiting medical conditions can be in direct opposition with family wishes, putting health care providers in the middle of a cultural *faux pas*.

The United States (US) Asian population reflected the greatest growth rate between 2000 and 2010 than any other foreign group (Hoeffel, Rastogi, Kim, & Shahid, 2012). More specifically, the total US population grew 9.7 percent between 2000 and 2010, while the Asian population grew by 43 percent. Texas counties near Houston and Dallas are reported to have the highest concentrations of two of the more common Asian groups: Chinese and Vietnamese. Japanese immigration to the US was non-significant until the 1950’s-1960’s when US-Japanese trade increased (Rhoads, 2010). Like the Chinese and Vietnamese, the Japanese population is more concentrated in the Houston and Dallas areas. More than 100 Japanese business firms are located in the Houston area (Rhoads, 2010).

No specific scientific evidence could be located regarding first generation Asians who live in the south-central region of the US regarding disclosure practices and conflict resolution for persons who are terminally ill. Evidence-based information in practice settings is sparse. In this article, we discuss a qualitative study of first generation Japanese, Chinese and Vietnamese persons who live in the south-central part of the US and their disclosure practices and conflict resolution preferences for care once a diagnosis of a life-limiting disease has been delivered to the family.

Background and Significance

Revealing the truth to a person who has limited time to live was observed in the literature to be referred to as either truth-telling or disclosure. Tracing back to the era of Hippocrates and Plato, disclosure or non-disclosure depended on how it would affect the dying person (Sokol, 2006) and concealing the truth could be considered beneficial to the patient. Sokol explains how this line of thinking eventually influenced the American Medical Association’s first code of ethics in 1847 and discouraged disclosure to the patient. Subsequently, the Progressive Era of the early 20th century brought change as Richard Cabot, an American physician and reformer, began advocating disclosure and the belief that this approach was more humanistic and ethical (Dodds, 1993). Concealing the truth has wide and varied practices that have religious/spiritual, cultural, and experiential foundations (Sokol, 2006). The boundaries of maintaining hope through non-disclosure and of recognizing the patient’s ability to “take the truth” continued to be blurred throughout the 1950’s (Sokol, 2006).

This eventually led to the classic landmark grounded theory study by Glaser and Strauss in the early 1960’s (Glaser & Strauss, 1965) regarding awareness of dying and an integrated substantive theory about awareness contexts. In the process of answering questions about interactions involving health care providers and hospitalized dying patients, Glaser and Strauss determined that the answers all related to one central concept—an awareness context, which

was defined as awareness of the patient's fate by all involved parties. They identified four levels of awareness: (a) closed; (b) suspicion; (c) mutual pretense; and (d) open awareness. These were respectively conceptualized as: (a) patient did not know of terminality; (b) patient suspected terminality; (c) health care providers and patient knew of terminality but pretended they did not know; and (d) all involved knew of the patient's terminal condition.

Although Western society values the attributes of full disclosure (Nie, 2012; Rosenberg, Starks, Unguru, Feudtner, & Diekema, 2017), these qualities can be challenged in EOL situations when people have limited time to live. Controversy has surrounded this topic for decades, and continues today (Blackhall, 2013; Collis & Sleeman, 2013; Glaser & Strauss, 1965). Weeks et al. (2012) reported that patients with Stage IV lung and colorectal cancer (69% and 81% respectively) had incorrect expectations of the non-curative properties of palliative chemotherapy they received. Interestingly, those patients who scored high on physician communication reflected higher risk for inaccurate expectations. The authors argued that not being informed of this could likely interfere with informed decision-making. Over the past three decades, the ethical principle of autonomy has taken precedence in the US (Searight & Gafford, 2005), which clashes with principles of beneficence and non-maleficence which is present in Middle Eastern and, more specific to this current study (O'Kelly, Urch, & Brown, 2011; Sokol, 2006; Tsai, 2008).

Family members from different cultural groups can influence, or attempt to influence, clinicians' decisions to provide or withhold information concerning patient care (Hancock et al., 2007). Family-initiated non-disclosure is well-supported in Asian populations and stems from: 1) belief that EOL information is inappropriate or not good for the patient, 2) desire to protect the patient, 3) belief that it is considered bad luck, and 4) desire to keep hope alive (Brotzman & Brotzman, 1991; Orona, Koenig, & Davis, 1994).

In the last decade, scientific evidence has affirmed that Asians are more likely to prefer family-centered decision making. Results from focus groups with 18 Japanese families revealed that Japanese families prefer a group-oriented approach, wherein consensus between the family and the physician is cultivated (Bito et al., 2007). For some Japanese people, the family's role is intended to remove the burden of making treatment decisions from the ill patient (Kwak & Haley, 2005). Data from Yoshida et al. (2011) supports the view that Japanese family members have a special role in communicating prognoses, yet the majority of family members report that improvement is needed in methods of prognostic disclosure.

Chinese families also avoid telling the truth to their ill relatives and are hesitant to disclose bad news for reasons of non-maleficence (Tse, Chong, & Fok, 2003). Chan (2011) reported that Chinese family members (82.5%) were informed of a patient's prognoses more often than the patients (49.5%) receiving palliative care services. Back and Huak (2005) reported that advanced patient age, female gender, palliative treatment, and non-English speaking patients were significantly associated with family-initiated non-disclosure of diagnoses. Intentional non-disclosure of diagnoses was present in 17.6% of the patients, and discussion of prognoses was avoided in 36.8% of the patients (Back & Huak, 2005). In the majority of these cases the family gave specific directions in advance to avoid disclosure. This family-initiated rate of non-disclosure of diagnoses confirms the presence of potential ethical dilemmas for U. S. health care providers related to veracity and conflict with end-of-life care.

Though no specific studies could be located regarding Vietnamese disclosure or conflict resolution at EOL, this topic is fraught with numerous and complex perspectives. Autonomy is a right that is recognized in the Vietnamese population when it comes to disclosure (Nguyen, 2015) but from the perspective of having the choice to not disclose. Nguyen (2015) demonstrated the beliefs of non-disclosure in a case study of a Vietnamese man who would not be considered "older" at the age of 42, and living in the US, and requested non-disclosure of his terminal condition to his family. The collectivism described here serves the purpose of

protecting his family from the pain of knowing his terminal condition. Dinh, Kemp, and Rasbridge (2000) discussed traditions of non-disclosure in situations of terminal conditions and the clashes that result between Western beliefs of autonomy and the more traditional Vietnamese beliefs of non-disclosure.

Disagreements among family members regarding decision making for terminally ill loved ones can result in conflicts and make difficult and sensitive times more challenging (Weeks et al., 2012). In Asian cultures, disclosure about family members' prognoses has influenced the decision-making process (Ersek et al., 1998; Kwak & Haley, 2005). Communications about EOL wishes among these individuals have often been poor, resulting in family or caregiver conflicts with EOL decision making. Although the US has become more ethnically and culturally diverse, little is known about EOL preferences in first generation Japanese, Vietnamese, and Chinese persons living in the US. Ethnic minorities, particularly Asians, are more likely to report that their providers do not understand their background or values (Ngo-Metzger, Legedza, & Phillips, 2004). Scientific evidence about disclosure beliefs among Asian cultural groups living in the US is limited and requires further exploration (Tse et al., 2003). This paper reports a portion of a larger study conducted on multiple aspects of EOL care and reports information about disclosure practices and conflict resolution for Asian persons born in Japan, China, and Vietnam but living in the southern part of the US. The primary author has a longstanding passion for EOL care that reflects recognition and respect for one's individual values and beliefs. Observing patients who suffered needlessly in their last days of life due to lack of health care provider and at times, family insensitivity and/or knowledge as to what the desires of the dying person were instigated this passion 35-40 years ago while working as an acute care nurse. More recently in the past 10 years while working as a hospice nurse in an in-patient setting revealed that guidelines for various religious and cultural groups were not evidence-based, and reflected broad recommendations written by a single spiritual leader in the community. She recognized that health care providers needed more specific and evidence-based guidelines for delivering EOL care that facilitated a individualized values and preferences-based dying process.

Methods

This descriptive qualitative study sought to answer two overriding research questions. In first generation Japanese, Chinese, and Vietnamese people currently living in Texas: (1) What are persons' attitudes and preferences for care regarding disclosure of EOL, and (2) What are persons' practices regarding conflict resolution of EOL decision-making for a loved one? These settings were chosen for two reasons: (a) the locations were accessible for the researcher to conduct face to face recruiting and interviews, and (b) we operated under the assumption that great variations in cultural beliefs may exist in geographical locations outside of these areas. Descriptive qualitative research oftentimes falls within the realm of those studies that do not "fit" into the more traditional approaches of phenomenology, ethnography or grounded theory, and is done to understand and describe a phenomenon (Bradshaw, Atkinson, & Doody, 2017). This study was initially designed and conducted as a descriptive qualitative research study because according to Sandelowski (2000) and Polit & Beck (2017), qualitative description has a credible and valid place in scientific inquiry. Sandelowski explains that qualitative descriptive studies reflect a comprehensive summary of an event with the goal of seeking a valid and accurate account of something. This summary would be validated as accurate by researchers and participants, as this current study was. Additionally, 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. Findings in this study were determined following extensive, in-depth immersion into the data, and

according to Sandelowski (2000), “researchers conducting qualitative descriptive studies stay closer to their data ... than researchers conducting grounded theory” (p. 336) and other qualitative methodological studies.

Sample

Convenience and snowball sample recruitment techniques were employed following approval by the academic Institutional Review Board under expedited review. The researcher contacted key persons within the community to facilitate access to persons meeting eligibility criteria for the study. Inclusion criteria included (1) being born in Japan, Vietnam, or China, and living in the southern part of the U. S. where data collection would take place; (2) living by the majority of their homeland cultural values, and (3) speaking English or willingness to have an interpreter assist with the interview process. Flyers were distributed in Asian business areas and key contact persons delivered verbal announcements and emails about the study in their respective organizations. Participants responded directly to the researcher either in person or by email of their interest, and following that, a mutually-agreed upon place and time was arranged for the interview. At that time, the informed consent process was instituted that included the purpose, risks of the research, the option of participating freely and voluntarily both initially and once the study had started. Three Japanese participants in the East Texas region initiated the sample, followed by a mixture of Chinese and Vietnamese participants. Because data saturation had not yet been achieved in any of the groups, additional recruitment efforts via networking in the central and southeastern regions of Texas (all within a 200 mile radius of the East Texas area) were successful in recruiting enough participants to achieve data saturation in each group. Fourteen Japanese, 18 Chinese, and 13 Vietnamese participants comprised a final sample size of n=45. Demographic information for each group is shown in Table 1. Sampling continued for each group until data saturation was achieved.

Table 1. Demographics of Participants

	Chinese	Vietnamese	Japanese
Gender	Females: 14 Males: 4	Females: 8 Males: 5	Females: 9 Males: 5
Age range	29-82 years;	21-74 years;	30 to 64 years;
Mean Age	Mean age of 50	Mean age of 54	Mean age of 44
Time in US	8 months - 48 years	6-35 years	2-39 years
Mean Time in US	Mean of 15 years	Mean of 19 years	Mean of 14 years
Occupations	Engineering, Nursing, College Faculty, Ministry, Accounting, Navigation, Pharmacology, And Clerical	Midwifery, Journalism, Nursing, Engineering, Business Owner, And Law	Nursing, Dental/Medicine, Public Relations, Oil and Gas, Primary Education.
Religious affiliations	Christians: 5 Buddhists: 4 None: 9	Christians (fundamental): 3 Catholic: 2 Buddhist: 5 Cao-Dai: 1 None: 2	Christians: 4 Buddhist/Shinto: 4 Supreme Being: 2 None: 4

Data Collection

Prior to initiating the interview, the purpose and study expectations were explained to each participant, participant understanding, and consent were verbalized, and written consents signed. The primary researcher conducted digitally-audio recorded, semi-structured interviews in mutually agreed upon settings and times. Most of the interviews took place in participant homes, workplaces, and in the researcher's office. Interviews began by asking demographic questions regarding employment, education, and time living in the US. Interview guide questions with relevant probes first addressed disclosure through a hypothetical scenario. These participants were not considered to be at end of life, so they could not have experienced the phenomenon of attitudes and preferences for care at EOL, so scenarios were used to elicit as in-depth a description as possible. These helped to provide a more contextual description of the phenomenon. Interview guide questions are embedded within the scenarios. For example, the researcher asked each participant these questions which were followed by relevant probes:

1. If you were a patient and a physician told your family that your prognosis was very poor, and you were not expected to survive longer than 3-6 months:
 - a. Would you want your family or HCP to tell you the truth?
 - b. If there was disagreement among your family members about telling you the truth, how would that conflict be resolved? Would any specific family members have priority influence or decision making regarding this situation?
 - c. Imagine that you could not speak for yourself, and a HCP approached your family about discontinuing life sustaining measures (tube feedings, mechanical ventilation), If there was disagreement among your family members about discontinuing life support measures, how would that conflict be resolved? Would any specific family members have priority influence or decision making regarding this situation?
2. If your spouse or loved one had a very poor prognosis and not expected to survive longer than 3-6 months:
 - a. Would you want your family or HCP to tell that person the truth?
 - b. If there was disagreement among you and your family members about telling that person the truth, how would that conflict be resolved? Would any specific family members have priority influence or decision making regarding this situation?
 - c. Imagine that this person could not speak for themselves, and a HCP approached your family about discontinuing life sustaining measures (tube feedings, mechanical ventilation), If there was disagreement among your family members about discontinuing life support measures, how would that conflict be resolved? Would any specific family members have priority influence or decision making regarding this situation?

Field notes were documented immediately after each interview to capture contextual information and non-verbal communications. Contextual information included the physical environment, time of day, the researcher's intuitive sense of perceived tensions and/or ease of the interview process, emotions, other persons present, and any other relevant information that may influence data interpretation and analysis.

Data Analysis

Thematic content analysis reflected non-linear, iterative approaches recommended by Krippendorff (2004) which are reported in the Japanese spirituality component of the larger study from which the disclosure and conflict resolution component came (Duke, 2013). Essentially, recorded interviews were transcribed verbatim. Transcripts were read line by line and labeled with code words. These codes were then synthesized to form sub-themes, which were collated into a higher level of abstraction resulting in themes that addressed the research questions. Field notes were particularly helpful when emotional tones were meaningful in interpreting the narrative content. Themes for disclosure and conflict resolution were elicited for each cultural group separately, and then because of similarity in themes across the groups, they were combined.

Strategies were incorporated from study conception through culmination of data analysis for credibility via an audit trail conducted by an internationally known researcher, member checks, data saturation, and application of Meleis' (1996) criteria for culturally competent research. Member checks were conducted in two primary ways: (a) checking with participants during data collection and analysis to clarify responses, and (b) sending results to each participant within their respective groups to verify results twice, two weeks apart. The response rate to the final member check was low with only about seven participants responding but those participants only had positive comments and no disagreements were received.

Findings

This study purported to determine attitudes and preferences for care regarding disclosure and conflict resolution in the last days of life. Data analysis process revealed that it was close to impossible to separate participant responses into attitudes vs preferences for care. As the researcher was immersed into the contexts and worlds of the participants during both data collection and analysis, there was no doubt that at least the vast majority of the time, attitudes reflected preferences for care, and any exceptions will be noted. Findings are organized according to themes and sub-themes for both disclosure and conflict resolution for each of the three groups. However, after more in-depth review it became apparent that the major group themes actually transversed all three groups. In the interest of simplicity and ease of understanding, the findings are presented according to these overriding themes. Any outliers that were identified in one group but not in the others are also discussed.

Overriding themes that captured participant perspectives regarding disclosure included the following: Protecting, Incongruity and Changing Times. Conflict resolution themes included the following: Honoring the Decision Maker, and Consensus Through Negotiating. Table 2 depicts disclosure and conflict resolution themes for each group as well as the combined, overriding themes that transversed all three groups.

Table 2. Themes for Disclosure and Conflict Resolution

	<u>Chinese</u>	<u>Vietnamese</u>	<u>Japanese</u>	<u>Combined Themes</u>
Disclosure	Conditional Truth	Hiding the Truth	Values of Truth	Protecting
	Hiding the Truth	Revealing the Truth	Incongruences	Incongruity
	Absolute Truth	Unity	Protecting	Changing Times

	Preparing Incongruity and Uncertainty	Minimizing Autonomy	Changing Times	
Conflict Resolution	Family Role	Dealing with Conflict	Honoring the Decision-Maker	Honoring the Decision Maker
	Negotiation	Making the Decision	Advocacy	Consensus Through Negotiating
	Giving In	Owning the Decision		Advocacy
	Pro-Action			
	Emotional Character			
	Discord			
	Spiritual Guidance			

Disclosure

Three major themes represented participants' beliefs about disclosure: Protecting, Incongruity and Changing Times. Protecting includes participants' statements about always telling the truth, truth being told under certain conditions, and hiding the truth for certain reasons. Incongruity reflects responses similar to when a participant believes in disclosure for self, but not for others. Changing Times dealt with remarks about how attitudes and practices about disclosure are changing both in the homeland and in the US. Statements by three participants regarding uncertainty dealt primarily with intuitive knowledge about one's condition or being unsure as to what they wanted or would do regarding disclosure. This was considered worth mentioning as part of the findings but not as a major theme.

Protecting. All three groups believed to at least some extent in full disclosure for reasons of autonomy. Protecting in this sense included disclosure to protect them from not being prepared for the "inevitable." A Japanese male expressed concern about cheating people out of the opportunity to live life the way they desire and stated that people "need to know" (so they) can live the way they want to live in the last part of their life." The perception that full disclosure ultimately brings peace was expressed: "Possible reasoning (for not telling the truth) is you will shock them and they will die faster or something...but...not true...they will come to terms with things and they die more at peace." Similar to the Chinese, most of the Vietnamese participants wanted the truth for themselves but not as much so for loved ones. They were also adamant that when full disclosure occurred, the person be told the truth by family only, not a health care provider. Several statements related to reasons for absolute and unconditional disclosure by and to Chinese parents, grandparents and other family members included the following: preparing for the "last days"; honoring wishes for the truth despite the desire to not tell the truth; and children should know the truth. A Vietnamese participant was emphatic about disclosure: "...tell them the truth in order for them to realize that their days are ending, and they would be preparing their soul." The Chinese and Vietnamese felt that with disclosure came the responsibility to first "prepare" the person for the truth. The Chinese participants believed that preparing the person was felt to offset the "shock" the person would feel in knowing the truth, and family would progressively "drop small hints" in order to prepare the person for the truth. Preparing the person for the truth by and to parents, grandparents and

other family members included progressive disclosure with a little bit at a time. A Chinese participant stated this was what she wanted so that she could gradually prepare. A Vietnamese female stated “(the person) ... has a countdown and preparatory before death...before you die you want to do some things...prepare.” This same woman also acknowledged that despite possessing values of her homeland country, “it’s better here” in terms of acknowledging a patient’s autonomy and helping them to prepare for death.

Conditional truth was the most dominant subtheme across the groups and included conditions that permitted disclosure of a terminal diagnosis. If these conditions were not present, the truth about a terminal illness or poor prognosis was most likely not disclosed. One Chinese participant said it depends on the “open-ness” of the family. Conditions varied under which Chinese participants reported they would tell the truth. One who stated her grandfather was not told the truth, but she may “tell truth to grandmother—she have strong mind...but never (if) young.” Another remarked “for some, better no truth ... (they may) “collapse ... and situation just is worse.” Others echoed these sentiments about disclosure if the parent or grandparent had a strong mind or strength in general. One stated four years ago she would not tell the truth, but now would but only because of life experiences and states she is independent of Western influence. Other conditions for disclosure included: high tolerance (low tolerance equals to not being able to “take the truth”); being closer to death; if the patient asks for the truth (this was inconsistent: it was about equally split between some would and some would not tell the truth if the person asked); educational levels (the less educated, the more family listens to physician’s advice to not tell the truth); passing a “test” for strength for disclosure; and presence of family when truth is told. Vietnamese participants reported that most of the time, the truth was to be told only under certain conditions such as, when the person wants to know and it might make them “feel better”; younger ages; strong endurance; time for preparing; spiritual reasons; perception of intuitive knowledge of the truth; truth is “logical,” and fulfillment of last wishes. Very little was said about conditions under which awareness of one’s prognosis would be revealed, but the general consensus among Japanese participants was that only family members should make decisions about disclosure, since they know the patient better than health care professionals. Disclosure in the Japanese population would also “depend on the individual” in terms of strength and ability to understand.

Hiding the truth included statements by participants that reflected no truth would be told under any circumstance. This applied mostly in reference to parents or grandparents either withholding the truth to another, or not being told the truth by the participant. Several reasons for hiding the truth in the Chinese group included: protecting the loved one from “shock” and worry was the most popular reason. One stated “if we tell him the truth, he is going to be shocked, and it is not going to be good for his health, because when people get shock and then it’s going to facilitate the death.” In fact, one participant stated that he would give her “fake evidence” and “fake hope” to convince her of the “lie.” Other reasons included: fear of dying sooner due to “giving up”; knowing the person’s inability to deal with reality; not telling the truth brings family peace because it is a “good lie”; potential for causing a negative attitude about death; sense that death is one’s destiny; and fear of liability of HCPs due to patient dying sooner. One Vietnamese participant talked about a friend’s (in the US) mom with colon cancer who received surgery and chemotherapy, but never knew the purpose of the chemotherapy: “they just tell the patient that it is like a prevention treatment...” An older Vietnamese male who had been in the US for 15 years stated through his interpreter that he “...wouldn’t want his child to be sad. He would want his child to keep being happy and hopeful.” He later added that suffering as a parent is enough and that “you wouldn’t want to see your child suffer.”

Three participants would not tell their spouses the truth. In addition, participants talked about using strategies to hide the truth from loved ones, the importance of always talking to the family first (likelihood of family anger if this does not happen), and one participant stated

that this is common practice, even in the US. Japanese participants focused on fear of the truth. Disclosure would not be allowed if the perception of fear is linked with knowing the truth, that it is “better” for the patient, and at times, a loved one, to not know the truth. However, most of the reasons given for not telling the truth supported the conviction that a person may not be emotionally stable, including responses such as “too weak,” “scared” or “fears death.” Findings also support that refraining from disclosure helped the family because the family “is not prepared for that.” Situations for hiding the truth in Vietnamese participants included family members who were “close;” providing protection; perception that a person does not want the truth; authoritative conditions, such as the “man of the family”; and the sense that without the truth hope will prevail. The notion that the truth is not a logical approach, such as “why would I tell?” was also identified. Moreover, not wanting to make a person feel sad, and seeing death seen as destiny was also expressed by Vietnamese participants.

Incongruity. Incongruity reflected statements that truth would not be told even though there may be the desire to know the truth, or, the person may have intuitive knowledge about the truth but is still not told the truth. In other words, although a person’s intuitive thoughts may be correct or their desires to know the truth are known, a different course of action is taken. For example, a Vietnamese participant acknowledged “You couldn’t lie because the doctor’s reaction ... be obvious ... (the person) eventually realize the truth.” An underlying subtheme of minimizing one’s autonomy included many statements about not recognizing a person’s autonomy when they wanted the truth but were not told the truth. These types of actions were more prevalent in the Vietnamese group, compared to the Japanese or Chinese group. It is important to note that autonomy was on occasion honored, as one Vietnamese participant stated “...that’s her body.” Lack of autonomy was most evident in statements that reflected little or no input from the patient being necessary. For example, one participant stated, “...when we (speaking of the Vietnamese culture) decide something the family decide, not the patient.” Three Vietnamese participants alluded to being uncertain with statements about the ethical dilemmas this can cause as well as not knowing for themselves what they would want when that time comes.

Some Japanese responses reflected that some people do not tell the truth to loved ones, even when the person really wants to know. Some participants also express that even when the truth is held back, there can be an intuitive knowledge about the truth that causes anxiety and panic in loved ones. A Japanese man stated that his father would not tell his mother the truth, even when she asked to know. According to him, his father’s perception about avoiding disclosure was “...a cultural thing.” Six Chinese participants indicated this theme through their discussions, with two believing their children would not tell them the truth even though they believed they may want the truth. About half of the Chinese participants stated that if truth was requested, it would not be honored. Inconsistencies also arose across all three groups regarding participants’ thoughts about what their spouses would do regarding disclosure for their children.

Changing times. The last theme, Changing Times, was not dominant but warranted inclusion in this report, and could be considered a qualitative outlier. This theme reflected ideas and trends prone to full disclosure and were stressed by Japanese participants almost exclusively. For example, influences of medical-related media and medical television dramas depict disclosure as positive. Some younger participants, including those who have been in the US a very short time, embraced disclosure for children and adults, establishing a potential generational divide. Although several Japanese participants acknowledged the evolving trend of disclosure within their respective culture, they demonstrated concern that many Japanese people continue the practice of non-disclosure about a poor prognosis. A Japanese participant

shared the same belief of other study participants, maintaining that although trends are changing, about half of persons living in Japan still do not know the facts about their own prognoses. Some Japanese participants also expressed that disclosure in the US may not be as big of a problem as it is in Japan, presumably because of US policies that facilitate one's right to know about their conditions and options for treatment, and therefore disclosure is more likely to occur in the US.

Conflict Resolution

Overriding themes that transcended all three groups regarding conflict resolution when disagreements occurred regarding decision-making for loved ones included: Honoring the Decision Maker, Consensus Through Negotiating, and Advocacy. Other themes particular to specific groups will be discussed as "outliers" of qualitative themes. When a hypothetical scenario regarding disclosure was presented, some participants acknowledged extreme difficulty with how they would proceed with decision-making if conflicts arose, but most were decisive about the decision-making process.

Honoring the decision-maker. This theme included variations in the family role as the "final" decision-maker. Family roles in the Japanese group included the father, the eldest son, the mother (or eldest son if the dying person was the father), eldest brothers of the mother or father, and family members who were geographically closer than the primary care provider. A female participant stated that "...usually the spouse have strong decision" and that if spouse is deceased, the oldest child would make the decision since "...the oldest child is supposed to take care of the parents in my country." Another participant stated that he would not intervene in a conflictual decision because "...it is not my right ... younger sister cares for them." In some cases, if the father were the patient, then the mother would defer decision-making to the children. One of the Chinese participants indicated that according to Chinese culture it was proper to always ask the father first, then the oldest son. According to many participants, in the absence of the father the oldest son would make the decision for their family. One stated, "We value son better than daughter," while another responded that in her culture, "If you want to be a good woman, you obey your husband" and "if your husband dies, you obey your son." In the absence of an older son, the oldest daughter or sometimes the mother would make the decision, depending on the mother's preference. Another common response was that the spouse would make the decision for the other spouse, except when the mother defers decision making to an oldest child. Some statements were made by the Chinese that alluded to "giving in" which refers to decisions being made by the designated decision-maker, even when the participant or family member disagrees with the decision. The Chinese also felt that a potential decision-maker's emotional character was important, especially when referring to children making the decisions who were not necessarily the oldest, but the strongest or most emotionally stable. At times the decision would also be made by the relative living geographically closest. These types of decisions in the Vietnamese group were usually by a designated person in the family, and this sentiment was not a popular one. One participant shared that gender, family role, or age was linked to the decision because "we are all children of the parents." Most commonly, the final decision maker was the spouse, followed by the male in the family, and if the male was a child it would be the oldest male, then followed by oldest daughter. A female Vietnamese participant stated, "Remember that in Asian culture the parents are not like over here where they make individual decisions...so man of the family usually makes those decisions." Another participant indicated that the person in her family who was the major care provider would be the decision maker.

Consensus through negotiating. This was a theme that represented family members proceeding through discussions and reaching consensus. Some Japanese participants reported that one person was not responsible for making the decision among the children, and if disagreement occurred, they would talk among themselves until a consensus was reached. They negotiated anytime there were family discussions, and decisions were ultimately reached by talking it out, consensus building, persuasion, or simple majority. Among the Chinese group, negotiation and giving in were dominant sub-themes. However, like the Vietnamese, they were more interested in averting conflict through being proactive and determining the person's wishes in advance. Common strategies expressed by the Vietnamese group were to analyze the situation, "talk it out" with family members, discuss it with individuals who knew the person the best, and to recognize the person's autonomy by attempting to determine what that person would want. One Vietnamese female stated her father would disagree with her about telling her mother the truth if her mother requested it (and only if she requested it), but "he (is) sensible ... I get him ... (to) walk in my mom's shoes."

Advocacy. Conditions under which a decision would be made based on the dying person's wishes or other characteristics and conditions reflected this theme. For example, the Japanese felt that if the patient's wishes were heard or written, then those wishes would be honored most of the time. Empathy with patients who had terminally ill conditions and conditions of significant intractable pain were also circumstances where life sustaining measures would be discontinued. Three Japanese participants also identified fear of death as another condition, remarking that knowing that death was not feared was influential in decisions to discontinue life sustaining measures. The Chinese and Vietnamese groups spoke the least about the advocacy theme as defined here, but two of the Chinese participants mentioned that decisions were sometimes made through empathizing with the dying person and respecting the decisions of others. In addition, a Vietnamese participant stated that she knew her wishes would be honored because her children recognized her as a "strong woman," and she informed her children of her wishes so there would be no conflict. A related sub-theme for the Vietnamese crossed the lines of the Consensus theme in that consideration of the person's autonomy would be incorporated into the process.

Thematic outliers not crossing all three groups were identified, and due to their dominance in a particular group, they are worthy of mentioning. Discord and spiritual guidance were only present in the Chinese group and not present in the other two. Discord was a theme moderately apparent throughout participant responses and referred to comments, conflicts, or anticipated conflicts within the family. Spiritual guidance was identified in participants' comments about using prayer as part of the family discussion, or as a single strategy for the decision-making process. Avoiding conflict by "not talking about it now" until forced to do so was fairly common among the Vietnamese participants. Pro-action was discussed by Chinese and Vietnamese participants who spoke about the importance of planning and communicating in advance.

Discussion

Non-disclosure is referred to by Glaser and Strauss (1965) as "closed awareness" when the patient has no knowledge of terminality and by Collis (2006) as not telling the truth but at the same time not telling any lies. While closed awareness, or hiding the truth was more common in this study, statements regarding disclosure only under certain conditions were expressed. Most of these reasons are reflected in the literature, and dealt also with total non-disclosure in order to protect the person, such as, avoiding a negative impact, being of strong character, and not losing hope (Begley & Blackwood, 2000; Glaser & Strauss, 1965; Hancock

et al., 2007; Kazdaglis et al., 2010; McLennon, Uhrich, Lasiter, Chamnes, & Helft, 2013; O’Kelly et al., 2011).

The Protecting theme captured the range from total non-disclosure to full disclosure. While Japanese, Chinese, and Vietnamese groups in this study all expressed some level of interest in wanting truth for themselves, the responses from the Japanese group reflected stronger tendencies toward protecting one’s autonomy through full disclosure. This self-determination is similar to Western principles of autonomy which are highly valued in the US. (Bowman, Singer, & Richard, 2007). However, the Protecting theme in this study reflected other views that valued non or partial disclosure. Other cultures tend to practice paternalistic deception (Collis, 2006) in order to value beneficence and non-maleficence (Searight & Gafford, 2005) through limited or non-disclosure, and thereby “protecting” the patient from potentially harmful news. The concepts of collectivism, familism, and filial piety arise when addressing Asians and health care decision making and disclosure. Filial piety, communalism, and familism have been shown to cluster closely with each other and have been identified as “family/relationship primacy” which was very closely related to collectivism, but was weakly related to independence (Schwartz et al., 2010). Asians typically have a collectivism form of decision-making that tends to be less individualistic and more family oriented (McCabe, Wood, & Goldberg, 2010; McLaughlin & Braun, 1998) that signifies absolute loyalty to the immediate and extended family (Carteret, 2011).

The Protecting theme is also supported by Chinese cultural beliefs which maintain that adverse emotional reactions to knowing the truth can impair an individual’s health (Bowman et al., 2007). Disclosure in Chinese families was congruent with traditional societal roots, maintaining influences of Confucianism in most aspects of daily Chinese life (Lin, Pang & Chen, 2013). Lin et al. (2013) argued that Confucian philosophy still plays a part in “patients compromising their own preferences for the common interests of the family” (p. 276). Patients continue to rely on family members as “liaisons for information” and as personal “advocates” (Lin et al., 2013), and family is always consulted prior to final decision-making regarding patient care (Cong, 2004). As a result, family and patriarchal roles are major components in conflict resolution with regard to health care decision-making and validates the powerful effect of “family” on the “individual patient” (Cong, 2004; Lin et al., 2013).

As reflected in this study through the Protecting theme and is similar to the Japanese and Chinese cultures, Vietnamese beliefs about disclosure revolved around the principle of familial decision-making. Vietnamese cultural beliefs affirmed that hiding the truth can provide protection and enable individuals to maintain a sense of hope. Although very few scientific studies exist regarding Vietnamese disclosure, Lasky and Martz (as cited in McLaughlin & Braun, 1998), maintain that medical decision-making in the Vietnamese culture is influenced by the Buddhist belief of karma, a fatalistic attitude concerning life, death, and fate. Advance care planning is perceived as unimportant and saying “no” to a physician is perceived as disrespectful (McLaughlin & Braun, 1998). Dinh et al. (2000) acknowledge that attempts to avoid conflict are common among Vietnamese people, however, if conflicts do arise, they are typically settled by the family’s oldest male, or possibly a strong influential female. The notions of “not talking about it” and “giving in” to avoid conflict are reflective of Buddhist influences (Dinh et al., 2000) in the Vietnamese culture. Most Vietnamese patients accept that family members safeguard their best interests (Fan & Li, 2004).

The Incongruity theme in this study was supported by “suspicion awareness,” when the person suspects a poor prognosis but it is not acknowledged; this was identified by Glaser and Strauss (1965) and was discussed by participants in all three groups within the context of preparing loved ones for the truth. Glaser and Strauss discuss how a patient may progress from “closed awareness” to one of suspecting due to several reasons: the patient may be knowledgeable about health care, awareness of acute changes, lengthening stay in the acute

care setting, seeing an alarming term, that is, cancer, and health care providers and family members dropping “hints” or “cues” that something may be “more radically wrong than...thought” (p. 49). Glaser and Strauss assert that a myth exists among some health care providers that a patient must know they are dying due to multiple, incidental, and inadvertent activities that surround a patient in an acute care setting. Kazdaglis et al. (2010) state that disclosure is complicated which somewhat validates why sometimes beliefs are not put into practice. Saying one thing and doing another was reflected in this study and has been demonstrated in the literature (Hancock et al., 2007). For example, some participants discussed the value of disclosure and that they would want disclosure for themselves, but they would not practice full disclosure to a loved one.

This study elicited the theme of Changing Times which was supported by participant data supporting a trend toward more disclosure, and evidence of this has been reported in the literature (O’Kelly et al., 2011; McLennon et al., 2013). Despite this trend, McLennon et al. (2013) report that disclosure is one of three major ethical issues that oncology nurses face today, and nurses are conflicted about this issue, both personally and professionally. However, controversy and ambiguity continues to exist nationally and internationally as to patients knowing the truth about terminality and the obligation by health care professionals for full disclosure (Blackhall, 2013; Collis & Sleeman, 2013; Glaser & Strauss, 1965; Kazdaglis et al., 2010).

Scrutiny of the scientific literature and evidence from this study have demonstrated that conventional cultural standards of Asian groups are still evident in modern day society, regardless of previous socialization to Westernized practices. In the Japanese, Chinese, and Vietnamese cultures observed in this study, EOL decision making practices maintained a hierarchical family approach. Family served as an instrumental factor in the decision-making process, clearly demonstrating a demarcation between Western societal norms and Asian standards. If Western practitioners are to provide care that is respectful of Asian cultural beliefs, yet maintain the US ethical norm of autonomy to protect and promote patients’ medical rights and decision making, consensus must be reached about how to best approach disclosure practices and manage conflict resolution to maintain quality care that benefits both the patient and the family.

Implications for Health Care Professionals

Care providers must recognize that within society’s multicultural-mix, not all patients have the same personal convictions and providing care requires flexibility in the approach to disclosing patient information (Searight & Gafford, 2005). Due to a wide variety of cultural convictions, US health care providers are challenged with maintaining ethically competent care within a society of multicultural needs. Culturally competent assessments must be conducted that include thoughtful and ethical solutions to patient and family needs, especially with regard to EOL decision making. However, it should be noted that the issue of disclosure continues to be a global debate (Blackhall, 2013; Collis & Sleeman, 2013; McCabe et al., 2010). Autonomy regarding disclosure can be conceptualized as empowering, but it can also be burdensome in some cultures (Blackhall, Murphy, Frank, Michel, & Azen, 1995), and though it is a right, Sokol (2006) asserts it is not an obligation. One may ask to what extent do we impose this right to those of other cultures who do not share Westernized beliefs about disclosure? Blackhall et al. (1995) acknowledges the existence of a wide diversity of beliefs regarding disclosure within and among ethnic groups, and this study demonstrates that over 20 years later this continues to be true. They also suggest that emphasis on autonomy for a family centered model of decision-making, as this study reflected, could disrupt family harmony which carries a higher value than that of individual autonomy. Sokol (2006) believes it is a breach of integrity to mandate

disclosure in instances that it goes against cultural norms and emphasizes the importance of skilled communication training for health care providers to apply in related discussions with patients and families. These communications include proactive determination of family and patient preferences for disclosure and decision making. Blackhall et al. (1995) argue that while autonomy recognizes respect for persons, the process of living and dying occurs within a complex web of interrelationships, and as such, insistence on patient autonomy counteracts the "...deepest values of the patient ... (and) ... may be a another form of the paternalistic idea that 'doctor knows best'" (p. 825).

While self-selected participants indicated they were comfortable talking about dying, it is not known if those who were uncomfortable addressing this topic would have reflected similar beliefs and preferences for care. For example, one participant expressed "is scary—end of life" while signing the informed consent. Also, this study took place within a 250-mile radius of the northeastern part of Texas. Caution should be used with generalizing findings beyond this population sample. Since no other studies could be located regarding the target population in this geographic location, findings may be useful in a variety of health care settings.

Conclusions

Globalization and multiculturalism create major challenges for health care professionals (Nie, 2012), especially within the US regulatory statutes, to effectively meet the needs of Asians living in the US with regard to disclosure of "bad news." This study has demonstrated how the impact of Confucianism and family collectivism have influenced many Chinese and Vietnamese people, and to some lesser extent Japanese people, to see disease as a disrupting force towards the harmony of family life. On the other hand, practices of withholding information are seen as a restriction on the patient's autonomy in Western culture. In the US, health care providers are expected to tell their patients the truth. This stark variance is a testament to the difference in the field of healthcare between these two cultures. The strong value placed on family compels the Asian culture to care for their ill family members at all costs. This includes the extreme practice of not disclosing family members' diagnoses.

Though acculturation may influence Asians to be more influenced by Western thinking about disclosure, health care providers must be cognizant of the differences in belief systems that exist among Asians living in the US today. Asian Americans have deeply rooted cultural values and beliefs that can clash with Western beliefs regarding EOL care (Chew, 2012), potentially causing conflicts that can further complicate challenges associated with EOL issues for patients and their family members. Chew (2012) asserted that family-centered decision-making is still dominant in Asian American households because of the fundamental belief that it eases patient burden. Xue, Wheeler, and Abernathy (2011) point out that US physicians are obligated to tell the truth but must learn to approach doing so in a strategic manner. US health care providers must recognize and synthesize multi-ethnic and cultural beliefs into practice, to promote culturally competent and ethically sound care within the US health care system.

This study reveals disclosure beliefs of Japanese, Chinese, and Vietnamese participants who live in the US that reflect differences in US norms. It informs health care providers of their preferences for care and considers different patterns of health care decision making regarding conflict resolution for EOL decision making from Asian cultural perspectives. These findings offer health care providers talking points to consider during EOL discussions with patients and their families, but the most important "take home" message is for health care providers to have a heightened consciousness of the diversity of beliefs, even within the same culture. While there were similarities among the three groups, differences existed also. Health care providers must avoid stereotyping and be very sensitive to the unique and individualized needs of their patients. Strongly recommended are studies to test interventions for best practices for

addressing disclosure and conflict resolution among Asians and other diverse ethnic groups who live in the US.

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