

What Matters Most at the End-of-Life for Chinese Americans?

Gerontology & Geriatric Medicine
Volume 4: 1-7
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DOI: 10.1177/2333721418778195
journals.sagepub.com/home/ggm



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Abstract

Background: To provide optimal end-of-life (EOL) care in the Chinese American population, we need to have a better understanding of what matters most at EOL from their perspective. Experiencing a “good death” at the EOL is the optimal goal of palliative care. Studies show that the meaning and description of good death varies across cultures in different populations. In the United States, Chinese Americans comprise the largest Asian demographic. **Aim:** To describe EOL wishes, which define a good death for Chinese Americans. **Method:** Qualitative study using focus groups. A convenience sample of 60 Chinese Americans was recruited from a community organization in Maryland. Ten focus group discussion sessions were conducted. **Results:** Wishes at the EOL that defined a good death for the participants in this study included being pain-free, not being a burden to family, being with family, having a trusted physician, maintaining dignity, and prayer. **Conclusion:** A good death is a complex concept. What matters most to patients at the EOL differs depending on their cultural background. When caring for Chinese Americans, a comprehensive EOL care plan should include cultural considerations in addition to physical, psychosocial, and spiritual needs.

Keywords

end-of-life wishes, good death, Chinese American, culture, death and dying

Manuscript received: March 21, 2017; **final revision received:** November 23, 2017; **accepted:** January 4, 2018.

Background

End-of-life (EOL) care is the support and care provided at the terminal phase of life. Experiencing a good death is the optimal goal for persons dying from any cause. It is essential that family members and health care providers understand how to best incorporate the values and wishes of the dying individual while providing EOL care. However, limited research explores what constitutes a good death, and there is not a consensus on the definition of this term (Meier et al., 2016; Cheng et al., 2008). In 1997, the Institute of Medicine suggested that a good death was one that was free of unnecessary stress and suffering, where individuals received care that was aligned with their EOL wishes, cultural needs, and expectations (Institute of Medicine, 1997). Weisman (1988) defined a good death from four components: awareness, acceptance, propriety, and timeliness. Steinhauser and colleagues concluded that a good death included eight themes: mental awareness, funeral arrangement, life completion, not a burden to family, not a burden to society, help to others, peace with God, and praying (Steinhauser et al., 2000; Steinhauser et al.,

2001). Although studies show that the meaning and description of a good death vary across cultures in different population groups and individuals (Shin et al., 2011; Steinhauser et al., 2000), few studies explore what a good death means to the Asian population (W. Chan & Epstein, 2011; Cheng, Dy, Hu, Chen, & Chiu, 2012). No studies were found that specifically defined a good death for Chinese Americans (Hales, Zimmerman, & Rodin, 2010).

Chinese Americans represent the largest proportion of Asian Americans in the United States; a group that is rapidly growing (U.S. Census Bureau, 2015). Barriers to exploring the concept of a good death in Chinese individuals include cultural beliefs and moral concerns. In traditional Chinese culture, discussion of death and

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dying is taboo and thought to bring bad luck to one's family. Initiating a discussion about these topics is traditionally considered disrespectful. In managing EOL care of parents, a good and "filial" child is expected to do everything to prolong their parents' life (Lee, Hinderer, Kehl, 2014; D. Wong, 2013; Zou, O'Conner, Peters, & Jiejun, 2013). These cultural and moral concerns may explain why limited studies about the experience of a good death exist in Chinese populations, both globally and in the United States. The lack of knowledge related to defining and measuring a good death hinders the refinement of quality EOL care for Chinese Americans. This pilot study aimed to describe EOL wishes that matter most to Chinese Americans, ultimately to shed light on the definition of a good death for Chinese Americans.

Method

Design

A qualitative focus group method was used.

Instruments

Three items were used to collect demographic data. The concept of what a good death means was explored using the Go Wish Card© game (Coda Alliance, n.d.). The sensitive, and perhaps unfamiliar, nature of discussing death and what one might experience as a good death for Chinese Americans led the research team to use a gaming approach to help make the context of discussions less uncomfortable and thus more approachable. The Go Wish Card© game was a structured, conversational game to explore EOL wishes in a nonthreatening manner (Potthoff, 2015). The Go Wish Card© game was previously used in inpatient and community settings (Lankarani-Fard et al., 2010; Menkin, 2007). The game contains 36 cards, each representing items recognized as important at the EOL. To play the game, the player sorts the importance of each card until he or she has ordered the cards to demonstrate what is most important to that individual. The cards include specific preferences relative to physical, psychosocial, and spiritual aspects of EOL care (Coda Alliance, n.d.). For this study, we distributed a list of the Go Wish Card© statements instead of cards.

Ethical Considerations

This study was approved by the institutional review board (IRB) of the University of Maryland, Baltimore (HP-00058059).

Participants

A convenience sample of 60 participants was recruited from a large Chinese community organization in

Maryland. This center has about 1,000 regular members. Potential participants were recruited over a 3-month time period. Community center leaders sent emails and newsletters to recruit participants. Participants contacted the research team to join the study. All participants were self-identified Chinese Americans, aged 18 years or above, and spoke either Chinese or English. Participants were divided into 10 focus group discussion sessions based on availability and language preference. Most groups had seven participants; only one group had two participants because of last minute cancellations or schedule changes.

Procedure

The purpose of the study, risks, benefits, and voluntary nature of the study were explained to participants prior to study participation. Verbal consent was obtained. The procedure for playing the Go Wish Card© game was presented to participants. A list of the items from the Go Wish Card© game were presented in both Chinese and English to participants in the focus group. Participants were asked to sort this list and rank the top five items that were most important at EOL. Participants were given private time to work on their individual list. After everyone had completed their list, we invited them to share their list and explain why they chose those items on their list. The Go Wish Card © list was used as a reference; participants could add and share things that were not on the original Go Wish Card©.

Focus group discussion sessions were conducted by the first author in 2013. The first author is a native Chinese palliative care researcher who is fluent in Cantonese, Mandarin, and English and has experience in conducting qualitative research. Focus groups were offered in all three languages; however, none of the participants preferred English. Nine focus groups were conducted in Mandarin and one group in Cantonese. All focus group sessions were held in a conference room at the Chinese community center. All sessions were audio-taped for translation and transcription. Each session was about 2 hr. Field notes were made during the focus group discussions.

Data Analysis

Descriptive analysis was used to summarize the results of the ranking of items from the Go Wish Card© game. NVivo software was used to organize the data. Responses to the core questions and Go Wish items were analyzed, guided by the thematic approach. Thematic analysis is preferred to order and structure qualitative data (Marshall & Rossman, 1999; Van Manen, 1990). First, the authors of the manuscript read all transcripts independently, several times, to become familiar with the data. Next, data were organized into categories and themes that contained descriptions of important items at EOL. A team

Table 1. Frequency of Items That Being Ranked as the Top Five and the Top Priority at EOL (N = 60).

Value listed on card	Ranked in top five priority n (%)	Ranked as the top priority n (%)
To be free from pain	42 (70)	24 (40)
Not being a burden to my family	39 (65)	6 (10)
To have my family with me	27 (45)	4 (6)
To trust my doctor	21 (35)	3 (5)
To maintain my dignity	20 (33)	1 (2)
To pray	20 (33)	8 (13)

Note. EOL = end of life.

approach was used to analyze the qualitative data, and discrepancies were discussed to reach consensus.

Rigor

This study applied the four criteria from Guba and Lincoln (Lincoln & Guba, 1985; Morrison-Beedy, Cote-Arsenault, & Feinstein, 2010) in establishing the trustworthiness of the results. In addition, we applied a checklist for reporting focus group data to address important details of this study (Tong, Sainsbury, & Craig, 2007). Trustworthiness of the results was increased as we included language that participants preferred to facilitate expression, discussion, and sharing of their opinions without needing an interpreter. We encouraged quiet participants in the group to share and ensured everyone in the focus group had an opportunity to voice opinions. We provided detailed descriptions of the study design, methods, and setting for replication. We reported quantitative ranking results with qualitative descriptions for readers to decide if the results might be transferred to other settings. All transcripts were prepared by the same professional consultant company to decrease discrepancy in transcription. We used a team approach in data analysis to decrease personal bias in interpretation. We conducted multiple sessions in the same setting and used a procedure guide to maintain consistency. Data saturation refers to adequate data being collected to interpret the meaning of the item selected (Popay, Rogers, & Williams, 1988).

Findings

The sample had a mean age of 53 years ($SD = 18.33$), age ranged from 29 to 79 years. About 25% of the sample was male. Half of the participants (50%) had at least one chronic disease that required regular physician visits and prescribed medication. In this study, the wishes considered most important about EOL and thought to constitute a good death, of priority, were as follows: (a) to be free from pain, (b) not being a burden to my family, (c) to have my family with me, (d) to trust my doctor, (e)

to maintain my dignity, and (f) to pray (Table 1). Several items contained in the Go Wish Card© game were not ranked or selected by participants in the focus groups and are described below.

Physical Needs

To be free from pain. Approximately 70% of participants voted pain-free as one of their top five priorities related to a good death, and 40% of them stated that being free of pain, a physical aspect of care, was the most important wish at their EOL. The discussion about pain focused on physical pain described as a feeling of suffering and of being tortured. Participants believed pain came not only from illness and disease, but also could be from treatments intended to save or prolong life. Regardless of intent, being pain-free at the EOL was very important to participants. Specific statements about pain included,

If there is a lot of suffering (to survive), then I would choose to give up.

If when it comes to a situation of suffering, then there is no need to (use) rescuing measures. Let me die.

To trust my doctor. In this study, 35% of participants mentioned that the physical need of having a trusted physician was one of their top five priorities of care related to a good death, and 5% of participants said that a trusted physician was the most important wish when facing EOL. A trusted physician was described as a person who the participant could rely on, and had confidence in, related to the decisions made about their medical treatments. A trusted physician had knowledge in medicine, and a caring character for sick patients. Most participants agreed that a trusted physician was particularly important for making EOL decisions and plans. The following statement summarized most of the comments about the benefits of having a trusted physician.

(It is important to) talk in detail with my trusted doctor regarding what I would like to do and the things that need to be clarified.

Psychosocial Needs

Not being a burden to my family. The notion of not being a burden to family, a psychosocial aspect of EOL care, followed by being free from physical pain in importance to the focus group members. About 65% of participants listed this as one of their top five priorities, and 10% of them shared that not being a burden to family was most important to them at EOL. Participants did not want to become a burden to family, particularly to their children. The burdens described included financial, physical, and/or emotional. They did not want family members to spend all their money for treatment if the chance of recovery was low. Participants were afraid that their debilitated status at EOL would require the family to take care of them physically, and the poor prognosis near EOL might cause their family stress and create negative emotions. Some examples are included in the following:

Yes, emotional, financial, and time, burden for all aspects. They (family) have to give a lot. I don't want to become that kind of burden.

I have told our family doctor if the disease requires a lot of care, then just let us go.

To have my family with me. Another psychosocial need related to a good death included having family members present to create a sense of security and comfort. A total of 45% of participants included this as one of the top five priorities, and 6% of participants listed it as the top priority at EOL. Participants defined family mainly as children rather than siblings or other relatives. They expressed that having all children around the deathbed was a blessing. Following was one of the stories they shared.

She wants to live for a few more days to wait to see some of her children who were not there yet. (and wait until) all the children are there with her . . .

To maintain my dignity. Maintaining dignity, another psychosocial need, was ranked by 33% of participants as being a defining characteristic of a good death. About 2% of participants said dignity was the most important item at the EOL. Participants described dignity at the EOL as being treated with respect, showing that they are worthy, and being honored as a human being. Loss of independence at EOL was perceived as a risk of loss of dignity in life. Participants would accept a sudden death to maintain ones' dignity. The following are some examples of the description of dignity at EOL:

She died quickly and didn't give anyone any trouble. She died with dignity.

When you lose your ability to look after yourself, life is meaningless without dignity.

Spiritual Needs

To pray. Prayer, a spiritual need at EOL, was defined as to communicate with their God and seek his help. Of this group, 33% of participants chose prayer as one of the top five priorities related to a good death, the same ranking as to maintain my dignity. Participants about 13% said prayer was their first priority for a good death. Participants shared that prayer was a source of their strength in life, and it would help them to continue the life journey when facing despair. Following is an example of the discussion of prayer:

The most important thing at the time of dying is to know that. . . the Lord helps . . .

Unmentioned Go Wish Card© Items

Of the 36 items in the Go Wish Cards, four items were not ranked by any participant: to have human touch, to be able to talk about what death means, to die at home, and to be able to talk about what scares me. In addition, no participants suggested wishes that were not on the Go Wish Card©.

Discussion

Wishes that define a good death for Chinese Americans at EOL in this study were categorized into three levels: physical, psychosocial, and spiritual needs. Although care priorities of a good death as ranked by participants focused strongly on physical needs, discussions in the focus groups were mainly about psychosocial needs followed by spiritual and physical needs.

Physical Needs

To be free from pain. Among the physical needs at EOL, being pain-free was the top element of a good death in the current study. Lankarani-Fard and colleagues (2010) found similar results using the Go Wish Card© Game in a sample of 133 non-Asian inpatients who also ranked "to be free from pain" as their most important goal at the EOL. This finding was also consistent with studies of Japanese and Taiwanese individuals (Cheng et al., 2012; Miyashita, Sanjo, Morita, Hirai, & Uchitomi, 2007). Pain at the EOL represents not only physical discomfort but a combination of symptoms from physical, psychosocial, and spiritual distress (Rao, 2016; Saunders & Sykes, 1993).

Although being free from pain was important for Chinese Americans in the present study, research has shown that Chinese Americans were less likely than non-Chinese American patients to ask for pain relief (E. M. Wong & Chan, 2008). Enduring pain is considered a positive characteristic in Chinese culture (Tung & Zhizhong, 2014). Chinese patients may view the need for pain medications as a sign of weakness and tend to

keep their pain private (Narayan, 2010). Other barriers to effective pain management include fear of being a bother to the health care providers and family, worry about the side effects of medications, being dependent on medication, and difficulty with English communication (Duke & Petersen, 2015). In the United States, health care professionals could provide reassurance of their intent to offer services, provide adequate medication information, and use an interpreter when caring for Chinese Americans to ensure culturally appropriate care at EOL.

To trust my doctor. Chinese Americans depend heavily on physicians' professional opinions when making health care decisions and prefer physicians to make health care decisions for them (Tse, Chong, & Fok, 2013). It is not surprising that having a trusted physician is one of the priorities for Chinese Americans at EOL. In a Population Study of Chinese Elderly in Chicago (The PINE Study), Dong (2014) found that many older Chinese Americans had high levels of trust in their physicians. Similarly, in a Japanese study with 2,548 individuals from the general population and 513 bereaved individuals, trusting the physician was ranked second among stated components of a good death (Miyashita et al., 2007). Therefore, for most Chinese Americans, a trusted physician relationship is essential in providing quality of EOL care.

Psychosocial Needs

Not being a burden to my family. Participants in this study extensively discussed not wanting to be a burden to family. Many participants expressed that life would not be worth living if it was a burden to their children. The expression of sacrificial love is an example of filial piety, a core virtue in the Chinese culture describing the reciprocal expectations and obligations of caring, loving, and giving in the parent–children relationship (Dong, 2014). This finding was similar to a cross-sectional study of 1,462 participants in exploring factors that were considered important at EOL and found that 89% of participants agreed that not being a burden was very important for them at EOL. However, this study also revealed that only 58% of physicians thought that not being a burden was important to patients (Steinhauser et al., 2000). Another study of 133 seriously ill patients in a hospital, including Caucasians, African Americans, and Latinos, also ranked concern for family burden as a high priority at the EOL (Lankarani-Fard et al., 2010). Likewise, Miyashita and colleagues (2007) found not being a burden as a concern at the EOL. These findings further support the importance of this value to patients and their concerns for their loved ones. Knowing the priorities and values of patients, which may vary from those of providers, will facilitate a care plan that is in alignment with their wishes.

To have my family with me. In the current study, being with family at the EOL was a key element to a good death. In contrast, a systematic review of studies related to top priorities for quality EOL care in a predominantly Caucasian sample did not find being with family at EOL as a high priority (Meier et al., 2016). However, traditional Chinese values place family as the foundation of the individual's existence. Having family/children around is a symbol of being blessed particularly at the time of difficulty in sickness and when facing death. It is also an expectation from society that children with filial piety will stay close to serve parents in need (D. Ho, 1996; D. Wong, 2013). Although not ranked as high as in the current study, being with family was also seen as important in the inpatient population in the United States (Lankarani-Fard et al., 2010) and in cancer care in Japan (Miyashita et al., 2007). The concept of family is strongly rooted in Chinese culture. Therefore, the priority of wanting family around at EOL for a good death is an example of cultural and social expectations influencing individuals' decision making that health care providers need to accommodate.

To maintain my dignity. Dignity is an important concept and has been widely discussed in EOL care (Chochinov, 2007). However, it is an abstract concept with no consensus on definition (Dilley & Palpant, 2013), making it difficult to apply in clinical setting. Dignity is a multidimensional concept; it is individualized, value-based, and highly influenced by culture. It has been described as respect, autonomy, empowerment, and communication in the literature (Kennedy, 2016). Dignity, as discussed by participants in this study, was similar to that of a study by Hoy and colleagues (2016), and related to social dignity. The concept of social dignity contends that individuals are able to maintain self-worth, self-control, and respect by others in social interactions (Hoy et al., 2016). In traditional Chinese culture, the concepts of living in a nursing home away from family or needing to be "cleaned up" by others who are not family members are examples of losing dignity for the individual and not fulfilling *Xiao* by their children (A. Ho et al., 2013). The way individuals define dignity will determine their approach to a good death at the EOL. It is essential for health care providers to understand the cultural implications in maintaining patients' dignity at EOL.

Spiritual Needs

To pray. Prayer and spirituality were seen as essential to a good death in Chinese Americans in this study. Likewise, patients at EOL found peace and comfort through prayer (A. Ho et al., 2013). Being at peace with God and to pray were the two most important wishes in a study of 100 cancer patients (Delgado-Guay et al., 2016). A qualitative study of Hong Kong Chinese explored the attributes of spirituality and found comparative results with

existing publications that spiritual needs could be fulfilled when patients were living with purpose and content with the meaning of life here and now. Inner peace from prayer could also be found by forgiving and forgetting the wrong-doing of others (Mok, Wong, & Wong, 2010). Spirituality is a key element in EOL care and culturally sensitive spiritual care is essential in caring for individuals from diverse backgrounds at the EOL (Fang, Sixsmith, Sinclair, & Horst, 2016). The meaning of prayer is specific to each individual. Therefore, a patient-centered assessment is critical when providing spiritual care to meet the cultural needs at EOL.

Unmentioned Go Wish Cards©

Several statements from the Go Wish Cards© were not addressed or sorted at all. These results were comparable with another study using Go Wish Cards© in an inpatient setting (Lankarani-Fard et al., 2010). It is not surprising that participants did not suggest EOL wishes that were not on the Go Wish Card© as this topic is culturally avoided. As concepts of death, EOL, and a good death are not discussed openly among Chinese, this is an area that is in need of more research to increase the understanding and measurement of what might be considered a good death in Chinese Americans.

Conclusion

Understanding what is meant by experiencing a good death is a complex concept. The definition differs depending upon cultural background and disease process (E. M. Wong & Chan, 2008). This study shows that cultural beliefs influence priorities at the EOL such as need for pain management, respect for dignity of the individual, importance of clinician and family involvement for Chinese Americans. A comprehensive EOL care plan for Chinese Americans should include considerations in the physical, psychosocial, and spiritual needs.

Authors' Note

Permission to use the Go Wish Card© was obtained from Coda Alliance.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was funded by the University of Maryland Baltimore, School of Nursing.

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