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Original Research Reports

**Dying and Relational Aftermath Concerns among Terminal Cancer Patients in China**

Yanmei Cao<sup>1</sup>, Wendy Wen Li<sup>2</sup>, Yunzhen Xue<sup>1</sup>

1: Shanxi Medical University, China

2: James Cook University, Australia

## **Abstract**

The need to make sense of one's mortality is of central concern for death studies. We aimed to explore the meaning of aftermath concerns in the process of preparing for dying. Using a qualitative approach, we explored aftermath concerns among 25 participants with terminal cancer in China. Three aftermath concern themes were developed from the participants' narratives: mental concerns about parents, material concerns about children, and spiritual concerns about the self. Aftermath concerns are relational because they are not about what happens within an individual, but between individuals which are manifested within the broader cultural, social, economic and political contexts.

**Key words:** Palliative care, dying, aftermath concerns, filial piety, cobweb self

## **Dying and Relational Aftermath Concerns among Terminal Cancer Patients in China**

All dying patients and their family members, regardless of culture, experience times of sadness and fear as part of coming to terms with the fact that the patient is close to the end of life (Chochinov, 2006). Kübler-Ross proposed what is perhaps the best-known model of dying. In her ground-breaking work *On Death and Dying* (1969), Kübler-Ross drew public attention to the needs of people who are close to death (Parkes, 2013). Based upon her clinical work with the dying, Kübler-Ross developed five stages to conceptualise how an individual responds to a terminal diagnosis (Hall, 2011): Denial, Anger, Bargaining, Depression, and Acceptance (Kübler-Ross, 1969). Although Kübler-Ross devoted attention to the need for older people to reflect on their lives with a sense of closure, completeness, and acceptance so as to maintain a stable emotional condition instead of despair when approaching the end of their lives (Ho et al., 2017), the model fails to address the complexity and diversity of physical, psychological, social, cultural, and spiritual needs experienced by the dying person (Hall, 2011). It also fails to capture the autonomy and dignity that the dying person maintains.

From a dignity conserving perspective, Chochinov (2002, 2006) proposed a model of dignity that he developed from a qualitative analysis of experiences of 50 people with terminal illnesses. According to Chochinov (2002), dying with dignity refers to the maintenance of a person's autonomy at the end of his or her life. Chochinov's model identifies three areas that influence a person's perception of dignity: illness-related concerns; dignity-conserving repertoire; and the social dignity inventory. Illness-related concerns are those that directly result from the illness itself, and threaten to, or actually do, impinge on the dying individual's sense of dignity. These concerns include physical distress, psychological distress, medical uncertainty, death anxiety, and level of dependency. Dignity-conserving repertoire incorporates the aspects of the patient's psychological and spiritual landscape,

which is based on pre-existing personality characteristics and internal resources that influence the patient's sense of dignity. There are eight aspects in dignity-conserving repertoire: continuity of self, role preservation, maintenance of pride, hopefulness, autonomy, legacy of transcending death, acceptance, and resilience. Social dignity inventory refers to social issues or relationship dynamics that enhance or decrease the person's sense of dignity. It comprises five elements: privacy boundaries, social support, care attitudes of other people, burden to others, and aftermath concerns.

Chochinov's (2002) model of dignity is a commonly used framework in palliative and end-of-life care and hospice service research (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Gurdogan, Kurt, Aksoy, Kinici, & Sen, 2017; Ostlund, Brown & Johnston, 2012). Chochinov's model has been adopted to study dignity among dying patients from various groups across cultures (Chochinov, 2002; Hack et al., 2004; Ho, Chan, Leung, Chochinov, Neimeyer, Pang, Tse, 2013; Ostlund et al., 2012). Although the findings from different cultures support the concerns that the Chochinov model identifies, one concern appears to have cultural variation—the aftermath concerns. Aftermath concerns refer to fears or worries that a dying person holds about the impact that his or her death will have on loved ones (Chochinov, 2006; Hemati et al., 2016; Ostlund et al., 2012). When dying persons perceive that their death will impose future burdens or challenges on others, they may develop aftermath concerns (Chochinov, 2002). This form of psychological distress is similar to worries over being a burden to others, but refers more specifically to concerns after the patient dies. For example, aftermath concerns may include anxieties about how their children would fare in the wake of his or her death (Chochinov, 2006).

Ostlund et al. (2012) conducted a systematic review on 39 studies that had used Chochinov's model to explore dignity interventions at end-of-life in Western countries. The researchers concluded that dignity conserving care at end-of-life was consistent with all

concerns proposed by the model, except aftermath concerns. In the review, none of the studies found that patients had aftermath concerns. Similarly, Hall, Longhurst, and Higginson (2009) explored the views on maintaining dignity of 18 residents of nursing homes in the UK and found no evidence for aftermath concerns. The findings suggest that individuals in Western countries tend to worry about the current situation and fear the impact of death on themselves instead of on others. In contrast, Ho and colleagues (2013) found that older terminal cancer patients in Hong Kong were not anxious about death itself, but concerned more with the burden they brought to their families and the difficulties that their families would face after their deaths. These findings suggest that culture may play a role in aftermath concerns among patients with terminal illness.

### **Dying in the Chinese Cultural Context**

As illustrated by Zheng, Guo, Dong, and Owens (2015) in their study of Chinese oncology nurses' experience of caring for dying patients, the patients' understandings of dying reflect, and are influenced by, their cultural values and beliefs. For example, culture shapes the way through which patients understand themselves as dying persons. In the Chinese culture, the self is regarded as a "cobweb self" which is being-in-relation with other people; the self is perceived as integrated within society through the interactions with other people (Yang, 2006). The cobweb self is centrally situated in a dynamic cobweb that connects the patient to other individuals and that links the dying person with the environment and beyond (Li & Forbes, in press; Yang, 2006). Any movements by the Chinese self will lead to reshaping the cobweb and all other people associated with the cobweb (Li, 2013). For instance, when a Chinese patient dies, the significant others in his or her cobweb need to "re-cobweb" themselves. In this way, aftermath concerns can be understood as concerns related to the process of the dying person's significant others re-cobwebbing.

Among all relationships in the Chinese cobweb, the child-parent relationship is considered the most important. This relationship reflects the Confucian tenet of filial piety. Traditionally, filial piety prescribes children's obedience to their parents, attendance to parental needs mentally and materially, and provision of care and support to aged parents (Li, Hodgetts, Ho, & Stolte, 2010). In the Chinese family, filial piety defines a hierarchical relationship between generations, particularly between the parent and the child. As said by Confucius, filial piety is premised on the Chinese cosmology that one's body exists solely because of one's parents. This belief affirms that the greatest debt a child owes a parent is his or her life itself (Li, 2013). In that regard, a child dying before a parent will not be able to repay the debt by fulfilling filial duties to the parent.

Apart from the reflection of the cultural cobweb self and filial piety, aftermath concerns among Chinese palliative patients are also consistent with the Chinese conception of an afterlife that is based on a combination of Chinese Taoism and Buddhism (von Glahn, 2004). In ancient China, there was an important death ritual performed as soon as a person died. The purpose of the ritual was to summon the souls of the dead back to their homes where their living souls still existed. The ritual was driven by the belief that the dead might be brought back to life if the departed soul could be summoned back to the living soul (Yu, 1987). The ritual was established based on the belief that when the departed soul fails to summon back to, and separate from, the living soul, the soul will leave the human body. As a result, life comes to an end. The belief in the afterlife in the Chinese culture fosters the hope for reunion or reconciliation of the dead with bereaved family members (Chan et al., 2005).

In summary, many Chinese people, including those who are at the end of their lives, are reluctant to discuss death with their family members because of the belief that the discussion of death would invoke bad luck for those who are involved in the conversation (Zheng et al., 2015). In the Chinese culture, the concept of dying appears to be framed and

shaped by relationships where dying does not only concern the dying individual but also other people. Such being-in-relations provides an important basis for understanding cultural-based dying and aftermath concerns in Chinese people that may serve as one of the relational tools that enable the dying person to relate to others. Within this cultural context, limited research has explored aftermath concerns among Chinese palliative patients. To address this research gap, the present study aims to investigate the meaning of aftermath concerns in the process of preparing for dying among terminal cancer patients in China.

## Method

### *Participants*

The criteria for inclusion in the study were patients aged 18 years and over with stage III or IV terminal cancer. Thirty-two participants were recruited in the oncology department of the affiliated hospital of a medical university, and the hospice department of an oncology hospital, in a city in the central region of China. Three patients did not complete the interview because of declining physical conditions and four patients dropped out due to early discharge from hospital. The final sample comprised 13 women and 12 men between the ages of 36 and 84 years. Participants were in-patients ( $n = 9$ ) who had relapsed after previous surgery, radiation, or chemotherapy and were highly dependent on the medical care; or out-patients ( $n = 16$ ) with advanced stages of cancer who were receiving palliative care at home. Table 1 shows the characteristics of the 25 participants.

Table 1. *Participant Characteristics*

Pseudonym & Place of Care	Age	Sex	Employment	Marital Status	Highest Education	Cancer types	Diagnosis Time (yrs)	Cardinal Symptom
Lee (Home)	80	M	Retiree	Widowed	Undergraduate	Pancreatic cancer	0.5	Distending pain, weakness
Zhang (Hospital)	60	F	Retiree	Married	Primary school	Gastric cancer	1	Shortness of breath, weakness
Feng (Hospital)	81	F	Retiree	Widowed	Primary school	Ovarian cancer	0.5	Fatigue, weakness
Wang (Home)	57	F	Retiree	Married	High school	Ovarian cancer	1	Distending pain
Deng (Home)	84	M	Retiree	Married	Polytechnic	Bladder cancer	0.5	Distending pain, fatigue



Yang (Hospital)	43	F	Accountant	Separated	Polytechnic	Breast cancer with bone metastases	8	Shortness of breath
Fang (Home)	57	F	Retiree	Married	High school	Breast cancer	6	Distending pain, left paralysis
Zhao (Home)	62	F	Retiree	Married	Primary school	Left lung cancer	2	Distending pain, constant coughing
Huang (Hospital)	83	M	Retiree	Married	Polytechnic	Oesophageal cancer	0.5	Ache and fatigue
Zhou (Home)	64	M	Retiree	Married	Polytechnic	Liver cancer	6	Distending pain
Kong (Home)	66	F	Retiree	Married	Polytechnic	Left lung cancer	6	Sore and ache
Xu (Home)	73	M	Retiree	Married	High school	Right renal cancer	5	Sore and tired
Zheng (Home)	65	F	Retiree	Married	Intermediate school	Uterine cancer	3	Distending pain
Ma (Home)	64	M	Retiree	Married	Intermediate school	Pubic bone sarcoma	6	Dull pain
Wu (Home)	64	M	Retiree	Married	Intermediate school	Oesophageal cancer	1	Pelvic pain
Pei (Home)	61	M	Retiree	Married	Intermediate school	Rectum cancer	2	Piercing pain
Guo (Home)	73	F	Retiree	Married	Primary school	Left lung cancer	0.5	Ache and fatigue
Cui (Home)	36	M	Worker	Married	Primary school	Carcinoma of penis	2	Throbbing pain
Gao (Hospital)	57	F	Retiree	Married	Intermediate school	Breast cancer	6	Fatigue
Tao (Hospital)	80	M	Retiree	Widowed	Primary school	Liver cancer	2	Backache
Luo (Home)	45	M	Retiree	Married	Primary school	Right lung cancer	1	Radiating pain
Sun (Hospital)	68	M	Retiree	Married	Intermediate school	Gastric cancer	1.5	Swelling
Liang (Home)	80	F	Retiree	Widowed	Primary school	Ovarian cancer	0.5	Distending pain
Xie (Hospital)	61	F	Retiree	Married	Polytechnic	Breast cancer	0.5	Visceral traction pain
Song (Hospital)	48	F	Worker	Married	Intermediate school	Right jaw adenoid cystic carcinoma	2	Cough, weakness

## ***Materials***

A semi-structured narrative interview guide in Chinese was developed in consultation with three experts on hospice in China. The first section of the guide facilitated collection of participants' demographic data (such as age, gender, education, and marital status) and health conditions (such as their medical diagnosis, diagnosis time, and self-report cardinal symptoms). The second section allowed exploration of participants' experiences of diagnosis and treatments and the meaning of aftermath concerns. Questions included: "What concerns do you have when facing death?" and "Do you have concerns after you pass? If so, what are the concerns?". The interview guide was pilot tested in three interviews to identify whether

the interview questions were easily understood and suitable for investigating the topics of dying with dignity and aftermath concerns.

### ***Procedure***

Ethical approval was obtained from the Research Ethics Committee of Shanxi Medical University (Ref. 201566085). Potential participants were provided with an information sheet in Chinese. The first author met with the patients who agreed to participate in the study to negotiate the time and place for the interview and answer any questions participants had. The interviews were conducted by the first author or one of the three research assistants in Chinese. The research assistants all had nursing or psychological backgrounds and participated in qualitative interview training (DiCicco-Bloom & Crabtree, 2006) organised by the research team. . The interviews did not proceed until the participants assured the interviewers that they understood the research and their involvement in the research and signed consent forms. The interviews took place between August 2015 and February 2016. The interviews lasted 30-60 minutes and were held at a convenient location, usually at participants' homes or hospital wards. Each participant was interviewed over two or three sittings to avoid patient fatigue. All interviews were digitally recorded with permission from the participants.

### ***Analysis and Quality***

After the interviews were transcribed, a preliminary thematic analysis was carried out in Chinese and then translated into English for further analysis. The thematic analysis included the following steps: 1) research team members familiarised themselves with the data; 2) four team meetings were organised to work collectively to reorganise each participant's narratives collected in the interviews into a single chronological biographical narrative; 3) themes were developed through identifying relational issues of aftermath concern for participants; 4) the themes were reviewed and refined by the research team to

ensure that data within themes were meaningfully coherent, and there were clear and identifiable distinctions between themes (Braun & Clarke, 2006). Data extracts were selected to illustrate the three themes.

Strategies were employed to maximize the quality of data collection and analysis. First, triangulation, in which two (or more) methods were used in data collection and analysis, was employed to add complexity, depth and thoroughness to the investigation to improve the credibility and trustworthiness of the analysis (Flick, 2006). Specifically, data triangulation was achieved through collecting data in different settings and locations (e.g., homes or hospitals) and on different dates. Analysis triangulation was reached through three authors from different sub-disciplines (e.g., clinical psychology and social psychology) working as a team in the analysis process in order to provide multiple perspectives on the data and extracted themes (Li & Tse, 2015).

Second, translation issues, such as the difficulty of finding appropriate English words to capture the meaning in the Chinese language, especially the words reflecting the participants' emotions (Li & Chong, 2012), were carefully addressed in the process of translation. Using the translation methods in Li, Hodgetts, and Sonn's (2014) study, the Chinese transcriptions were first translated by the second author who is fluent both in English and Chinese. To ensure that the translation reflected the full depth of meaning as transcribed in Chinese, the translated transcriptions were checked by two Chinese academics who are fluent Chinese and English speakers. Subsequently, a native English academic was invited to confirm the meaning of the extracts that appear in this article.

Third, the second author took the re-arranged chronological biographical narratives and summarised interpretations of the quotations to the participants who were willing to review narratives and interpretations with the researcher. The participants were asked to assess how the quotations fitted together and if the interpretations made sense to them (Li,

2013). Twenty one participants agreed to take part in the process and all participants confirmed their narratives.

### **Findings and Interpretations**

Three themes were developed: mental concerns about parents, material concerns about children, and spiritual concerns about the self. Each is presented below, along with data extracts that illustrate each theme.

#### ***Mental Concerns about Parents***

Scrutiny of the interview data showed that five participants, all of whom had living parents at the time of interview, were concerned about their parents' mental health after their deaths. For example, Yang said:

I feel so sorry for my Mom [crying like a child for more than five minutes and saying "Mom, Mom, I am so sorry"]. She has been so caring for her children in her life time. But I will not be able to accompany her in the future. My Mom has looked after me since I have been sick. I feel so guilty. I do not want the white-haired person sending off the black-haired person.

In a similar vein, Cui stated:

I have thought of my parents constantly since I have been diagnosed. It is very brutal to let them know that I am in the final stage of my life. You know, in our culture, it is very hard for a white-haired person to send off a black-haired person.

Yang's and Cui's accounts both independently reflect the Chinese idiom that "a white-haired person sends off a black-haired person". The idiom exemplifies the cultural belief that a child dying before a parent is an unbearable grief, perhaps the saddest possible situation for the aged parent. As reviewed previously, a child is the essential part of the Chinese cobweb self for the parent. The child is the embodiment of the self, parental hopes and dreams and also the link between the parent's past and future (Mun & Ow, 2017). When

a child dies, the parent often loses the hope of the future, which can greatly impact the parent's mental health.

From the cultural perspective of filial piety, a filial child should bring comfort and happiness to the parent. The belief that a child's death results in unbearable grief for the aged parent thus symbolises the failure of the child being filial. Moreover, the death of a child suggests that the child fails to fulfil his or her filial obligation to the parent in the future (Mun & Ow, 2017). According to Confucianism, an individual can never be a moral person if he or she fails to succeed in familial responsibilities assigned by filial piety (Li, 2013). As a result, Yang felt sorry and guilty for her aged mother and was worried that her mother would not be well taken care of after she died. Yang continued to express her concerns about her mother:

My mother has been my most important support since I was diagnosed with cancer. I don't want to see her crying at my funeral. She will not be able to bear the pain if she is present at my funeral. I am so sad that my mother as a white-haired person will have to send me off in the near future... She will not have me around when she is sick and when she dies. It is the saddest thing in my life [sobbing].

It is believed in Chinese culture that, to avoid the pain and sadness that an aged parent suffers when he or she sees his or her child dying, the aged parent should not attend his or her child's funeral to overtly mourn (Mun & Ow, 2017). The death of a parent in Confucian discourse is hardly ever portrayed as a natural process, a welcoming relief from suffering, or an unavoidable part of life, as in Western cultures (Li, 2013). Instead, the parent's death is seen as a very extreme circumstance that demands the fullest extent of filial piety from the child. A child is expected to be present at the parent's funeral to express gratitude for the parental love (Mun & Ow, 2017). Hence, for many Chinese people, the greatest regret that a child could have is an eternally lost opportunity of serving parents with medicine and soup on their deathbeds and not being present when they die (Lin, 1993). It is clear from the quote

above that Yang expressed such regret and sadness that her filial duties to her mother will be unfulfilled.

### ***Material Concerns about Children***

Among 25 participants, 23 participants talked about their concerns about their children. Different to the emotional concerns about parents discussed previously, which suggested strong distress of the participants, the concerns about children could be categorised as less worried and very worried. Sixteen participants were less-worried, while seven were very-worried, about their children.

Careful examinations of the transcripts of the less-worried participants suggested that the children of the participants had nice jobs with good salaries and owned their own houses. For example, Fang stated: “My daughter is working in Russia. Her salary is very high. I don’t need to worry about her after I die.” Similarly, Deng said, “I don’t worry about my children very much. All of my children have good jobs and their own houses. Their financial situations are very good. They don’t need financial support from me.” Xu stated, “I am not worried about my children. I have purchased a house for my youngest son.”

Compared to the participants in this category, the very-worried participants (Huang, Zhao, Wang, Kong, Zheng, Sun, and Xie) often had children who could not financially support themselves and needed material support from the participants. Hence, the dying parents were greatly worried about their children’s life quality after they die, as asserted by Kong:

My son has not been married yet. This is my biggest concern. I have been working very hard to save money because I want to buy a house for my son. After I die, he won’t have enough money to buy a house. If he doesn’t have a house, no girl will marry him [wiping eyes].

Traditionally, providing financial support to parents is considered a key element of filial piety. Nowadays, although material support to parents is still widely practiced in China, it is less important than in traditional Chinese society (Li et al., 2010). Moreover, the one-child family policy (enforced from 1979 to 2012) limited a couple to producing only one child, resulting in the situation that young couples, who are both only children, are required to provide support to four aged parents (Li, Huang, Chen & Li, 2016). Many young people may not be able to support their aged parents, and may instead ask for financial support from their parents. Kong's account reflects this phenomenon.

The phenomenon of material support from parents to children can be understood from a cultural perspective. Confucianism conceptualises family using the analogy of the human body. Each part of the human body symbolises a family role, and together the family constitutes an inseparable entity. The father is the head, the mother is the body, and the children are the four limbs (Hwang, 1999). Because parents and children are conceived of as parts of a body, they are expected to support one another when in need.

Kong's excerpt also reflects a cultural phenomenon that in China it is the man's responsibility to purchase a house before he proposes to a woman. It is referred to as "no house, no marriage" in Chinese popular culture (Jacobs, 2011). A study on Chinese marriage and family in 2010 reported that more than 70 percent of participating single women would marry only if the prospective husband owned a house (The Chinese Research Association of Marriage and Family, 2010). With China's unrelenting real estate boom in the past two decades, many working-class men require their parents to help them purchase a house in order to get married. As stated in Kong's account, her son will lose her financial support and may never be able to buy a house. It seems that Kong's death will leave an empty space in her son's cobweb, which again may not be filled by other people.

Material concerns about children were particularly strong in the case where the children had a disability. Such concerns were frequently raised in reference to the insufficient support of the social welfare system in China. For example, Wang said:

I do not fear death itself. But I am worried about my daughter who has a level-one disability [a person who has a permanent and diagnosed disability, lost the ability to work, and needs assistance in everyday life]. She receives the minimum living allowance from the government, which is 680 Yuan a month [nearly US\$100]. This money cannot even cover her medical treatment. She is our only child. I just do not know how she will survive after I die [frowning and sighing].

In China, the Minimum Living Standard Guarantee System provides minimum living cost support. This financial support is for those who have long-term sickness/permanent disability, have lost their ability to work and/or live in abominable or calamitous natural environments. The financial support is lower than the minimum wage in the city (Zhang, 2009). As demonstrated by Wang's account, such support is very limited and she expressed concern that her daughter would become a case of urban poverty after she died.

### ***Spiritual Concerns about the Self***

Six out of 25 participants mentioned their cerements (cloth that the deceased wears right after he or she dies) and considered their cerements to be an important part of the preparation for their death. Attaining a nice and expensive cerement appeared to function as a spiritual support for participants, as stated by Pei:

My son is a filial son. He has bought a nice cerement for me. It [the cerement] makes me feel that death is not as fearful as I thought previously, and I believe that I will pass peacefully.

Pei's account is consistent with the Chinese mourning ritual that plays an important role in supporting the deceased to transition through the underworld and have a quick and



favourable rebirth. Wearing an extravagant cerement and having one's children burn paper goods and spirit money is thought to assist the newly deceased soul on its journey (Ikels, 2004). In the Chinese culture, before the deceased is placed in the coffin, the body is often cleaned with a damp cloth and dressed in a cerement. In the Chinese language, a coffin is called "Guan Cai", literally translated as "official" and "wealth". As posited by Li (1993), Chinese values place emphasis on material afterlife as an official or wealthy person. As such, many Chinese people believe that wearing an expensive cerement is a symbol of wealth and will help the deceased be reincarnated into a rich family and have a wealthy afterlife (Li, 1993; Wolff, 2007).

Mourning, including preparing a shroud for the dying parent, has long been considered the paramount expression of filial piety (Kutcher, 1999). In a sense of spirituality, Pei's account showed that the shroud prepared by his son functioned to maintain the relationship and interaction between the dying father and the son, and a continuity of the family. The shroud also brought him courage to cope with his emotions as he approached the end of life. Tao expressed a similar feeling:

Why should I fear death? Everyone will die. I have had my cerements bought. I do not fear death anymore. Please let me show you my cerement. It is one of the best articles of clothing I've ever had in my life.

Tao showed the first author his cerement. The shroud was a dark-red colour, with a Chinese Tang design and high collar. The cerement was made of a silk-like material and had wide sleeves. There is a cultural belief that narrow cerement sleeves will bring financial strain to the children of the deceased. Furthermore, the cerement had no pockets. In Chinese culture it is believed that the deceased may use such pockets to take away the wealth of his or her children. The cerement is symbolic of relational aftermath concerns in Chinese culture. The cerement also serves as a moderator to facilitate the participant to deal with the end-of-

life stage difficulties and to increase togetherness, belongingness, acceptance, and participation among family members (Park, 2018).

### **Discussion**

This article explored the meaning of aftermath concerns among 25 terminal cancer patients in China. As conceptualised by Chochinov et al. (2002), aftermath concerns refer to the worry or fears associated with anticipating the burden or challenges that one's death will impose on others after the person dies. The current study identified three themes from the participants' narratives that exemplify aftermath concerns: mental concerns about parents, material concerns about children, and spiritual concerns about the self.

In Chochinov et al.'s (2002) study exploring dying with dignity, a 51-year-old male outpatient with metastatic lung cancer expressed aftermath concerns regarding the future of his children in the wake of his death. However, Chochinov and his colleagues did not develop themes related to aftermath concerns. The aforementioned research by Ho et al. (2013) is one of the few studies to investigate cultural understandings of dignity among older Chinese palliative patients using Chochinov's model of dignity. Similar to Chochinov et al.'s (2002) study, although Ho and colleagues (2013) found that aftermath concerns were clearly identified among 16 terminal cancer patients living in Hong Kong, they did not offer information as to the precise nature of participants' aftermath concerns. To the knowledge of the authors, there is no research that has developed themes or categories of aftermath concerns. The findings of the present study add new value in this research field by depicting aftermath concerns from a cultural perspective.

The three themes suggest that aftermath concerns among participants is relational in that they are not about what happens within an individual, but between individuals. Participants' aftermath concerns are all related to the cultural concept of the cobweb self. Children and parents are the most significant persons in the participants' cobwebs and in their

aftermath concerns. For the participants, the cobweb self is concerned with connectedness and caring between participants and their children and parents (Li & Forbes, in press). As demonstrated in the findings section, participants' accounts present their aftermath concerns as something that should not be understood as a tightly circumscribed entity that merely focuses on the death itself, but rather as something that emerges within and through relations to other people (primarily parents and children in the cases discussed). In that regard, a Chinese person can never separate aftermath concerns from others.

Moreover, the Chinese concept of filial piety seems to be an important element in the aftermath concerns of participants. Traditional filial piety practices emphasise children providing care for their sick parents. Support and concerns from children to parents has remained a cornerstone of hospice care in the Chinese culture. In her qualitative study on older Chinese people's experience with regards to filial piety, Li (2011) proposed the term *parental piety* to refer specifically to support from parents to their children. The participants' aftermath concerns echo the notion of parental piety, which highlights the existence of reciprocal exchanges between children and parents. While the participants were concerned about their parents' mental health, they were also concerned about their children's financial health.

Such reciprocity between generations is demonstrated in Confucian thought. Confucius (1885) stated that "what the rules of propriety values is that of reciprocity. If I give a gift and nothing comes in return, that is contrary to propriety; if the thing comes to me, and I give nothing in return, that also is contrary to propriety" (p. 65). For the participants, filial piety functions as a set of guiding principles shaping general patterns of their aftermath concerns. In a cultural sense, aftermath concerns are fundamentally about relationships; relationships between the dying person and his or her children and parents. This finding is consistent with Ho et al.'s (2017) end-of-life dignity enhancement study in which the Chinese

patients with terminal illness and their family members identified that filial compassion plays a role in family support when they came to grips with death and dying. The finding is also supported by Park's (2018) notion that dying is all about family and filial piety provides a cultural space for the dying person and family members to work together to deal with dying and death, including aftermath concerns.

Furthermore, this study provides empirical support to develop holistic palliative care. Palliative services in China predominately focus on pain and symptom management. There is a lack of services that address socio-cultural-spiritual concerns (Ho et al., 2017), such as the aftermath concerns that the participants in this study voiced. The findings of the study enrich knowledge on end-of-life aftermath concerns and offer empirical evidence in relation to aftermath concerns for the development of holistic palliative care interventions, such as dignity therapy (Chochinov, Hack, Hassard, & Kristjanson, 2014), for patients and families facing terminal illness.

The findings of the study suggest that relational aftermath concerns are manifested within the broader cultural, social, economic and political contexts. Some participants' material concerns about their children highlight the limitation of the social welfare system in China. For example, the government support to people with disabilities, which is lower than the minimum wage in the city in which the person lives, appears to be insufficient. The responsibilities of supporting disabled children seem to lie on the parents' shoulders. As a result, the dying parent's concerns centre on their disadvantaged children not having sufficient access to financial resources.

The study has its limitations. First, the sample size is small and all participants were from urban areas with a population of 3.7 million people. It is important to note that the city also has a rural population of 0.7 million. The study may not have captured the aftermath concerns of those who live in rural areas because the differences between rural and urban

areas might have an impact on patients' aftermath concerns. Second, the findings might not generalise to Chinese people living in other cities in China. A strength the study is that it is built upon the voices of the participants, this article adopts a framework of theoretical and conceptual abstraction (Chamberlain, 2009) to theorise the understanding of the participants' aftermath concerns. Focusing on what their narratives mean, the analysis moves beyond offering thick descriptions towards more theoretically informed interpretations (Rogers, 2009).

Despite these limitations, this study allows for cultural knowledge of participants' relational aftermath concerns which can be viewed as a set of psychological, social, and cultural processes that transcend the actual physical context of the death. As participants made clear, death hurts. It deprives people of opportunities, futures, dreams, and imaginings. For the participants in the current study, it also deprives them of their filial responsibilities and obligations, for both their parents and children. Moreover, the study calls for more attention on the social issues raised by people with terminal illness, which expands the responsiveness of policy making in relation to aged care and hospice services provision. Such work is crucial at a time when China is facing severe challenges with its growing ageing population.

## References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- Chan, C., Chow, A., Ho, S., Tsui, Y., Tin, A., Koo, B., & Koo, E. (2005). The experience of Chinese bereaved persons: A preliminary study of meaning making and continuing bonds. *Death Studies, 29*(10), 923-947. doi:10.1080/07481180500299287
- Chamberlain, K. (2009). Constructing knowledge in contemporary psychology: Some critical comments. *Psychology Aotearoa, 1*, 47-52.
- Chochinov, H. (2002). Dignity-conserving care: A new model for palliative care: Helping the patient feel valued. *Journal of the American Medical Association, 287*(17), 2253-2260.
- Chochinov, H. M., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002). Dignity in the terminally ill: A developing empirical model. *Social Science and Medicine, 54*(3), 433-443.
- Chochinov, H., Hack, T., Hassard, T., & Kristjanson, L. (2004). Dignity and psychotherapeutic considerations in end-of-life care. *Journal of Palliative Care, 20*(3), 134-142.
- Chochinov, H. (2006). Dying, dignity, and new horizons in palliative end-of-life care. *CA: A Cancer Journal for Clinicians, 56*(2), 84-103.
- Confucius. (1885). *Li Chi: Book of rites part 1* (J. Legge, Trans.). New York, NY: Kessinger Publishing.
- DiCicco-Bloom, B., & Crabtree, B. (2006). The qualitative research interview. *Medical Education, 40*, 314-321.
- Flick, U. (2006). *An introduction to qualitative research* (3rd ed.). London, UK: Sage.

- Gurdogan, E., Kurt, D., Aksoy, B., Kinici, E., & Sen, A. (2017). Nurses' perceptions of spiritual care and attitudes toward the principles of dying with dignity: A sample from Turkey. *Death Studies, 41*(3), 180-187. doi:10.1080/07481187.2016.1231242
- Hack, T., Chochinov, H., Hassard, T., Kristjanson, L., McClement, S., & Harlos, M. (2004). Defining dignity in terminally ill cancer patients: A factor-analytic approach. *Psycho-Oncology, 13*(10), 700-708.
- Hall, C. (2011). Beyond Kubler-Ross: Recent developments in our understanding of grief and bereavement. *In Psych, 33*(6), 8-12.
- Hall, S., Longhurst, S., & Higginson, I. (2009). Living and dying with dignity: A qualitative study of the views of older people in nursing homes. *Age and Ageing, 38*, 411-416. doi:10.1093/ageing/afp069 reserved.
- Hemati, Z., Ashouri, E., AllahBakhshian, M., Pourfarzad, Z., Shirani, F., Safazadeh, S., Ziyaei, M. ... & Taleghani, F. (2016). Dying with dignity: A concept analysis. *Journal of Clinical Nursing, 25*, 1218-1228, doi:10.1111/jocn.13143
- Ho, A., Chan, C., Leung, P., Chochinov, H., Neimeyer, R., Pang, S., & Tse, C. (2013). Living and dying with dignity in Chinese society: Perspectives of older palliative care patients in Hong Kong. *Age and Ageing, 42*, 455-461. doi:10.1093/ageing/aft003
- Ho, A., Car, J., Ho, M-H., Tan-Ho, G., Choo, P., Patinadan, P. ... Chochinov, H. (2017). A novel Family Dignity Intervention (FDI) for enhancing and informing holistic palliative care in Asia: Study protocol for a randomized controlled trial. *Trials, 18*, 587-599.
- Hwang, K. K. (1999). Filial piety and loyalty: Two types of social identification in Confucianism. *Asian Journal of Social Psychology, 2*, 163-183.

- Ikels, C. (2004). Serving the ancestors, serving the state: Filial piety and death ritual in contemporary Guangzhou. In C. Ikels (Ed.), *Filial piety: Practice and discourse in contemporary East Asia* (pp. 88-105). Stanford, CA: Stanford University Press.
- Jacobs, A. (2011). *For many Chinese men, no deed means no dates*. Retrieved from <https://www.nytimes.com/2011/04/15/world/asia/15bachelors.html>
- Kubler-Ross, E. (1969). *On death and dying*. New York, NY: Scribner.
- Kutcher, N. (1999). *Mourning in late imperial China: Filial piety and the state*. Cambridge, UK: Cambridge University Press.
- Li, S. (1993). The funeral and Chinese culture. *Journal of Popular Culture*, 27(2), 113-120.
- Li, W., Hodgetts, D., Ho, E., & Stolte, O. (2010). From early Confucian texts to ageing care in China and abroad today: The evolution of filial piety and its implications. *Journal of US-China Public Administration*, 7(7), 48-59.
- Li, W. W. (2011). Filial piety, parental piety and community piety: Changing cultural practices of elderly support among Chinese migrant families in New Zealand. *OMNES: The Journal of Multicultural Society*, 2(1), 1-30.
- Li, W. W., & Chong, M. D. (2012). Transnationalism, social wellbeing and older Chinese migrants. *Graduate Journal of Asian and Pacific Studies*, 8(1), 29-44.
- Li, W. W. (2013). *Shifting selves in migration: Home, ageing in place and well-being*. Beijing, China: Central Compilation & Translation Press.
- Li, W. W., Hodgetts, D., & Sonn, C. (2014). Multiple senses of community among older Chinese migrants to New Zealand. *Journal of Community and Applied Social Psychology*, 24(1), 26-36.
- Li, W. W., & Tse, S. (2015). Problem gambling and help seeking among Chinese international students: Narratives of place identity transformation. *Journal of Health Psychology*, 20(3), 300-312.



- Li, W. W., Huang, X., Chen, Y. & Li, H. (2016). Aged care and mental health in China. In W. W. Li, S. Cummings, I. Ponnuswami, & H. J. Park (Eds.), *Ageing and mental health: Global perspectives* (pp. 151-165). New York, NY: Nova Science Publishers.
- Li, W. W., & Forbes, A. (in press). Fang-tan in research among Chinese communities in New Zealand and Australia: A cultural approach to engagement. *Qualitative Research in Psychology*.
- Lin, Y. T. (1993). On growing old gracefully. In C. Sommers & F. Sommers (Eds.), *Vice and virtue in everyday life* (3rd ed., pp. 751-757). Fort Worth, TX: Harcourt Brace Jovanovich.
- Mun, S., & Ow, R. (2017). Death of a child: Perspective of Chinese mothers in Singapore. *Journal of Religion & Spirituality in Social Work: Social Thought*, 36(3), 306-325.
- Ostlund, U., Brown, H., & Johnston, B. (2012). Dignity conserving care at end-of-life: A narrative review. *European Journal of Oncology Nursing*, 16, 353-367.
- Park, H. J. (2018). Lessons from filial piety: A social-life-span approach to building the connection that survives death, *Death Studies*, doi10.1080/07481187.2018.1516703
- Parkes, C. M. (2013). Elisabeth Kübler-Ross, On death and dying: A reappraisal. *Mortality*, 18(1), 94-97. doi10.1080/13576275.2012.758629
- Rogers, W. S. (2009). Research methodologies. In D. Fox, I. Prilleltensky, & S. Austin (Eds.), *Critical psychology: An introduction* (2nd ed., pp. 335-354). London, UK: Sage.
- Santrock, J. W. (2007). *A topical approach to life-span development*. New York, NY: McGraw-Hill.
- The Chinese Research Association of Marriage and Family. (2010). *Chinese people love and marriage status report 2010*. Beijing, China: the All-China Women's Federation.

- von Glahn, R. (2004). *The sinister way: The divine and the demonic in Chinese religious culture*. Berkeley, CA: University of California Press.
- Wolff, J. (2007). Emperor Qin in the afterlife. *The Archaeology of Death*, 20, 10-16.
- Yang, C. F. (2006). The Chinese conception of the self: Towards a person-making perspective. In U. Kim, K.-S. Yang, & K. K. Hwang (Eds.), *Indigenous and cultural psychology: Understanding people in context* (pp. 327-356). New York, NY: Springer.
- Yu, Y-S. (1987). "O Soul, Come Back!" - A study in the changing conceptions of the soul and afterlife in pre-Buddhist China. *Harvard Journal of Asiatic Studies*, 47(2), 363-395.
- Zhang, H. (2009). Poverty and politics the Evolution of Minimum Living Standard Guarantee System in China in the period of transition. *Asia Pacific Journal of Social Work and Development*, 19(2), 5-20. doi10.1080/21650993.2009.9756060
- Zheng, R-S., Guo, Q-H., Dong, F-Q., & Owens R. (2015). Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study. *International Journal of Nursing Studies*, 52, 288-296.