

Original Article

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# Caregiver burden and bereavement among family caregivers who lost terminally ill cancer patients

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**Abstract**

**Objective.** Family caregivers (FCs) in China provide hospice care to terminally ill cancer patients; however, few studies have been conducted in China on caregiver burden and bereavement experiences as a process that continues over time. The purpose of this study was to identify the main elements of caring and bereavement experiences for FCs caring for patients diagnosed with terminal cancer.

**Method.** Twenty in-depth qualitative semistructured interviews were conducted with FCs providing care in a hospice unit in Shenzhen, Southern China. Interview transcripts were analyzed via thematic content analysis.

**Result.** A framework based on the following eight principal themes was developed through content analysis of our FC interviews: symptoms of the illness, the truth-telling process, attitudes toward death, the “color” of death, social and professional support, the moment of death, and grief and loss.

**Significance of results.** The analysis showed that caregiving may positively or negatively influence the bereavement process.

## Introduction

Hospice care focuses on caring for (rather than curing) people facing the end of life as well as caring for their families. Hospice care is defined as a team-oriented approach to delivering expert medical care, pain management, and emotional and spiritual support to patients and their family caregivers (FCs) (Hui et al., 2013). Hospice care is provided at hospice centers, hospitals, nursing homes, and other long-term care facilities (Holland et al., 2015).

Increasing attention has been paid to the specific needs of FCs; however, an exploration of FCs' experiences is warranted to identify their needs while caring for patients with terminal cancer and how this influences the bereavement process. Additional knowledge is needed to help health professionals identify FCs at a higher risk for experiencing prolonged grief and to intervene in a preventive manner to provide support to FCs (Lichtenthal et al., 2011). Indeed, the difficulties experienced by FCs may affect their longer term psychological health and particularly, during the bereavement process. According to the literature, certain people experience persistent difficulties following the loss of a loved one (Burke et al., 2014; Keyes et al., 2014). Studies have demonstrated that certain factors are likely to influence bereavement outcomes, including an FC's mental and physical health, perceived social support, views surrounding death, and levels of psychological burden (Åberg et al., 2004; Cannaerts et al., 2004; Dumont et al., 2006); however, few studies have qualitatively examined FCs' experiences (Breen et al., 2015; Funk et al., 2010).

In this study, the author explored how one Chinese cultural context shapes the particular needs and experiences of FCs providing care in hospice settings. Hospice care is a latecomer to the Chinese healthcare system. Tianjin Medical College opened the first public hospice unit in mainland China in July 1988. In 1992, the Department of Hospice Foundation Fund was established within the China Elderly Foundation. Since then, cities such as Beijing, Shenzhen, Guangzhou, and Wuhan have developed hospice facilities. At present, there are more than 150 hospice institutions in China.

There are some similarities between Chinese and Western approaches to hospice care, but that there are also potentially important cultural differences. Approaches to hospice care for Chinese people do not differ markedly from the palliative care approaches used in Western countries. One notable difference is that Chinese patients might not receive information directly because truth-telling is believed to cause patients to feel hopeless and unable to cope with their problems.

Through this qualitative study, therefore, the author aimed to identify caregiving factors that may influence the bereavement experiences of Chinese FCs who provide care to terminally ill cancer patients. Few studies have been conducted in China on caregiver burden and

bereavement experiences as part of a process that continues over time (Chiu et al., 2010). Related studies have largely adopted different scales to measure caregiver burden and bereavement patterns. Greenwood et al.'s (2008) systematic review of qualitative studies on caregivers revealed that caregivers rarely use the term burden to describe their caregiving experiences despite the preponderance of the term in the quantitative literature. Ganguly et al.'s (2010) qualitative study found that caregiver burden is always incorporated into traditional burden measures. These examples demonstrate that the quantitative measures used in research settings may conceptualize burden in ways that differ from caregivers' actual experience. In addition to the previously mentioned contributions, the author also offers a valuable contribution to the ongoing debate on how social worker education processes in China might be modified to help these individuals better support their clients.

The purpose of this study was to explore and understand FCs' experiences in China during their transition from hospice to bereavement with a focus on their thoughts and reflections. For the purposes of this study, the author defines bereavement as the way FCs view their experiences of caregiving after the death of a loved one and how they understand the meaning and effects of loss and of the transition to a new beginning. To meet these study objectives, the following research questions were posed: (1) What facets of FCs' experiences positively or negatively influence the bereavement process? (2) How do FCs experience the bereavement process? and (3) What thoughts and reflections do FCs associate with the transition from hospice care to bereavement?

## Methods

### Research site

The first hospice unit in mainland China was founded in 1998 by the Li Ka Shing Foundation (LKSF) for the delivery of free home-based hospice care to terminally ill cancer patients. Hospice care services in China were in their infancy at the time and such services differ from those provided in the United States because most hospice services are provided in patients' homes. All hospitals with hospice units receive donations from the LKSF and provide healthcare professionals and facilities. By June 2017, 37 hospice units, distributed across 31 cities of 26 provinces in mainland China were in operation. More than 170,000 patients have been served. The hospice unit at Shenzhen Renmin Hospital is among those units funded by the LKSF (2017). The China Association of Social Work Education organized 10 universities to participate in a project on hospice care supported by the LKSF. The project focused on FCs and on hospice care and it was part of a larger study on hospice care.

### Participants

For this qualitative study, the author focused on the caring and bereavement experiences of 20 FCs who served as the primary caregiver for a terminally ill cancer patient. To be included in this study, FCs were required to: (1) have acted as the primary FC to a terminally ill cancer patient within a hospice unit, (2) have daily provided care and assistance to a cancer patient, and (3) have lost a cancer patient six months before the interviews.

Recruitment was conducted in collaboration with oncology social workers in the hospice unit of Shenzhen Renmin

Hospital. Informed consent and qualitative data on caring experiences were obtained from FCs who were interested in participating in this study. The main qualitative data presented here were collected six months following the patient's death. This study was approved by the Research Ethics Committees of Shen Zhen University and Shenzhen Renmin Hospital. The data were gathered from November 2014 to December 2015.

### In-depth interviews

The questions discussed in this paper were examined as part of the previously mentioned project. The interview schedule was designed to yield exploratory, descriptive, and qualitative data on FCs' experiences and explored the following three open-ended questions: (1) Can you tell me about challenges faced while taking care of a terminally ill cancer patient? (2) Can you tell me about your feelings regarding your caring role? and (3) Can you tell me about your feelings regarding losing a family member with terminal cancer?

Caregivers were continually recruited to participate in interviews until data saturation was reached. Approximately 300 registered patients had been admitted to the hospice unit. Three oncology social workers were screened to recruit participants from the 300 registered patients. These social workers referred us to our participants, and we contacted 28 FCs. Eight FCs withdrew because they did not wish to discuss issues related to death. The author interviewed the each FC at the hospice center or at the FC's home. Each interview lasted approximately 90 minutes. Twenty participants who were enrolled in the study so they could be tracked postloss, were consulted at baseline while acting as FCs of a terminally ill cancer patient, and data were collected 6 months after the death of the patient. The sampling process achieved saturation. Because of the numerous factors that can determine the sample sizes of qualitative studies, some researchers (Bertaux 1981; Guest et al., 2006) propose that a sample of 15 individuals is the smallest sample acceptable for qualitative research. Twenty participants were a sufficient number to conclude that no new information or themes were likely to emerge from further data analysis.

### Data analysis

The author also served as the interviewer. The author's primary research focuses on oncology social work in China. Before starting this research, the author served on an academic faculty for 10 years. The interviews were conducted in Chinese, and the data were translated with the help of a certified translator who is also a lecture at Shenzhen University in China. All the interviews were recorded and transcribed verbatim by a professional transcriber to facilitate the analysis. The data were analyzed using a thematic analysis approach (Patton, 2002; Strauss & Corbin, 1994) as follows: coding, developing thematic categories, and identifying interrelations between themes. The themes were identified by the author. The independent reviewer was a university psychology professor with research training in and experience with qualitative methods who discussed and provided feedback on all major themes identified (Table 1).

## Results

The age of the participants at the time of the interviews ranged from 37 to 69 years; most of the participants were women. The

**Table 1.** Example of data analysis

Example of a quotation/meaning unit	Categories	Theme(s)
I saw him getting thinner and thinner each day. I felt upset. I saw him in pain, and his condition deteriorated every day. I didn't know what to do. I felt helpless. The feeling is very uncomfortable. It seemed he was going to die soon.	Vulnerability	Death moment

sample included 11 FCs who provided care to their spouse, 3 FCs who were mothers, 1 FC who was a father, 2 FCs who were daughters, and 3 FCs who were sons (Table 2).

Serving as an FC to a patient with terminally ill cancer can be a rewarding experience, but it can also be psychologically and physically demanding and particularly in the final moments of a cancer patient's life. Some FCs reported adjusting well to bereavement and perceived the caregiving process was perceived as an opportunity to undergo personal growth. Some FCs noted that they experienced difficulties throughout the bereavement process and that caregiving was a disruptive experience that negatively influenced their adjustment to bereavement. In analyzing the FCs' responses, the principal elements associated with caregiving that may affect the bereavement process were identified. Caregiving experiences can be complex because terminal cancer is often associated with intense symptoms that can be difficult to control, causing the patient's needs to fluctuate dramatically from one day to the next.

The author used a theme map (Figure 1) to illustrate the themes identified in the interviews and to better understand how the Chinese cultural context shapes FCs' experiences in hospice settings. Part of an individual's social reality or life-world is related to his or her life experiences, which can be considered in relation to specific topics of interest, such as caregiving (Taylor et al., 2015). Using this theme map, the author examined the experiences of 20 FCs in terms of their experiences of losing a terminally ill cancer patient. The author used this framework to guide the study, from the development of the interview guide to the interpretation of results.

The following eight major themes were identified in this study: "illness symptoms," "caregiving has a negative influence on the bereavement process," "attitudes toward death," "the truth-telling process," "the color of death," "informal and formal support," "the moments of death," and "grief and loss." These themes are discussed further to highlight their positive and negative impacts on FC bereavement processes.

### Theme 1: Illness symptoms

The management of cancer patients' symptoms was found to influence the adjustment to bereavement. Loss of the patient tended to be easier for FCs when the patient did not suffer and was able to preserve a certain quality of life. However, the presence of certain symptoms and of major changes in behavior were identified as aspects of caregiving that rendered end-of-life experiences more difficult for the bereaved family. The interview data illustrated that these symptoms (e.g., depression and anxiety) can be destabilizing for FCs and result in them no longer recognizing the patient to whom they were devoted. Furthermore, FCs' views of their patients did not typically remain intact throughout

their experiences, and new perceptions might have affected their reactions to their patients' death. One female participant, whose mother had breast cancer, explained

I knew I would see my mother pass by, shoulders rounded and head lowered. She walked like a little mouse. She went to the bathroom and came back. I think I would always see her go by that way. It affected me a great deal (F6).

One female participant who cared for her husband with lung cancer for 11 months described the same illness symptoms:

I thanked death afterwards for coming and taking him away. He didn't suffer a lot. I was alone and depressed. I could not have seen him live that way. It put me at peace when I thought that he at least he didn't suffer. It helped to get through grieving (F2).

### Theme 2: Caregiving has a negative influence on the bereavement process

Researchers have suggested that the act of caregiving itself may influence bereavement experiences (Koop & Strang, 2003). Generally, when caregiving experiences were perceived as negative, caregivers reported experiencing feelings of guilt, depression, and heightened distress and anxiety, which potentially negatively affected the bereavement process. For example, F7, a 66-year-old woman, who cared for her husband for four months, felt exhausted:

I was so exhausted when I got through caregiving that I didn't even have the energy, even if I did have friends out there, to phone them (F7).

F12, a 69-year-old woman who cared for her husband for three months, expressed the same feelings: "Some days I just sat there and just bawled. I went down to the downtown and I bawled some more. I felt tired. I couldn't do it anymore" (F12).

### Theme 3: Attitudes toward death

The art of dying well has been a quintessential subject in both the West and the East. Chinese attitudes and practices related to death and dying are rooted in cultural values, such as filial piety, centrality of the family, and hierarchy. According to the participants in the current study, Chinese families regard death as a "taboo" subject of conversation and carry a significant fear of death. This phenomenon was exemplified by F8, who cared for her mother and did not discuss the death with her family.

I have not discussed the topic of death with my mother. In my family, it was hard to get into the topic of death for further discussion. It was like a taboo. I don't think she is prepared to welcome death (F8).

In a similar vein, M3, who cared for his son, who had nasopharynx cancer explained:

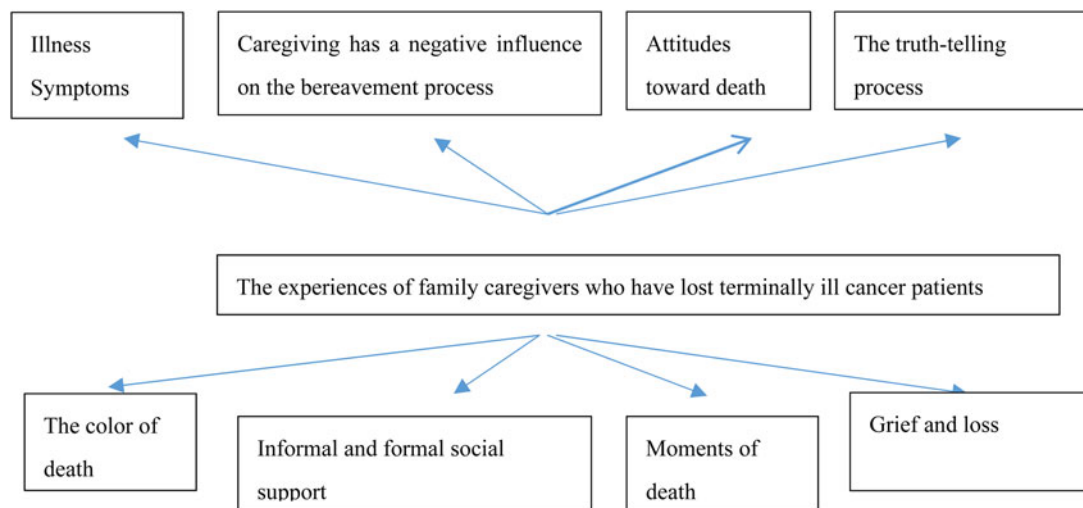
My son was afraid to face death, although he had known his true condition. The doctor has told him that he would die in 6 months. When he was alive, we had no chance to talk about something after his death (M3).

Several philosophical views of death exist in Chinese culture, such as Confucian and Buddhist views. For example, according to Confucian philosophy, one should not discuss the truth of a disease with the patient. F3 stated that as a Chinese person, she would not tell the truth to her mother as a Chinese person.

**Table 2.** Participants' backgrounds as family caregivers of terminally ill cancer patients

Interviewee*	Caregiving period	Patient's relationship to the FC	FC's age	Patient's diagnosis
F1	4 months	Spouse	66	Gastric cancer
F2	11 months	Spouse	69	Lung cancer
F3	10 months	Mother	43	Liver cancer
F4	6 months	Spouse	47	Lung cancer
F5	6 months	Daughter	66	Colon cancer
F6	3 months	Mother	37	Breast cancer
F7	4 months	Spouse	66	Cervical cancer
F8	9 months	Mother	45	Lung cancer
F9	1 year	Spouse	71	Bone cancer
F10	10 months	Spouse	52	Gastric cancer
F11	6 months	Spouse	56	Liver cancer
F12	3 months	Spouse	69	Lung cancer
M1	4 months	Daughter	65	Liver cancer
M2	4 months	Spouse	68	Breast cancer
M3	5 months	Son	62	Nasopharynx cancer
M4	10 months	Spouse	60	Gastric cancer
M5	1 year	Father	41	Pancreatic cancer
M6	7 months	Son	65	Colon cancer
M7	8 months	Son	62	Lung cancer
M8	5 months	Spouse	62	Breast cancer

\*F or M indicates that the participant was female or male, respectively.



**Fig. 1.** Theme map

According to Buddhist views, one should not be afraid of death. F8's mother was a Buddhist who was not afraid of death, similar to F6 whose mother also was a Buddhist. She explained:

My mother was a Buddhist. She was not afraid of death, because she regarded death as a process of rebirth. Family harmony makes everything successful and prosperous. Truth telling in China may also be influenced by cultural and ethical factors. The reason why I didn't tell the truth

about cancer was I worried that my mother could not take the emotional impact (F6).

**Theme 4: The truth-telling process**

Issues of truth-telling regarding death were debated between families and cancer patients regarding death given the various opinions

held across cultures. Several studies have focused on views of truth-telling. Several participants in this study believed that sharing information can strengthen the trusting relationships between patients and medical professionals. Extensive efforts have been made in Western cultures to ensure patients' rights to know the truth as a natural facet of medical practice (Rising, 2017). One participant described why she did not tell her mother the truth:

I didn't want to tell her the truth about the cancer disease because I was concerned that her health condition would deteriorate further, but her bodily feelings could not be hidden. She would always ask my father and me. Finally, I had to tell her the true condition. On the contrary, she felt comfortable on the contrary (F3).

A cancer diagnosis is critical information for the entire family. Core family members can make decisions for cancer patients. Another participant described why he did not tell his son about a cancer diagnosis:

I didn't tell my son that he had colon cancer. We held a family conference that included my wife, my daughter and other relatives. We decided that he'd be better off not knowing his true conditions (M6).

### Theme 5: The color of death

The Chinese word for "color" is yánsè. In classical Chinese, color refers to certain values and more accurately refers to "emotion." For example, white symbolizes brightness, purity, and fulfillment. White is also deemed the color of mourning after death, is associated with death and is used predominantly at funerals. Chinese people wear white clothes only when they mourn the dead. Red is another color that is traditionally used in funerals. Colors were found to be central to the FCs' experiences with bereavement regardless of the specific colors with which individual FCs identified. As one participant, F2, who regarded black as death color, explained,

I thought black was the death color. Death was a horrible thing. When my father died, we had to wear black gauze during the funerals. Death was an unknown thing. All of us didn't know what the death world was (F2).

Another participant, F8, regarded blue as a death color. She explained,

I drew a picture in blue. Blue was a light color. When a person died, his body became lighter and lighter, and it seemed to be flying overhead. Death was a natural thing. Everyone will die some day (F8).

### Theme 6: Informal and formal social support

Social support helps cancer patients adjust to the stresses of the disease. Because of their intense fears (e.g., fear alone or fears of the disease itself), cancer patients are more likely to find it difficult to receive adequate social supports from FCs who are willing to listen to them resolve their fear about cancer. Informal social support is received from family members, relatives, and friends, whereas formal social support is given by social workers and other professionals. One participant, F10, who cared for her husband for 10 months, explained that her sister was "the most helpful one" for her.

I found my sister was the most helpful one for me when I lost my spouse. For example, my sister called me one morning and said she would take my

son to go climbing, although I had not asked her to do so. She has always given me emotional assistance since the death of my spouse (F10).

Other participants, such as F6, who cared for her mother, and M4, who cared for his son, responded that oncology social workers were an as important formal support. These participants explained,

Before my mother died, an oncology social worker told me some important information, including dying symptoms of cancer patients. This let me face the final moment more comfortably and cope with my mother's death better (F6).

Because my son suffered from liver cancer, it led to family economic tensions. An oncology social worker helped me apply for government subsidies to alleviate the economic pressures (M4).

### Theme 7: Moment of death

The death moment depends on the circumstances and how a person experiences it. The event of death was experienced as a traumatic moment for some FCs who had cared for a terminally ill cancer patient. For other FCs, the moment of death, including being present at the time of death, experiencing a beautiful death and preparing for death, helped the FCs proceed through the mourning process.

The moment of death is defined as the end of the caregiving process and is an emotionally charged event. According to the FCs, a beautiful death refers to a peaceful and serene death in which the patient's dignity is preserved, and that characteristic positively influences the reactions to loss.

Preparing for loss was identified as another aspect of hospice care that facilitates the bereavement process. Bereavement typically begins at the moment when loss is perceived to be inevitable. Experiencing loss associated with death while still providing care to a cancer patient constitutes one way in which grief is initiated before death occurs (Robinson et al., 2017). For example, F4 stated that she could not sleep with her husband after being informed of his imminent death. The actual moment of death was identified as very difficult for the people who had provided care to patients with terminal cancer. Indeed, the FCs reported that they were unable to witness their loved ones die, particularly those who did not feel prepared for the event. Participants expressed that they experienced bereavement distress when observing certain characteristics at the moment of death (e.g., shortness of breath, yawning, lack of smell, lack of responsiveness).

It had been 36 years that we slept together. The last night we slept here. Near four o'clock in the morning, we both got up and cried together. We said to each other that it really was the last time that we would sleep together. We realized it together and everything. It was not easy at the time, but it helped me later (F4).

My husband said that he would take care of me because he knew that I would be very tired. Before he died, he showed me all of the practical business because it was him who took care of all that. We even went together to make his funeral arrangements before he died. That was helpful for me. Now, I feel less worried (F2).

### Theme 8: Caregiving experiences and the views of death

The FCs acknowledged their vulnerabilities and paradoxical feelings about the loved ones' progressive decline. The FCs experienced loss not only at the time of their patients' death but also

throughout the entire caregiving process. In general, the FCs felt that doctors had not provided their best care when treating their loved ones, because of a lack of effective communication between the doctors and FCs. When the patients entered the terminal stage of cancer, the FCs and patients felt uncomfortable with the atmosphere. For example, the FCs experienced unease, sadness, and helplessness because they wanted to be assured that their patients were offered good care and were not experiencing pain. It was considered important to be with the patient during the dying process. Sadness was a shared emotion among the FCs and patients. The family members knew that their relatives were dying, and most experienced deep sorrow as a result. As M2 explained,

I didn't want to see him suffer. When he was in distress, I couldn't help him. I felt pain. It had happened too fast. There were so many difficulties in front of me. I didn't know how to deal with his final hours (M2).

A second participant, F9, further explained, "I saw her getting thinner and thinner each day. I felt upset. I saw her in pain, and her condition deteriorated every day. I didn't know what to do. I felt helpless. The feeling was very uncomfortable. It seemed she was going to die soon" (F9).

## Discussion and recommendations

In this study, the author identified the major themes associated with caregiving experiences that influenced the bereavement process by conducting interviews with FCs. Caregiving was viewed as an opportunity to undergo personal growth by certain FCs. However, caregiving was reported by other FCs to have a negative influence on the bereavement process.

### *Truth-telling is challenging in the Chinese context*

Doctors in mainland China often inform family members of the true nature of a disease instead of informing the patient. The current study's implications can therefore apply to cross-cultural care settings involving culturally Chinese FCs and patients from outside of China. Cross-cultural differences are also reflected in the roles played by patients' families. In the Chinese context, the family serves as an integral part of treatment decision-making and as a gatekeeper. Critical information, such as cancer diagnosis, is disclosed, shared, absorbed, and addressed by the entire family. Core members of a Chinese family who typically make decisions for cancer patients include the spouse, adult children, or the spouse and adult children together, as was the case for M6. Based on the themes identified from the interviews, the following recommendations are given to help service providers implement culturally sensitive bereavement practices.

### *Discovering and creating meanings of burden and death*

The FCs reported that they felt confident and experienced their own sense of personal growth when they provided good care and observed their care recipients' positive responses. Meaning can be both discovered and created, suggesting that the FCs' conditions can be changed or transformed.

First, according to Confucian thought, the self is generally not expressed, which has an important impact on Chinese FCs' caregiving experiences. In China, clinicians assume that the value of filial piety causes the psychological distress (Wang et al., 2014). This study found the opposite that filial piety plays a protective role in limiting the negative effects of stressors, enhancing the

positive effects of appraising factors on caregiver burdens and strengthening norms related to parental authority (Pan, Jones, & Winslow, 2017).

Second, through their difficult caregiving experiences, the interviewed FCs found meaning in burden and death based on their values, choices and degrees of openness (Bogensperger & Lueger-Schuster, 2014; Kvåle & Synnes, 2017). Provisional and ultimate meaning were found to coexist (Gelkopf & Roe, 2014; Hasson-Ohayon, 2015). Provisional meaning refers to transitory experiences that provide meaning to life, while ultimate meaning refers to a person's exploration of the deeper meanings of life (Joarder, Cooper & Zaman, 2014; Missinne & Willeke-Kay, 1985).

### *Further assessment of clinical forms of distress observed in FCs and the bereaved*

The interviewed FCs were observed to experience or reported experiencing negative mood, a loss of interest in activities, and an avoidance of reminders of their loss. It remains unclear whether individuals who suffer greatly following the loss of a loved one experience symptoms because of the death or when their loved ones begin to experience death symptoms; whether grief is a proxy or is comorbid with prior depression for the caregivers in this study remain unclear (He et al., 2014; Xiu et al., 2017; Xu et al., 2015). Notably, depressive disorders and complicated grief frequently coexist (Boerner & Schulz, 2009). The findings might have clinical implications. Screening cancer caregivers who lost their loved ones for depression is of great importance. In future studies, researchers need to adopt clinical depression scales to measure depressive symptoms and to determine whether FCs meet clinical thresholds.

### *Oncology social workers and clinicians help ease the psychosocial symptoms of FCs*

Oncology social workers help families by reaching out and attending to the needs of FCs caring for terminally ill cancer patients. Referring an affected family to available social support resources and programs can also be empowering. With regard to "illness symptoms" and "the truth-telling process," oncology social workers and clinicians provided information to caregivers to ease their feelings of uncertainty (O'Brien & Steele, 2017).

Regarding "the moment of death" and "grief and loss," oncology social workers provided information to FCs regarding the distress associated with uncertainty and the actual moment of death. In terms of "social and professional supports," oncology social workers provided FCs with available resources. The study showed that many FCs in China might require oncology social workers to help connect them to appropriate resources.

## Summary

In this study, the author used quotes to illustrate the points raised in the discussion section, which included "truth-telling is challenging in the Chinese context," "discovering and creating meanings of burden and death," and "oncology social workers and clinicians help ease the psychosocial symptoms of FCs."

The study demonstrated that in the Chinese context, FCs faced cultural challenges with regard to truth-telling; however, their conditions could be transformed by discovering and creating a meaning for death. They also were observed to experience negative moods, so future researchers should recognize this

phenomenon and adopt clinical depression scales to measure depressive symptoms. FCs should pay more attention to the skills of how to disclose a cancer diagnosis. Oncology social workers can help families by reaching out and attending to the needs of FCs caring for terminally ill cancer patients.

### Limitations

This study presents certain limitations. First, it was conducted in one hospice unit in one city (Shenzhen) and cannot be generalized to FCs across China. Second, the FCs interviewed in this study generally had a positive relationship with their terminally ill cancer patients. FCs with a negative relationship with their patients may not have wanted to participate in the study. Third, the author interviewed each study participant only once. Multiple interviews could have provided the study participants more opportunities to reflect on their experiences and provide more nuanced data. Finally, although the interview data were translated by a certified translator, the author found that certain nuances of the transcripts were lost during the translation process.

### Conclusion

This study offers deep insight into how FCs experience the transition from hospice to bereavement and into their perspectives. The effect of the psychosocial needs of FCs and the profound effects on their lives were examined in-depth. The data on FCs suggest that they have unmet psychosocial needs and lack support from oncology social workers. Education and guidance resources that ease the psychosocial symptoms of FCs are needed. Before oncology social workers can adequately assist FCs with hospice care, several issues regarding FCs must be clearly identified.

First, the identified themes could be used as a framework for understanding the experiences of FCs. FCs have not received any education or training about hospice care. With further validation, this framework may prove useful for education and training.

Second, FCs caring for loved ones suffer from caregiver burdens throughout the death and dying process. Serving in a caregiving role increases one's risk of physical and mental morbidity (Rumpold et al., 2016). Psychological distress in FCs is eclipsed by the dying loved one. Some interviewees stated that they felt regret, fear, and sadness. Such distress may have negative effects on the care provided and thus on the well-being of the patient. To some extent, this study identifies issues that can both enhance and detract from FCs' bereavement experiences.


Third, the study findings suggest that some FCs struggle to cope with certain aspects of care both before and after the patient's death. Caregiving involves demanding tasks that require the dedication of significant time and psychological energy; therefore, although families can cope with the demands of caregiving, oncology social workers should be recognized as FCs' primary sources of support.

Fourth, few studies have explored FCs' experiences before and after the loss of a terminally ill cancer patient. The objective of this study was to address this gap by acquiring knowledge on the dimensions of the caregiving experience that influence FCs' bereavement. Change in FCs' psychological distress over time and how the factors associated with this distress vary throughout patients' cancer course. Further investigation is needed to assess the longitudinal trajectory of FCs' psychological distress because their needs likely change as the disease progresses and after death. Obtaining additional knowledge is imperative to better

respond to the needs of FCs. In this study, several FCs suffered chronic distress for months following the patient's death. Acknowledging the essential contributions of FCs and encouraging the development and continuity of social support initiatives that are better adapted to their needs is imperative.

Fifth, the practice of hospice care is relatively new in China. China is still a developing country and its social security system requires further improvement. Chinese people tend to personally provide end-of-life care to terminally ill patients rather than sending them to a hospice care center. Many scholars have studied the Chinese social welfare system from various perspectives (e.g., political science (Hsieh & Song, 2015), geography (Wang et al., 2015), demography (Imrohoroglu & Zhao, 2017), and economics (Ann et al., 2014)). The Chinese government has sought to create a new social security system based on individual employment contracts rather than holding employers primarily responsible for making contributions to medical insurance. In supporting the full integration of the hospice concept into the Chinese healthcare infrastructure, the government might also investigate the feasibility of a home hospice care structure, perhaps using inpatient facilities for a broader community care movement.

This study adds to the body of hospice care knowledge by explicating the voices of FCs in a Chinese terminal cancer context. The findings from this study can have an impact on social workers and clinical practice. With a growing number of Chinese people being diagnosed with cancer, this line of research will become increasingly important as the demand for informal caregiving increases in the future.

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