

# Challenges, personal growth and social support among family caregivers of terminally ill cancer patients in Southern China

Qualitative Social Work

0(0) 1–17

© The Author(s) 2018

Reprints and permissions:

sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/1473325018755890

journals.sagepub.com/home/qsw



**Yong Tang**

Shenzhen University, China

## Abstract

The purpose of this study was to obtain a deeper understanding of the experiences of family caregivers of terminally ill cancer patients in Shenzhen, Southern China. This study sought to describe how being the main caregiver influences family caregivers' daily lives. This article reports on the findings from individual interviews with 20 family caregivers of terminally ill cancer patients. The interview transcripts were analyzed using qualitative thematic analysis, which revealed that caring for a cancer patient over the course of his or her illness significantly affected many aspects of family caregivers' lives. Three major themes were identified in their experiences: (1) challenges, (2) personal growth, and (3) social support. In exploring these themes, this article offers insights into family caregivers' experiences in Southern China, particularly among family members of terminally ill cancer patients and presents implications for future professional practice, especially oncology social work.

## Keywords

Terminally ill cancer patients, family caregiver, challenge, personal growth, social support, oncology social work

---

## Corresponding author:

Yong Tang, School of Psychology and Social Work, Shenzhen University, Sheng 518060, China.

Email: tangyong@szu.edu.cn

## Introduction

Cancer affects not only patients but also family caregivers (FCs). A new report estimates that 4.3 million new cancer cases and more than 2.8 million cancer deaths occurred in China in 2015, with lung cancer being the most common type of cancer and the leading cause of cancer death. The incidence and mortality of cancer are increasing. Cancer is the leading cause of death in China and is a major public health concern (Chen et al., 2016). Research has found that problems associated with terminal cancer affect the quality of life of both patients and their families (World Health Organization, 2010). Caring for a dying family member with terminal cancer at home can lead to daily life burdens and challenges in daily life (Bee et al., 2009), social consequences (Northouse et al., 2012) and role changes (McCorry et al., 2009) in the lives of FCs. Providing care can also provide positive experiences (Bacon et al., 2009), personal growth, the needs for support (Kalmus, 2006), and changes in quality of life (Wang and Jiang, 2011). Although they are confronted with death daily, many FCs do not talk about death directly (Dumont et al., 2008).

Filial piety is a central value in traditional Chinese culture based on the strict principles of hierarchy, obligation and obedience; it has long influenced Chinese people, including FCs, particularly in relation to death. Although death is understood as a natural part of life, a unique belief about death has emerged among Chinese people post-integration.

Hospice care has also been influenced by traditional Chinese culture. It was introduced in China in the early 1990s but still faced big challenges, including insufficient economical input, traditional cognition about death and lack of professionals.

Most available studies that examine FCs have been conducted in Western countries, and few empirical studies have examined the experiences of FCs caring for terminally ill cancer patients in China. Better understanding of the needs of these FCs can help improve the care they and their loved ones receive. FCs experience a number of burdens during the caregiving process. Oncology social workers may help provide relevant services to FCs. This paper discusses how, in the Chinese context, FCs experience *living near a patient* with terminal cancer, how the terminal cancer affects the way they live and interpret their lives, and how they handle the various burdens and challenges they encounter. The paper aims to provide a deeper understanding of caring for terminally ill cancer patients in China and *suggests* implications for future professional practice, especially for oncology social work.

## Negative and positive experiences and social support among FCs

Significant research conducted outside of China has focused on the negative aspects of FCs' caregiving experiences. Studies have shown, for example, that FCs of cancer patients face a number of physical, social, and emotional problems

related to caregiving both during and after the patients' cancer treatment. FCs also experience varying emotional reactions to care-related stress, including uncertainty, helplessness, and a lack of control (Houldin, 2007). FCs take on many responsibilities and activities they are not ready to handle, and numerous studies have reported that FCs shoulder moderate or severe caregiver burdens, including depression, sleep disturbance, fatigue over time, and financial difficulty (Tuncay and Isikhan, 2010).

However, caring also has positive aspects and benefits for FCs, such as experiences of finding meaning, discovering personal strength and becoming stronger (Demiralp et al., 2010). Surveys in China have reported changes in the quality of life, psychological well-being, and level of social concern as well as signs of depressive symptoms among cancer FCs (Tang et al., 2007; Yang et al., 2012). However, few studies have focused on the challenges, personal growth, and social support among caregivers of terminally ill cancer patients in China.

## **The relationship between oncology social workers and FCs in the Western countries and in China**

FCs of terminally ill cancer patients experience many burdens as part of fulfilling their caregiving roles. Social workers may help provide relevant services to these FCs, but oncological social work has not yet been developed sufficiently in China to systematically provide such support.

In Western countries, oncological social work was one of the earliest fields in the emerging profession of social work, and *it is well developed* as a result. Some oncology social workers might have demanding jobs. They must address terminally ill cancer patients' pain, reactions, and feelings while also finding ways to separate themselves enough from these patients' experiences to protect themselves and preserve their own abilities to continue engaging compassionately. Over time, oncology social workers' services to patients and families have increased through various programs, and their collaboration with doctors has deepened. The work oncology social workers do in hospitals and other health-related areas has been systematically analyzed, tested, and empirically shown to be effective.

The role of oncology social workers has been well established, but there is still a shortage of oncology social workers. This shortage is expected to increase as the population ages, as patients with serious illness live longer, and as hospice care services expand into long-term care (Blacker et al., 2016; Liaw et al., 2016).

Nevertheless, the need for oncological social work services has been expanding. The demand for oncology social workers significantly exceeds their supply. Oncology social work is an important part of health care social work. Since 2000, when oncology social work was introduced in China, 34 hospice units have been established in hospitals.

As clinical practitioners, oncology social workers provide advocacy and clinical services to patients and their families; they work as important team members with

other health professionals. An oncology social worker who works with a family coping with cancer has information that can make those tasks easier for FCs. In addition to identifying the positive and negative consequences of caregiving for caregivers, this paper discusses the role of oncology social workers in supporting terminally ill cancer patients so that the energy of FCs can be focused on supporting the care recipient.

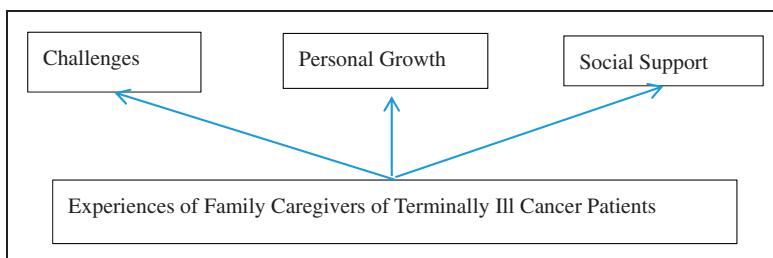
## Theoretical framework

The author's primary research focuses on oncology social work in China. Before starting the research, the author served on an academic faculty for 11 years. She was a visiting scholar for two years in the US, where her English was improved. From a strictly ethnographic point of view, she considered herself as an outsider and brought to the topic the advantage of distance and perspective, but she also regarded herself as an insider because she had provided caregiving for a cancer patient. All the interviews were conducted in Chinese.

The author used a social constructionist framework (see Figure 1) as a tool for understanding how the experiences of FCs shape their social realities as caregivers. Social constructionism is drawn from sociological theory and helps show how individuals and groups participate in creating their social life-worlds. Part of an individual's social reality or life-world is his or her lived experience, which can be considered in relation to specific topics of interest, such as caregiving. This framework enabled the author to examine the experiences of 20 FCs in terms of what they felt constituted caregiving and how they fulfilled their roles through specific caregiving behaviors. The author used this framework to guide this study, from the development of the interview guide to the interpretation of the results.

## Methods

This qualitative study used modified grounded theory as a method to guide the thematic data analysis (Strauss and Corbin, 1994). The research has been reviewed and approved by Shenzhen University's Research Ethics Boards.



**Figure 1.** Theoretical framework.

The author also served as the interviewer. The interviews were conducted in Chinese. The data were translated with the help of a certified translator who was also a lecture at Shenzhen University, China. During the interview process, she faced some challenges. For example, when some interviewees were asked to evaluate government hospice care services, certain dissatisfactions were not able to be readily expressed because, due to political constraints, interviewees worried about not receiving government funding if they expressed too much negative emotions. Some interviewees were not willing to tell the truth to their parents with cancer because they regarded it as unfilial action to the elderly. In relation to the data and participants' statements describing sadness when family members were growing thinner and dying, it was possible to explain more fully the meaning of these experiences in a Chinese context.

The study sample, 20 FCs of terminally ill cancer patients in a hospice care center at Shenzhen People's Hospital, located in Shenzhen, Southern China, was recruited between January and June of 2016 through a variety of convenience sampling methods. The hospice care center is one of the hospice care centers supported by the Li Ka Shing Foundation (LKSF), a Hong Kong-based charitable organization that was founded in 1980 by Hong Kong entrepreneur Li Ka-Shing. It initiated hospice service at Shantou Medical College in 1997 and expanded nationwide in 2002 to places such as in Shenzhen, Shanghai, and Changsha. These sites provide a wide range of community-based and in-home hospice and palliative care services (Li Ka-Shing Foundation, 2017).

Approximately 400 registered patients were admitted to the hospice unit. Two oncology social workers provided assistances by distributing study materials before the pilot study and contacting with 30 FCs who were willing to participate in the study. Ten FCs withdrew because the patients died or lived far away from the hospice unit. The author interviewed FCs in hospice centers because each FC went there to receive free pain medication for the care recipient every week.

The sample of 20 FCs (13 females and 7 males) comprised 10 spouses, 3 sons, 3 daughters, 2 fathers, and 2 mothers. At the time of the interview, participants were between 32 and 68 years of age. The cancer diagnosis of the participants' loved ones varied (see Table 2).

All 20 participants were an FC of a terminally ill cancer patient, and they were interviewed either at their homes or in the hospital. Participants were required to complete an informed consent form before the interviews were conducted. All interviews were tape-recorded and transcribed verbatim by the researcher. Participants included males and females, and all were at least 18 years old. To ensure that the interviews offered breadth and depth, the author sought out participants with diverse family situations, occupations, and family member diagnoses. Each interviewee agreed to participate after being invited, and none withdrew at any point during the study. Participants were assured that their responses would be confidential and that their participation in the study was voluntary.

The China Association of Social Work Education organized eight universities to participate in a project about hospice care supported by LKSF. The project

involved FCs, oncology social work, and hospice care. The questions discussed in this paper are parts of the above project. The interview schedule was designed to yield exploratory, descriptive, and primarily qualitative data about the overall caregiving experience, as well as more specific questions related to the demands this role placed on the caregivers' lives. Participants were asked three open-ended questions: (1) "Can you tell me about the challenges you experience in caring for your family member with terminal cancer?" (2) "Can you tell me about the aspects of caring for your family member with terminal cancer that feel like accomplishments?" and (3) "Can you tell me how oncology social workers and family members provide support to you when you face troubles or difficulty?" Each interview lasted approximately one and a half hours.

The interview audiotapes were transcribed verbatim by a professional transcriber to facilitate the analysis. The data were analyzed using a thematic analysis approach (Strauss and Corbin, 1994), which involved the below-described interactive process of examining the transcripts throughout the data period. The data were independently coded through an open coding process, which led the author to arrive at substantive codes. Two Master of Social Work students from Shenzhen University were involved in the interview and coding processes. Central themes were derived from this process. In this process, the author first read the transcribed interviews from beginning to end. Then, in the second reading, the author focused specifically on implicit issues to obtain a clearer understanding. Drawing on the work of Kuzel and Like (1991), the author summarized and paraphrased her interpretation of the information that the FCs conveyed in their interviews and then asked an independent reviewer to look for themes from two randomly selected interviews to check for inter-coder reliability. The themes identified by the author and by the independent reviewer were compared, and agreement was observed across all major themes (see Table 1).

## Results

The first major theme was labeled "challenges." When FCs summarized their negative experiences during the interview, some changes that had taken place in their

**Table 1.** Example of data analysis process.

Example of quotation/meaning unit	Categories	Sub-theme(s)	Theme(s)
Obviously, it was a terrifying period both for my husband and us. I was really tired.	Vulnerability loneliness	Depression, sleep disturbance, fatigue over time	Challenges
Sometimes I sat down in the square and cried. At that time, I was very vulnerable.		Stress process Emotional responses	

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

Interviewee	Caring time	Relationship with patient	Age	Diagnosis
F1	Three months	Spouse	65	Lung cancer
F2	One year	Spouse	68	Gastric cancer
F3	Nine months	Daughter	42	Breast cancer
F4	Seven months	Spouse	49	Liver cancer
F5	Five months	Daughter	47	Cervical cancer
F6	Four months	Mother	65	Breast cancer
F7	Two months	Spouse	62	Colon cancer
F8	Eight months	Mother	68	Gastric cancer
F9	One year	Spouse	70	Lung cancer
F10	Nine months	Spouse	58	Cancer in the bones
F11	Five months	Spouse	53	Gastric cancer
F12	Two months	Spouse	67	Liver cancer
F13	Three months	Daughter	46	Cervical cancer
M1	Two months	Son	70	Lung cancer
M2	Four months	Son	32	Liver cancer
M3	One year	Spouse	59	Breast cancer
M4	One year	Son	43	Nasopharynx cancer
M5	Six months	Father	62	Gastric cancer
M6	Five months	Father	58	Pancreatic cancer
M7	Seven months	spouse	64	Colon cancer

Note: "F" or "M" next to a respondent's number indicates that the participant was female or male, respectively.

lives represented significant challenges across three sub-themes: "depression, sleep disturbance, and fatigue over time"; "stress"; and "grief and loss". The second major theme, "personal growth," is the author's interpretation of the positive meaning FCs attached to their narratives; it also includes three sub-themes: "relationships with other relatives," "perspectives on life," and "changing life goals." The third major theme, "social support," includes "formal social support from oncology social workers," and "informal social support from family." These three main themes were then divided into 10 sub-themes (Table 3), each of which is outlined below with direct quotations from the text.

### **Challenges**

FCs face many challenges after a loved one is diagnosed with cancer. Some FCs knew that their relative received a cancer diagnosis, but they had not expected that their relative's health would deteriorate so quickly, which intensified the challenges they faced.

**Table 3.** Thematic analysis.

Major themes	Sub-themes
Challenges	Depression, sleep disturbance, and fatigue over time Stress Grief and loss
Personal growth	Relationships with others Perspectives on life Facing fears Changing life goals
Social support	Formal support from oncology social workers Informal support from family members

*Depression, sleep disturbances, and fatigue over time.* The caregivers seemed to expect that fatigue would be a part of their caregiving experience, but it was not considered a major concern or something that they would come to experience as a burden. As F2 described it, “I was very tired because I had to take care of my husband and my children at the same time. I had lost my weight. I could not sleep.”

F4 said, “*I had to perform the housework and work in the office. I felt tired. Even now, I don't know how I managed.*”

*Stress:* Caregiving for a loved one with a terminal cancer diagnosis was extremely stressful for participants. The patients' symptoms and personal care needs were the primary stressors. For FCs who observed their own situation as exhausting, stress related to caregiving seemed to influence other aspects of their lives, as well.

M4 said, “I had no time to connect with my friends because I had to devote so much of my time to caring for my father.”

F13 said, “I always had to get up in the middle of the night because my mother sometimes needed to change her clothes.”

*Grief and loss.* The caregivers acknowledged their vulnerabilities and their paradoxical feelings about their relatives' progressive decline. F7 said, “*I didn't want to see him suffer. When he was in distress, I couldn't help him. It was painful for me.*”

The FCs experienced loss not only at the time of the patient's death but also throughout the whole caregiving process. In general, the FCs felt that doctors had not tried their best to treat their loved ones. When the patients entered the terminal stage of cancer, FCs and the patients felt uncomfortable with the atmosphere. Sadness was a shared emotion among FCs and the patients. The family members knew that their relatives were dying, and most of them experienced deep sorrow as a result.

F9 said,

I saw him getting thinner and thinner each day. I felt upset. I saw him in pain and his condition deteriorated more every day. I didn't know what to do. I felt helpless. The feeling was very uncomfortable. It seemed he was going to die soon.

### ***Personal growth***

For many participants, caring for a relative with terminal cancer and facing the likelihood of that person's imminent death facilitated personal changes and growth within them. Four sub-themes pertaining to the sense of growth emerged from participants' accounts: "relationships with others," or the changes in their ways of relating to other relatives; "perspectives on life," or changes in participants' perspectives on their own lives; "facing fears," or confronting difficult and frightening things in their lives; and "changes in life goals," or refocusing their own life goals.

***Relationships with other relatives.*** The FCs often interpreted this as being caused by participants' changed attitudes toward relationships and their revaluing of connectedness, which tended to result in the resolution of past interpersonal conflicts within their families. The term "filial piety" refers to the extreme respect that Chinese adult children are supposed to show their parents; it includes many different components, including taking care of their parents and burying them properly after death, etc. This is illustrated by F6's account:

Of course, my mother was a huge part of that, of my changing attitudes and the way I thought and the way I lived. It made me go on my journey too to get myself in order and to repair damages that had been done within family and so on.

F8 said,

My mother will pass away soon. And I'm just sorry she wasn't here so I could tell her, but I was able to repair a few issues with family; that was because I was caring for her and I could see the sadness in her.

***Perspectives on life.*** Because they had experienced the challenges and difficulties associated with caring and had to witness the suffering and death of their loved ones with cancer, some participants experienced changes in their own perspectives on life. They described these changes as positive and rewarding. As F13 said, "I can experience the world because of my caring role and subsequent bereavement."

M4 said, "I think taking care of mother is one of my responsibilities. It will also serve as a good example for my children."

***Facing fears.*** The participants were also compelled to face their fears and their own shortcomings. This was not always easy, but the FCs understood it as an ongoing personal development process. As F12 said, "I found caregiving was not simply a matter of giving; it was also about receiving. My dying family member would share valuable insights."

*Changing life goals.* Some participants refocused their life goals as a result of their caregiving experiences. They had changed their attitudes about money, life, and relationships. As M3 said, "Now I treasure the relationship with my family members, not money. I now spend much more time with the kids to fulfill my wife's wishes."

F4 said, "In the process of taking care of my family, my psychological pain was indescribable. Now I built up my confidence from that feeling of helplessness."

### **Social supports**

Social support can assist caregivers of cancer patients with continuing treatment. Formal and informal social support helps provide emotional assistance.

*Formal social supports from oncology social workers.* Oncology social workers provide formal social support to terminally ill cancer patients. As part of the cancer care team, they provide emotional support and address complex family or social concerns that can arise at the end-stage of cancer treatment.

As F3 described, "The cancer diagnosis was a shock to the family, mentally, emotionally and physically. An oncology social worker works closely with us. We have various problems that occur around us."

*Informal social supports from family.* Informal social support, such as support from other family members and friends, is very helpful for FCs and terminally ill cancer patients. These networks play an important role in assisting FCs and terminally ill cancer patients in coping with the disease. Informal social support is part of the patients' total treatment experiences. As F3 said, "When I felt bad, my husband often enlightened me. Death is another kind of relief. He asked me to relax."

As F8 described, "When I feel tired from when taking care of my mother, my daughter will give assistance to me and let me rest."

## **Discussion**

### **Challenges and struggles**

Given the rising number of oncology patients in China, the need for FCs is also increasing. If patients and their FC are viewed as a unit, then the FC has a natural place in caring for the patient. To some interviewees, death is threatening. It devastates life and poses challenges and threats. FCs know that death is lonely and unknown, and they consequently constantly struggle with tensions and dilemmas during intense caregiving periods such as the ones described here; these challenges can dramatically change their whole lives. A number of studies have shown that the FCs of cancer patients experience various physical and emotional symptoms as a consequence of their role (Northouse et al., 2010; Ramos and Fulton,

2017). Depression is the most frequently mentioned symptom among FCs (Lai et al., 2017).

### *Caring is regarded as a personal growth experiences*

The positive aspects of caring identified by bereaved cancer caregivers in the present study reveal ways in which bereaved cancer caregivers can be supported. Notwithstanding the large body of research on bereavement issues for informal cancer caregivers, much of the research and theory on bereavement have positioned the responses to loss within a pathological frame (Bonanno, 2004). That is, such studies tend to see bereavement as an emotional response that may require medical or psychological interventions. From this perspective, it is understandable that some participants could construct their caring as a “personal growth experience.” Considering these findings, more emphasis must be placed on the various aspects of caregiving. Informal caregivers construct positive and rewarding experiences as a way to attain a broad understanding of the informal cancer caring experience. They can incorporate the above knowledge into interventions aimed at improving coping with caring as well as with loss.

### *Discovering and creating meaning*

The inner strength that sustained these participants came mainly from the love they felt for their relatives and from the validation and confirmation their relatives gave them as they performed caregiving tasks. In Confucian thought, the “self” is generally not expressed or manifested, and this has an important impact on caregiving. Chinese FCs are generally assumed to be insulated from psychological distress related to caregiving because strong cultural norms around filial piety tend to give families more traditional caregiving ideologies (Han et al., 2014). However, filial piety can also increase the strength of norms related to parental authority and family hierarchy, thereby causing additional conflicts and further contributing to the level of emotional distress Chinese FCs experience. “Filial piety” served as a protective function to reduce the negative effects of stressors and to enhance the positive effect of appraisal factors on caregiver burden.

The author translated spirituality, a Western conceptualization, into a Chinese context to elucidate this idea. In this view, Chinese desires for materials progressed after the collapse of the Qing Empire, leading Chinese intellectuals to launch a frontal attack on Confucian spirituality, which was seen to have caused China’s decline. Only after the development of Xiaoping Deng’s socialism with Chinese characteristics did Chinese intellectuals can again develop Neo-Confucian spirituality.

An existential perspective suggests that the process of finding meaning through difficult life experiences is based upon the values one embraces and the choices one makes, as well as one’s willingness to assume responsibility for one’s actions (Bogensperger and Lueger-Schuster, 2014).

The caregivers reported finding provisional meaning when they observed their care recipient's positive response to care, felt confident that they were providing good care, and experienced their own senses of personal growth or development as a result of caring for their relative in China (Lan, 2017; Ma, 2009). Meaning can be both discovered and created. This suggests that one's situation can be changed or transformed, and such a process can turn even mundane elements into positive experiences.

### ***Experiencing anticipatory grief at the upcoming loss of the care recipient***

FCs often felt grief, even though the person for which they were caring was still alive. This can occur when the person being cared for had a life-limiting condition. Although not everyone experienced anticipatory grief, some FCs felt the same emotions of mourning as if the person had already died. FCs might have a wide range of emotions, such as loss, guilt, and anxiety. FCs' grief might experience may not initially be for the person they cared for, but for the life they were leading. FCs might feel guilty about feeling this way, but it is a natural reaction to such a big change. Grieving before the person dies did not preclude FCs from grieving when they eventually passed away. Everyone reacted differently to these circumstances.

### ***Strategies for strengthening the role of oncology social workers***

Further interdisciplinary training opportunities should be provided to oncology social workers to encourage a deeper understanding of their roles and responsibilities. As oncology social workers provide innovative responses to the needs of vulnerable patients, they develop considerable expertise to further illuminate the role of their profession in healthcare. Further opportunities should be provided to enable them to share their skills and expertise.

## **Implications for end-of-life practice**

### ***Cross-cultural issues related to disclosure to terminally ill cancer patients***

This study concludes that a majority of the respondents would not inform a member of their own family if that person had a terminal disease. For many Chinese, not telling a patient his/her cancer diagnosis is a way for the family to protect the patient from further harm from the diagnosis and to preserve both individual and family harmony (Jiang et al., 2007). Oncology social workers have indicated that there is a clear need for more open disclosure of cancer diagnoses in all cultures (Martinez and Hebl, 2016).

The need for ethnic sensitivity in end-of-life care is well known, but the variations in care across cultures are less known (Hopp and Duffy, 2000). It is essential to understand that death in traditional Chinese culture is the foundation of the

family. Nonetheless, Chinese political policies and cultures continue to lag behind in this respect. Death used to be seen as taboo in China, but with its increasingly aging population, the country is tackling this dire issue. Under the influence of Confucian values, filial piety is highly valued in the Chinese cultures. Family is the predominant support mode in the Chinese community, and Chinese FCs are eager to provide care as a result of filial piety and familial obligations. It was the weakness of Chinese political policies, and the traditions of Confucianism that made China lag behind in end-of-life care.

Compared with their Western counterparts, doctors in Asian countries are more likely to withhold unfavorable information from patients at the family's request and to give treatments known to be ineffective (Chen et al., 2012). In Chinese culture, the family is an integral part of treatment decision-making and plays the role of a gatekeeper. Critical issues, such as a cancer diagnoses, are disclosed, shared, absorbed, and addressed by the entire family. Core family members who usually make decisions for cancer patients include the spouse, the adult children, or the spouse and adult children together. In this study, M5 said, "I don't want to tell the truth to the patient, but the oncology social worker advised me to tell my father the truth." Oncology social workers play a crucial role in helping FCs handle the disclosure of the bad news to dying family members.

In traditional Chinese culture, death is regarded as unlucky, for example, people who fear death are also more likely to believe that talking about death can bring bad luck. The predominant values of family harmony in Chinese society have determined the truth-telling approach in cancer care.

### ***Oncology social workers can mobilize support for FCs***

Social workers can make a difference for families by reaching out and attending to the needs of FCs caring for terminally ill cancer patients. Oncology social workers can provide information to FCs about the distress associated with uncertainty and the actual death event. Referring the family to available sources of social support and programming can also be empowering. Information provided to caregivers reduces their feelings of uncertainty.

The problems in China's social security system can be traced back to two key events: the break-up of the state-run economy and the creation of a new social security system based on individual employment contracts rather than the state being primarily responsible for contributions to pensions, medical insurance, etc.

FCs are regarded as the terminally ill cancer patients' most important supporter. They need oncology social workers to direct them to available resources. Many FCs in China may need oncology social workers to help connect them with appropriate resources. As M4 said, "Because my son suffered from liver cancer, it caused our family economic difficulty. One oncology social worker helped me apply for government subsidies to alleviate these economic pressures."

### ***Social work education curricula should include oncological social work competencies***

For oncology social workers, an important next step is to incorporate these kinds of competencies into social work education curricula at both research and practice levels of training. There is always a gap between research and practice with regard to supporting FCs. FCs need assistance in learning how to connect with other FCs and must receive emotional and social support services. Research has identified insufficient educational preparation as a barrier to effective and ethical practice in end-of-life care (Li et al., 2012). Oncology social workers in China state that they are inadequately prepared to work with dying and grieving clients (Gao and Yan, 2015). These competencies can be utilized to build relevant social work curricula at the bachelor's and master's levels as well as professional development and training programs. Incorporating this knowledge into social work curricula can help address this significant educational gap and enhance the contributions of social work to meaningful and effective end-of-life care.

This study provides valuable information for oncology social workers seeking to provide culturally responsive services and support in the final stage of cancer patients' lives.

### ***Oncology social workers are important for terminally ill cancer patients***

Oncology social workers are key members of medical teams in oncology settings and provide crucial services to patients and caregivers. Social workers should be more involved in research to validate their role in oncological care and to reinforce their roles as advocates for person- and family-centered care.

This study shows the importance of affirming the valuable contributions caregivers make and supporting them in finding positive meaning in their experiences. In the caregiving process, oncology social workers play a significant role in helping caregivers manage the multiple burdens and demands that caregiving places on their lives. Oncology social workers help patients and their family members cope with or adjust to illness and guide individuals and family members through health-care systems. The role of the oncology social worker is an integral and fundamental part of oncology care, and patients view that person as their emotional, spiritual, physical, and social health support.

The discrepancy in the interdisciplinary views of the role of an oncology social worker comes from what has previously been termed counseling or a practice concerned with emotional and behavioral problems. Social workers see these areas as a central part of their role, whereas other groups expect social workers' jobs to revolve around planning discharge, assisting clients with financial problems, and linking clients with needed community resources. As F9 said, "The oncology social worker helped me. She gave me the necessary financial information. I applied for 5,000 RMB. This eased my economic burden and enabled me to better accept the death."

### ***Need for policy on end-of-life care***

Establishing practice guidelines and appropriate policies are also important steps for China to undertake to overcome current obstacles to delivering end-of-life care. As in other parts of the world, the availability of specific guidelines and protocols for managing pain and other symptoms may support end-of-life care, as might specific symptom management coursework in oncology training programs.

### ***Implications for practice and education***

The current study results have implications for practice and education in other cities in China. From a practical perspective, it is important to understand the positive aspects of being an FC of a terminally ill patient. From an educational perspective, it is critical to balance descriptions of the downsides of FCs with the satisfaction of the work. Education on the positive elements of FC should be included in communications related to hospice care topics.

### **Limitations**

This study contains some clear limitations. First, findings from one hospice center in one city (Shenzhen) cannot be generalized to all FCs in China nationally. Second, the FCs in this study had a largely positive relationship with terminally ill cancer patients. However, the findings must be interpreted in the context of a hospice care setting in which caregivers receive support from hospice social workers. Third, the author interviewed each study participant only once. Multiple interviews would have given study participants the opportunity to think through their experiences and thus provide richer data.

### **Conclusions**

Social workers play an important role in the delivery of hospice care. Most social work practitioners will at some point in their careers encounter adults, children, and families who are facing progressive life-limiting illness, dying, death, or bereavement. Such social work interactions occur not only in health care settings but also wherever social workers practice.

This study adds to the body of social work knowledge by explicating the voices of FCs in a Chinese terminal cancer context, and it elucidates the caregiving experience from the perspective of caregivers attending to terminally ill patients with cancer. The findings from this study can have an impact on social workers and clinical practice. In addition, social workers must identify the spiritual, psychological, and physical needs of caregivers so that they can provide culturally sensitive care.

With the growing number of Chinese adults reaching old age in poorer health than previous generations, this line of research will become increasingly important as the demand for informal caregiving increases in the future.

## 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: The research received financial support from The National Social Science Fund (15BSH110).

## References

- Bacon E, Milne DL, Sheikh AI, et al. (2009) Positive experiences in caregivers: An exploratory case series. *Behavioral and Cognitive Psychotherapy* 37(01): 95–114.
- Bee PE, Barnes P and Luker KA (2009) A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *Journal of Clinical Nursing* 18(10): 1379–1393.
- Blacker S, Head BA, Jones BL, et al. (2016) Advancing hospice and palliative care social work leadership in interprofessional education and practice. *Journal of Social Work in End-of-Life & Palliative Care* 12(4): 316–330.
- Bogensperger J and Lueger-Schuster B (2014) Losing a child: Finding meaning in bereavement. *European Journal of Psychotraumatology*. Epub ahead of print 31 March 2014. DOI: 10.3402/ejpt.v5.22910.
- Bonanno GA (2004) Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist* 59(1): 20.
- Chen CH, Tang ST and Chen CH (2012) Meta-analysis of cultural differences in western and Asian patient-perceived barriers to managing cancer pain. *Palliative Medicine* 26(3): 206–221.
- Chen W, Zheng R, Baade PD, et al. (2016) Cancer statistics in China, 2015. *CA: A Cancer Journal for Clinicians* 66(2): 115–132.
- Demiralp M, Hatipoglu S, Iyigun E, et al. (2010) Living with a malignant musculoskeletal tumor: Experiences of family caregivers. *Orthopaedic Nursing* 29(2): 86–91.
- Dumont I, Dumont S and Mongeau S (2008) End-of-life care and the grieving process: Family caregivers who have experienced the loss of a terminal-phase cancer patient. *Qualitative Health Research* 18(8): 1049–1061.
- Gao JG and Yan MC (2015) Social work in the making: The state and social work development in China. *International Journal of Social Welfare* 24(1): 93–101.
- Han Y, Hu D, Liu Y, et al. (2014) Coping styles and social support among depressed Chinese family caregivers of patients with esophageal cancer. *European Journal of Oncology Nursing* 18(6): 571–577.
- Hopp FP and Duffy SA (2000) Racial variations in end-of-life care. *Journal of the American Geriatric Society* 48(6): 658–663.
- Houldin AD (2007) A qualitative study of caregivers' experiences with newly diagnosed advanced colorectal cancer. *Oncology Nursing Forum* 34(2): 323–330.
- Jiang Y, Liu C, Li JY, et al. (2007) Different attitudes of Chinese patients and their families toward truth telling of different stages of cancer. *Psycho-Oncology* 16(10): 928–936.

- Kalnins I (2006) Caring for the terminally ill: Experiences of Latvian family caregivers. *International Nursing Review* 53(2): 129–135.
- Kuzel AJ and Like RC (1991) Standards of trustworthiness for qualitative studies in primary care. In Norton PG, Stewart M, Tudiver F, Bass MJ and Dunn EV (eds) *Primary Care Research: Traditional and innovative approaches*. Thousand Oaks, CA: SAGE, pp.138–158.
- Lai C, Luciani M, Di Mario C, et al. (2017) Psychological impairments burden and spirituality in caregivers of terminally ill cancer patients. *European Journal of Cancer Care*. Epub ahead of print 14 March 2017. DOI: 10.1111/ecc.12674.
- Lan SJ (2017) Personal growth of social worker practitioners in China. *China Social Work* 13: 30–31.
- Li Y, Han W and Huang C (2012) Development of social work education in China: Background, current status, and prospects. *Journal of Social Work Education* 48(4): 635–653.
- Li Ka-Shing Foundation (2017) Available at: [www.ksli.com/](http://www.ksli.com/) (accessed 12 January 2018).
- Liaw SN, Sullivan A, Joselow M, et al. (2016) Impact of an interprofessional training program in pediatric palliative care on interprofessional competencies and career development of former fellows (S780). *Journal of Pain and Symptom Management* 51(2): 451–452.
- Ma HB (2009) Self-exploration and personal growth of social workers: An example of social workers in Longxiang social work services. *Social Work* 11: 48–49.
- Martinez LR and Hebl MR (2016) Adult survivors of childhood cancers' identity disclosures in the workplace. *Journal of Cancer Survivorship* 10(2): 416–424.
- McCorry NK, Dempster M, Clarke C, et al. (2009) Adjusting to life after esophagectomy: The experience of survivors and carers. *Qualitative Health Research* 19(10): 1485–1494.
- Northouse LL, Katapodi MC, Song L, et al. (2010) Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians* 60(5): 317–339.
- Ramos K and Fulton JJ (2017) Integrating dignity therapy and family therapy in palliative care: A case study of multiple sclerosis, depression, and comorbid cancer. *Journal of Palliative Medicine* 20(2): 115–115.
- Strauss A and Corbin J (1994) Grounded theory methodology. *Handbook of Qualitative Research* 17: 273–285.
- Tang ST, Li CY and Liao YC (2007) Factors associated with depressive distress among Taiwanese family caregivers of cancer patients at the end of life. *Palliative Medicine* 21(3): 249–257.
- Tuncay T and Isikhan V (2010). Psychological symptoms, illness-related concerns and characteristics of relatives of Turkish patients with cancer. *Asian Pacific Journal of Cancer Prevention* 11(6): 1659–1667.
- Wang JH and Jiang YF (2011) The investigation of caregiver burden of end-stage digestive system cancer patients. *Journal of Nursing* 30(2): 23–29.
- World Health Organization (2010) Definition of palliative care. Available at: [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/) (accessed 12 January 2018).
- Yang X, Wang L, He J, et al. (2012) Factors related to depressive symptoms among Chinese caregivers of cancer patients. *Psycho-Oncology* 21(10): 1063–1070.