



Understanding the experiences of older caregivers of patients with lung cancer during palliative chemotherapy in China: a qualitative study

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Received: 26 January 2022 / Accepted: 20 June 2022 / Published online: 28 June 2022
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Abstract

Purpose Although there has been an increase in research on caregivers of patients with cancer, there has been little focus on the specific experiences of older caregivers of patients with lung cancer and the effect of their cultural backgrounds on their experiences. This study explored the caregiver experience among the ageing population in China.

Methods Older caregivers of patients with lung cancer undergoing palliative chemotherapy were recruited. Data were collected using a qualitative descriptive design involving semi-structured interviews, which were recorded, transcribed verbatim and analysed qualitatively using inductive content analysis.

Results Eighteen caregivers aged 61–81 years completed the interviews. The following four themes were identified: physical difficulty, living with ambivalence, perception of role and role-related behaviour changes. These themes enabled a greater understanding of role-related behaviours in older caregivers and their challenges in addressing biological and psychosocial challenges related to older age.

Conclusion The present study highlighted the vulnerability and perceived challenges of the role of older caregivers. These findings help lay the foundation for interventions to improve the care provided to caregivers and their health outcomes, especially caregivers with chronic conditions.

Keywords Experience · Older caregiver · Lung cancer · Palliative chemotherapy · Qualitative study

Introduction

With an estimated 2.2 million new cancer cases in 2020, lung cancer is the second most common cancer worldwide with an estimated 0.82 million new cases in China [1]. Many patients are offered palliative chemotherapy rather than curative interventions to prolong their life [2]. Caregivers are an integral part of the cancer care system, and health-related aspects among patients and caregivers are interdependent. Adverse health outcomes of caregivers associated with caregiver burden, including social isolation [3], anxiety and

depression [4], have been identified as serious mortality risk factors for the patients they care for during palliative chemotherapy [5].

Rapidly ageing populations across the world present significant challenges to traditional family structures and social care models; older adults are increasingly serving as caregivers for sick spouses and other relatives [6]. The number of older caregivers in both absolute and proportional terms is increasing, and they are part of an integral but often ‘invisible’ workforce in the long-term care system [7]. Older caregivers reported more negative health changes, such as struggles with stress, exhaustion, sleep and pain [8], because of caregiving and mental health problems than that reported by young caregivers [9]. Thus, older caregivers were at more risk of health deterioration from caregiving-associated factors. However, caregiving gains may buffer the detrimental impacts of care-related stressors [4]. Caregivers’ abilities to derive meaning from their caregiving were reported to have a positive impact on their spiritual well-being [10]. A review stated that the deterioration of caregivers’ health can affect the quality of care they provide

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[11]. In the USA, 80% of adults aged ≥ 65 years report two or more chronic conditions [12]. Older caregivers with multiple chronic conditions (MCCs), such as hypertension and diabetes, are more likely to experience various adverse outcomes that impede their ability to provide care, making their work seem less rewarding to them [13].

Although research on the caregivers of patients with cancer has explored different aspects of their experiences, including emotional and physical problems, uncertainty of and preparation for the caregiving role [14–16] often aligned conceptually with stress–process frameworks [17]. The age of most caregivers reported in previous studies is varied. Older caregivers are likely to face distinct experiences and challenges because their chronic conditions lead to adverse outcomes and involve more complicated coordination of the care they provide. Furthermore, culture continues to have a strong impact on the motives of caregivers, their coping strategies and the resources used in caregiving [18]. Caregiving is essential and unique in Chinese culture, which can be explained by collectivism and Confucianism; individuals put their family's interests above their interests [19]. Recently, attention of health policymakers has been increasingly directed towards caregivers. However, little is known about how older caregivers' roles affect caregiving experiences, particularly in China. There is a need to examine the experience of older caregivers of patients with lung cancer during palliative chemotherapy, which can help healthcare providers plan training-support programmes compatible with caregivers' experiences.

Methods

This qualitative descriptive study involved participants sharing their experiences through in-depth interviews. The Standards for Reporting Qualitative Research guided the reporting of this study [20].

Participant recruitment

The participants were recruited from June to November 2021 from a tertiary comprehensive hospital in China

by purposive sampling. The sampling approach aimed to enhance the range of variation in the qualitative data obtained from caregivers. Caregivers who met the inclusion criteria and provided consent participated in this study. The inclusion criteria were as follows: caregivers of patients with lung cancer undergoing palliative chemotherapy, age of ≥ 60 years, caregivers with a family relationship with care recipients, those who could understand the questions and express himself/herself clearly in Mandarin. Participants with cognitive impairment or those who declined to participate in the study were excluded. Participant recruitment ended no new information emerged from the participant responses [21]. The local ethics committee approved this study.

Data collection

Data were collected via individual face-to-face, semi-structured interviews conducted by the first author, who was formally trained in qualitative research. The data collected were anonymised to reduce potential bias. The interview guide (see Table 1), which was pre-tested with two caregivers to assess its appropriateness and the caregivers' understanding of the questions, was developed based on a literature review and focused on exploring the experiences of the caregiver. The interviewer asked open-ended questions and asked for elaboration on certain topics or prompted the caregiver to recount in more detail about their experiences when their responses were unclear. Meanwhile, handwritten field notes were used to comment on impressions, environmental contexts and non-verbal cues and to record reflections and summaries. The time and location of the interviews were arranged according to the participants' convenience. Privacy was assured at all the interview venues, enabling the participants to talk freely about their caregiving experiences without any disruptions or concerns.

Data analysis

The interviews were audiotape-recorded, transcribed verbatim, proofread and subjected to inductive content analysis, an analytical process that allows researchers to conduct

Table 1 Semi-structured interview guide

No	Interview questions
1	Can you describe your experiences with caregiving?
2	Can you give me some insights into meaningful moments and hard moments during caregiving?
3	Can you explain how your daily life (such as family/work/social relationship) has changed after caregiving and how caregiving affects your life?
4	What does caregiving mean to you?
5	What do you think about its risks and benefits?
6	Is there anything else you would like to add about your experience of caregiving?

open-coding, create categories and abstract study data [22]. This method was chosen because the existing knowledge of research-related phenomena was fragmented [23]. Transcripts were read line by line by three researchers independently (MX, XC and HZ) after one interview was completed and then sent to the participants for them to verify if it is an accurate reflection of their experiences. Three independent coders (HZ, YZ and JL) analysed the transcriptions and generated a list of codes. Constant comparative analysis was used to compare the codes and data within and across transcripts [24]. Subsequently, codes were organised into sub-themes and then into themes until consensus was reached to provide an inclusive description of participants' perspectives. Any differences in the data interpretation were discussed among all team members to ensure accuracy and consistency and to maintain the integrity of the data.

Results

Data saturation was reached after 18 interviews (20 were invited, and two declined with reasons of no time or no interest). The interviews had an average duration of 53.8 min (range=36.0–77.0 min). The participants' characteristics are presented in Table 2. Participants were aged 61–81 years (see supplementary S1). The caregivers' experiences were categorised into four main themes, physical difficulty, living with ambivalence, role perception and role-related behaviour changes.

Theme 1: physical difficulty

Illness distress

Most participants experienced MCCs that jointly predisposed them to vulnerability during caregiving. Although no participant reported having poor functional capacity during the interview, they described diverse physical discomforts, which caused additional stress during caregiving alone because of their age and chronic diseases.

'You know, I am 70. Five years ago, the doctor told me that I had diabetes, and since then, I have been living with anxiety and fear. But now that she's sick...I live more intensely, and this is difficult...I can't be sick'. [C3]

Self-regulating fatigue

Fatigue was an important consideration for older caregivers as some participants indicated that they felt tired and powerless while performing certain tasks, such as medication administration and management of symptoms during caregiving, which

Table 2 Description of the participants

Participant characteristic	Mean \pm SD (min–max)	Number of participants (%)
Age (years)	68.28 \pm 5.20 (61–81)	
Duration of caregiving (month)	9.17 \pm 9.25 (1–29)	
Gender		
Female		11 (51.1%)
Male		7 (38.9%)
Education		
Elementary		9 (50.0%)
Junior high school		4 (22.2%)
High school or above		5 (27.8%)
Relationship		
Spouse		9 (59.0%)
Parents		2 (11.1%)
Adult children		5 (27.8%)
Siblings		2 (11.1%)
Number of chronic conditions		
0		1 (5.6%)
1		8 (44.4%)
2		5 (27.8%)
3		2 (11.1%)
4		2 (11.1%)

did not permit the caregiver to move and further complicated the caregiving process. Meanwhile, some expressed that living in such an environment took away their joy.

'It's a long-term thing. After a while you know it gets very tiring, and I get tired much more easily...everything is waiting for me ...'. [C15]

'I feel tiredness and powerlessness, and I don't know what to do... Everything is boring'. [C13]

Theme 2: living with ambivalence

Emotional difficulties and harvest

The caregivers experienced emotional ambivalence, with feelings of hope, uneasiness and sadness, which revealed that their life experiences were marked by symbiotic processes and emotional dependence.

'I could never believe that my wife was suffering from cancer (lung). I got sad more often than angry...I do not understand what to do when she cries out in agony...it was very tough'. [C10]

Several also said that despite knowing what was going to happen, they still held onto hope for a miracle. This was

perhaps also a state of denial where grief was put on hold. At the same time, sickness causes family members to grow closer and become better people.

‘Every time they give him chemotherapy, I have hope. I still clung to that slight bit of hope, some miracle will happen. I hoped my husband could get well... we’ve become very, very much closer now, and our children often come back... This has been actually the most rewarding thing that I’ve done in my life, which is taking care of him’. [C17]

Living in the moment and concerns about the future

‘Living in the moment’ involves accepting reality and focusing on leading a happy life at that moment. Caregivers expressed their concerns about the unpredictable nature of cancer and necessity of living in the moment.

‘It has happened. No reason to blame or be bitter. You have the option to live life happily or sadly. Why not stay with your loved ones, live a happy life and relish in experience?...eventually we just accepted it...I know...we cannot avoid whatever is coming... Now, I treasure what I have...I am the lucky one compared to those who lost a daughter’. [C18]

At some point during the illness trajectory, caregivers shifted from hoping for a miracle to accepting the inevitability of death. Some participants referred to moments when they were jolted into awareness of the physical aspects of dying.

‘I don’t know. I’ve never really thought about it. Well, deep in my mind, I didn’t want to accept bereavement as a reality. I knew I had to think about bereavement long before, but I just did not want to... we didn’t think she was dying’. [C16]

Theme 3: role perception

Commitment to caregiving

Family is very important in China’s culture. Based on caregivers’ strong family values, providing care for their loved ones has increasingly become a normative family function. Some participants thought they had helped perpetuate good Chinese virtues, such as filial piety. They did not perceive caregiving as a burden; it was undertaken out of a combination of their love and/or responsibility associated with family.

‘...it is my responsibility to take care of my dad. He took care of me all my years when I was younger... When I am old and need my daughter, she will do

the same thing... You know it (cancer) means death. I have only one chance to do it... I felt glad to have the opportunity to pay him back for what he had done for me’. [C14]

One spouse described caregiving as an act of showing love.

‘Being a wife, taking care of my husband was a way to express my love for him. No matter what happened... all I wanted to do was to take care of him... It’s just the way it is... Am I doing enough?’ [C7]

Age stereotyping

Negative age stereotypes lead to discrimination against the participation of older caregivers. Two participants expressed that age discrimination led to the social exclusion of older persons from meaningful caregiving roles and to them being viewed as a vulnerable group. They reported that health professionals often make decisions based on age rather than ability.

‘The doctor discussed his (patient’s) condition with his younger son and “bypassed” me. He (doctor) was afraid I couldn’t accept it, but I know everything...’. [C6]
‘The nurses have “moderate” attitudes towards us and doubt my abilities (caregiving) And ...they thought I could not take care of my wife because I am 81...’. [C12]

Theme 4: role-related behaviour changes

Participating in decision-making

Participants reported that diagnosis posed challenges of shock when they were asked to make important decisions quickly. Decision-making on behalf of the patient was commonly spoken about when patients were not aware of their condition, which was very difficult because they could not ignore the presence of the patients who are not yet ready to accept what is going on. The weight of the decision was heightened by thoughts that the patient’s well-being, and even their life, depended on them. This may lead to decision hesitation and regret, especially when opinions are divided, or the disease further worsens.

‘I have to make difficult medical choices alone. I find it difficult and feel that no one is there to help me... I am not sure that the chemotherapy I had chosen was right as I watch him slowly slipping into infirmity and pain, and I am not being able to do anything about it’. [C9]

Some participants tended to take passive roles in treatment decision-making and delegated it to their doctors or families.

‘I didn’t know what to do when faced with the diagnosis. They know so much and a little bit above my head. I try to listen but...now I have to depend on my son’. [C2]

Loss of sense of self

Many participants perceived the struggle to maintain a sense of self, as the tasks that they performed were extensive and challenging. However, some participants became mindful about everyday lifestyle health behaviour choices and subsequent health-related outcomes. Awareness of health behaviours was an awakening experience, and some expressed the need to push themselves to make healthy changes even when times were challenging.

‘I thought nothing was more important than life. As long as it would save his life, any kind of sacrifice was worth it... whatever it takes...forgot taking my own medicines...That’s changing...I had no thought for myself, my life was totally concentrated on caregiving’. [C4].

‘Exercise as an opportunity to gain control over my own health. ... now (I’m) walking, shadow boxing...It was an additional demand on top of an already stressful situation, we were committed to it. It’s good for me... However, I was often constrained by feeling of worry when I leave the house to exercise’. [C1]

Discussion

This study explored the experience of older caregivers of patients with lung cancer in the Chinese cultural context. The use of qualitative methods facilitated a greater understanding of the associations between role and role-related behaviours in older caregivers who have challenges in addressing biological and psychosocial challenges related to older age. Meanwhile, limited attention is paid to the care of older caregivers during palliative chemotherapy, which highlights the importance of the need for improvements in this area.

We found that caregiving may be physically challenging for caregivers, which was consistent with previous findings [25, 26]. Caregiver’s fatigue underscores the complexities of the caregiver experience. Besides facing an increasing load of tasks, these individuals must deal with their own ageing-related health problems throughout the care process. Research has shown that compared to no-caregivers, older caregivers, especially with MCCs, have a greater risk of being frail [27]. The burden and fatigue from caregiving may explain the association between providing care and developing frailty in older caregivers [28]. Roth et al. indicated that caregivers’ own health problems may hinder their ability

to cope with caregiving stress [29]. Caregivers with MCCs are more likely to face greater difficulties during caregiving [30], as caregiving stress and MCCs may interact and impede their ability to provide care. More recently, there is a growing emphasis on focusing on caregiver health and well-being [31]. Programmes and services to appropriately support caregivers are crucial to ensure better health outcomes [32]. Future research is warranted to provide insights into how the dynamic interplay of caregivers’ health conditions and caregiving progression unfolds to affect their experiences over time, which would help design life course interventions.

Our study contributes to evidence on how conflicting internal emotions are interrelated, which is associated with caregivers experiencing a high degree of conflict between their expectations from the therapy and anticipatory grief. The participants reported a range of mixed emotions that oscillated between feelings of hope and bereavement. The different feelings can mark the affective involvement of the caregiver during different periods. For most participants, caregiving is not a singular event but rather a trajectory that continues until the patient dies or enters remission. Bereavement can be more challenging for caregivers and has long-term emotional consequences [6]. In this study, caregivers tended to avoid talking about death, which could be interpreted as culturally inappropriate or ominous in China. Caregivers’ distress levels have been shown to negatively impact the homeostatic balance of the immune system, leading to cardiovascular disease, frailty and functional decline and are also associated with worse quality of life and dampened positive outcomes associated with the caregiver role [16, 33]. The benefits of psychosocial interventions, such as mindfulness [34] and cognitive behavioural therapy [35], are particularly promising for older caregivers experiencing psychosocial issues related to their caregiving responsibilities to help them manage stress across a variety of care contexts. Similar to previous research [36], we found that the feeling of harvest from caregiving increased meaning and purpose in life. Therefore, understanding the factors that maintain positive emotions may provide a new direction for interventions for caregivers, especially older ones.

The role-related findings were consistent with those of previous studies and highlight the understanding and transformation of roles [37]. An American study on caregiver perception of preparedness found that caregivers felt inadequately prepared for their role [38]; however, this was not reported in our study, which indicated that the participants considered caregiving as an expected part of life and viewed their role as an extension of the relationship [39]. Our study participants referred to themselves as spouses, sons or siblings rather than as caregivers. The importance of this relationship was central to their perception of the role, a culturally prescribed obligation and an expression of reciprocal love. Some participants

discussed that caregiving was worth their engagement and did not perceive it as a burden, which is associated with finding meaning in life and peace of the heart and mind [19]. However, some participants expressed that age stereotyping among healthcare providers led to their social exclusion from meaningful roles and relationships. Similarly, ageist stereotyping is more prevalent against caregivers with MCCs, and a negative effect of stereotypes on caregivers' health was evident [40]. Age stereotyping can be a chronic stressor for older people and can affect the quality and quantity of care that older people receive, leading to negative health outcomes [41]. In a collectivistic culture, age stereotyping may be partly due to Confucianism and filial piety values that might have led to higher unmet expectations of respect in our study, which might have different connotations than in individualistic cultures. Interventions to combat ageism are increasingly viewed as a critical component of healthy ageing. Thus, developing effective interventions to reduce ageism should be a priority.

The behavioural changes of caregivers' new roles are related to readjustments in their lives for stability [39]. Decision-making on behalf of the patient was reported in our study, with a focus on life-sustaining treatment rather than on end-of-life treatment, which is associated with keeping the cancer diagnosis a secret from the patient and avoiding discussions about disease progression. The involvement of decision-making was not limited to practical tasks and can add to a caregiver's sense of burden and total responsibility. Decision aids can help caregivers increase their knowledge of treatment options, reduce decisional conflicts and ensure that a decision is made in line with their own values [42]. Most participants reported that they were used to accepting and adopting treatment advice from the doctor rather than expressing their opinions, which could be attributed to the traditional Chinese culture [19]. Thus, caregivers need to be recognised as partners and core stakeholders, and decision aids are needed to help guide the treatment plan while considering the patient's wishes and best interests. Notably, the loss of sense of self occurred across the participants. Ignoring their own health status was reported, which could be attributed to time and energy limitations owing to caregiving activities. This is worrisome, as self-care activities are important for the well-being of caregivers, especially with MCCs, and for their ability to continue caregiving activities [43]. Previous studies have reported that caregivers want information and strategies to engage in self-management behaviours [44]. Dissemination of resources needs to be enhanced for caregivers to gain efficiency in self-care and to acquire complex problem-solving and coping skills.

This study has some limitations. Participants were recruited from a tertiary hospital and had different chronic conditions that were self-reported; hence, this may have influenced the findings and their generalisability. Second, the findings were based on the statements of participants

who showed interest in the study, and although refusal rates were small, those who refused to participate may have had different experiences. Further longitudinal studies are needed to explore the generalisability of the experiences. In addition, data saturation was a relative concept limited to the findings of this study.

Conclusions

Our study provides a comprehensive and culturally sensitive perspective for understanding the experiences of older caregivers of patients with lung cancer in China. These unique familial and cultural traditions should be considered when developing collaborative care models and tailoring interventions for these caregivers. Moreover, this qualitative study revealed several key aspects, including the experience of physical difficulties and age stereotyping. These not only warrant future research to generate new conceptual and experiential knowledge but also lay the foundation for the development of policies and services to meet the needs of older caregivers. Considering that functional decline experienced by caregivers and their chronic conditions would likely have an inactive ripple effect throughout the caring trajectory and care network, caregiving by older adults is understudied and is a much-needed focus area of gerontological practice in the future.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-022-07247-4>.

Acknowledgements We are grateful to all the caregivers for participating in this study and for their time, and we are grateful to the staff of departments involved in palliative care who assisted with caregiver identification.

Author contribution All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Min Xue, Xiaoyun Chen, Haiyan Zhao, Yumei Zhao and Jing Li. Jing Li recruited all the participants and Min Xue conducted the qualitative interviews. The first draft of the manuscript was written by Min Xue. Weijuan Chen supervised the overall project and critically revised the first manuscript for important content. All co-authors read and approved the final manuscript.

Data availability The authors have full control of all primary data and agree to allow the journal to review the data if requested.

Code availability Not applicable.

Declarations

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Shandong Provincial Hospital Affiliated to Shandong First Medical University, China (SWYX: NO.2021–497).

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication The authors affirm that human research participants provided informed consent for publication of the contents.

Conflict of interest The authors declare no competing interests.

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