



Financial toxicity among older cancer survivors in China: a qualitative study of oncology providers' perceptions and practices

Li Liu^{1,2} · Yingjuan Cao^{1,2} · Mingzhu Su^{2,3,4} · Jinxin Zhang^{3,4} · Yajun Miao⁵ · Nengliang Yao^{3,4}

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Abstract

Objective Despite oncology providers' significant roles in patient care, few studies have been conducted to investigate oncology providers' understanding of financial toxicity. This study aimed to explore oncology providers' perceptions and practices relating to the financial toxicity of older cancer survivors in China.

Methods A qualitative study was conducted. Individual interviews were conducted with 14 oncology providers at four general hospitals and two cancer specialist hospitals in China. Qualitative data was analyzed using descriptive coding and thematic analysis methods.

Results The perceptions of participants about the financial toxicity of older cancer survivors include (1) older adults with cancer are especially vulnerable to financial toxicity; (2) inadequate social support may lead to financial toxicity; and (3) cancer-related financial toxicity increased the risk of poor treatment outcomes. The interventions to mitigate its negative effects include (1) effective communication about the cancer-related costs; (2) improving the professional ability to care for the patient; (3) cancer education program as a way to reduce knowledge gaps; and (4) clinical empathy as an effective treatment strategy.

Conclusion Oncology providers perceive that older cancer patients' financial toxicity plays a key role in increasing the negative effects of diagnosis and treatment of cancer, as well as possibly worsening cancer outcomes. Some potential practices of providers to mitigate financial toxicity include utilizing effective cost communication, improving professional ability in geriatric oncology care, and promoting further cancer education and clinical empathy.

Keywords Cancer survivors · Older · Financial toxicity · Oncologists · Nurses · Qualitative

Introduction

Cancer is a major global health issue [1, 2]. As of 2020, China has reported 4.57 million new cancer cases and 3.00 million deaths, respectively accounting for 24% of newly diagnosed cases and 30% of cancer-related deaths worldwide [3]. Furthermore, China has the largest elderly population and fastest aging speed in the world [4]. Prior research has shown that cancer morbidity and mortality rates increase with age, and at present, older adults constitute more than 60% of cancer patients [5]. Due to increased rates of comorbidity, impaired physical and cognitive function, and lower socioeconomic status, older cancer patients are treated with more drugs and for longer periods of time [6, 7]. Therefore, those unique needs of older patients increase the economic burden of cancer.

Financial toxicity is defined as the harmful economic distress of cancer survivors with high cancer-related expenses

✉ Mingzhu Su
sumingzhu@mail.sdu.edu.cn

¹ School of Nursing and Rehabilitation, Cheeloo College of Medicine, Shandong University, Jinan, Shandong, China

² Qilu Hospital of Shandong University, Shandong, Jinan, China

³ School of Public Health, Centre for Health Management and Policy Research, Cheeloo College of Medicine, Shandong University, 44 Wenhuxi Road, Jinan 250012, Shandong, China

⁴ NHC Key Lab of Health Economics and Policy Research, Shandong University, Jinan, Shandong, China

⁵ Department Oncology, Shandong Province Third Hospital, Jinan, Shandong, China

and lower quality of life, even may lead to poorer health outcomes [8]. Previous studies have categorized measures of financial toxicity into material conditions (e.g., reduced income, depletion of savings, bankruptcy, or debt), psychological responses (e.g., worry or distress), and coping behaviors (e.g., delay/miss a scheduled visit) [9]. As we all know, health insurance plays a major role in reducing the financial burden for patients. There are two basic health insurance schemes in China: Urban Employee Basic Medical Insurance (UEBMI) is eligible for urban workers, and Urban–Rural Resident Basic Medical Insurance (URRBMI) is applicable for unemployed residents in urban areas and rural residents [10]. Employers and employees pay jointly for premiums of UEBMI. URRBMI is co-financed by both individual and government subsidies [11]. Despite health coverage for almost the entire population in China, the economic burden varies by insurance and disease types. Nearly 44% of older cancer survivors borrowed money because of cancer [12]. Financial toxicity has become a significant threat to older cancer survivors and their families, which brings negative effects to the public health care system [8, 13].

Oncology providers (oncologists and nurses) are important agents in patient cancer care experiences [14], and they normally have abundant experience in cancer management. Some oncologists and nurses do not feel comfortable discussing the cost of care with patients because of a lack of communication training [15]. Previous literature from developed countries showed that assessing financial toxicity has become essential to develop a care plan for a new cancer patient [16]. Therefore, increasing discussions and expectations are around the oncologists' pivotal role in preparing patients financially for cancer care [17]. However, relevant research on the financial toxicity of older cancer survivors is still in the beginning stages in China [10, 13, 18, 19]. Furthermore, studies have shown that patients desire active advising from their providers regarding their financial concerns [20]. Therefore, the study aimed to explore the current perspectives and practices of oncology providers regarding the financial toxicity of older cancer survivors.

Methods

Study design and setting

Researchers used a descriptive qualitative approach and conducted semi-structured interviews to collect data. Quiet places (such as nurses' or oncologists' meeting rooms) were selected to conduct the interviews, and researchers determined an appropriate time for data collection in advance with interviewees. Due to the COVID-19 pandemic, researchers also chose to use Tencent as a online meeting platform to interview oncologists and nurses.

Participants

The inclusion criteria were as follows: (1) licensed health care providers in China; (2) worked in the oncology department for at least 1 year; and (3) have treated or nursed older patients with cancer. Oncologists and nurses who were currently practicing, advancing, or training in the hospital at the time were excluded from the research.

Data collection

Data was collected using individual semi-structured interviews from January to April 2021 by convenience sampling and snowball sampling. The first author selected the first participant from oncology department of a tertiary hospital in Shandong Province. After obtaining the informed consent of the participants, two co-authors (L.L. and M.S.) began to record the interviews using on-site recording. During the interview, various interview techniques (questioning, summarizing, and responding) were used. After the interview, the first participant then provided the information of the second participant, then we interviewed the second participant, and he provided the information of the third participant, and so on. To understand the diversity of the theme under study, participants were recruited on a basis of maximal variation in demographic characteristics (age, gender, educational level, years working in the oncology department, and professional title). When the contents of the interviews were reviewed and no new themes appeared after analysis of the results, interviews would be stopped. The duration of the interviews ranged from 20 to 60 min, and the average duration was 40 min. Similar questions were given to both oncologists and nurses to capture similar or differing opinions. The main interview questions were as follows:

- What do you know about the financial burden of older cancer survivors?
- Do you have cases to share about older cancer survivors' financial burdens?
- How do you envision the role of oncology providers in alleviating the financial burdens of older cancer survivors?
- What interventions would be helpful in addressing costs of care for older cancer survivors?

Ethics considerations

This study was approved by the Ethics Committee of Health Management and Policy Research Center of Shandong University (ECSHCMSDU20200901). Before the survey, all participants were informed of the purpose of the interviews

and required to sign consent forms which allowed them to withdraw from the study at any stage. All participants remained anonymous throughout the study.

Data analysis

After the interview, researchers reviewed the recorded content of the live recording and interview outline. The recording data was imported from the mobile phone into a computer. First, iFLYTEK software was used to initially transcribe the recording by the first author. Other co-authors played back the recording, proofread, and collated the transcripts. Names were replaced with numbers to anonymize the data (e.g., oncologist O1, O2, etc., and nurse N1, N2, etc.). After uploading the recording and modifying the transcripts, researchers imported them into OneDrive for preservation. Second, the Braun-Clarke thematic analysis method was used for data analysis [21]. This method was used to identify key themes. An inductive approach was taken to identify themes in order to prioritize the participants' perspectives and minimize analytic preconceptions [22]. Analysis began with familiarity and open coding of the complete data by the first author. Descriptive coding was organized into highlighted themes through the participants' responses. These themes were discussed and revised with the second author. All interview content was independently reviewed by other co-authors to identify broad descriptive categories. Codes consisted of sentences, phrases, or words that illustrated a cohesive idea. The researchers then collaboratively discussed their individually identified codes and used the data to reach a consensus on a final set of themes. If discrepancies could not be resolved between the first two authors, all authors held weekly meetings to discuss the disagreements and problems encountered in themes analysis until a consensus was reached. Finally, the themes were revised and reviewed until a concise version was agreed upon.

Table 1 Characteristics of participants ($N=14$)

Code	Age	Gender	Educational level	Professional title
O1	43	Male	Ph.D	Chief Oncologists
O2	39	Male	M.D	Associate Chief Oncologists
O3	42	Male	M.D	Chief Oncologists
O4	51	Male	B.S	Associate Chief Oncologists
O5	35	Female	M.D	Attending Oncologists
O6	45	Male	Ph.D	Associate Chief Oncologists
N1	32	Female	B.S	Nurse-in-Charge
N2	24	Female	B.S	Nurse
N3	31	Female	B.S	Nurse-in-Charge
N4	23	Female	B.S	Nurse
N5	24	Female	B.S	Nurse
N6	37	Female	B.S	Nurse-in-Charge
N7	26	Male	B.S	Nurse Practitioner
N8	25	Female	B.S	Nurse

Professional background is denoted by: *O*, oncologist; *N*, nurse

Rigor

The lead researcher was a postgraduate in a school of nursing. Before the interview, the researcher conducted extensive literary research on qualitative interviews. Both oncologists and nurses were reassured that any data collected would not have a negative impact on their hospital care or relationship with the hospital. The interviewer practiced neutrality and impartiality in all participant interviews. All participants were treated with respect and encouraged to provide in-depth answers to interview questions. The researchers reported to the team (one Ph.D. student, one supervisor, and five post-graduates) weekly.

Results

Socio-demographic characteristics

A total of 6 oncologists and 8 nurses were recruited from four general hospitals and two cancer hospitals. The mean age of participants was 34 years old, and their ages ranged from 23 to 51 years old. Of the 14 participants, more than half ($n=8$) were female. All participants held a bachelor's degree or above. Table 1 summarizes the characteristics of the participants.

Characteristics of cancer survivors with financial toxicity described by oncology providers

Older adults with cancer are especially vulnerable to financial toxicity

Many participants had stated that natural physiological changes occur during the aging process, such as vision, hearing, and endocrine. The incidence of frailty increases with age and thereby increases the risk of falls, disability,

hospitalization, and mortality in older adults. Treatment plans are based on functional age, and older patients often have complex medication histories. Therefore, these aging-related medical expenses exacerbate the financial toxicity of patients. Combined with higher cancer-related costs and the potential for diminished work productivity, older patients with cancer have higher financial toxicity than younger patients and older patients without cancer.

In general, patients have lower expectations of survival with increasing age. Compared to their younger counterparts, older adults have more comorbidities such as hypertension and diabetes. (O1)

Inadequate social support may lead to financial toxicity

Some participants reported that, due to medicine's unceasing progress, the survival time of cancer patients has significantly increased. Good social support is an important pillar for cancer patients to rely on to help them overcome pain and gain confidence in their treatment. The first subtheme identified was "less financial support from adult children." Many older cancer patients and their children think conservatively, believing that cancer is an incurable disease. Furthermore, many people believe that older adults are unlikely to contribute as much to society as their younger counterparts do, so they tend to receive less financial and emotional support.

Many older cancer patients and their children think conservatively, inaccurately believing that cancer is an incurable disease. Therefore, many senior patients receive poor treatment to save money. (N3)

The participants also expressed that older cancer patients rely on surgery as treatment but cannot receive it due to financial reasons, but often receive conservative treatment. This is partly because patients' adult children cannot afford cancer-related expenses, as they thought the benefits of prolonged survival do not outweigh the impact of household debt.

Most medical decisions for older survivors are made by their children, and if their children are not willing to pay for further treatment, older cancer survivors must concede to their decision. (N7)

The second subtheme identified was "insufficient financial support from extended families." Participants also stated that patients felt embarrassed to borrow money from relatives or friends for long periods of time. Patients refused to borrow again if they had already borrowed or not yet paid it back. Participants found that online fundraising is an emerging tactic in China's public welfare system. Online fundraising platforms help ordinary families withstand the burdens of major health risks and serious diseases by pooling financial and moral support. But many older survivors

are not even adept at using smartphones, let alone these online fundraising services.

The patient informed me that he had borrowed money from friends and relatives, but it was not a long-term solution. (N4)

Only a small number of patients seek help through charity crowdfund platforms, but most do not even know how to use such services. (N6)

The third subtheme identified was "health insurance coverage was not generous." Some nurses claimed that out-of-pocket (OOP) expenses were a sword that inflicted catastrophic medical expenditures. Many patients choose hospitals based on reimbursement rate instead of medical quality. This reflects the inadequacies of the health insurance and social support systems.

The design of health insurance itself promotes financial toxicity. Many health insurance plans have a lower copay for care received at local hospitals, influencing cancer patients to refuse better quality treatment in allopatric hospital to save money. (N5)

Cancer-related financial toxicity increased the risk of poor treatment outcomes

Participants observed that these elderly survivors would often give up further treatment when they were informed of the treatment protocols and costs by oncologists from the outpatient department. This is because patients fear that they cannot afford these cancer-related expenses, causing them to view cancer-related expenses as catastrophic health expenditures. "Cancer cannot be worse than the medical expenses" is an oft-cited statement portraying the weighty influence financial toxicity holds.

Many patients forgo treatment due to financial difficulties. You can spend a mountain of gold on cancer treatments, and it still wouldn't be enough. (O1)

If the family is unable to afford further cancer treatment, the elderly patient may choose to see a local traditional Chinese medicine practitioner for palliative care instead. (N6)

Some participants expressed that older cancer survivors did not wish to burden their families. Higher OOP expenses resulting from cancer care can have a considerable impact on patients' treatment. There are typically two coping strategies patients adopt to minimize financial strain: (1) taking cheaper medication than recommended to make the medication last longer and (2) treatment delays (e.g., prolonging the indwelling line time).

When patients' families cannot afford cancer-related expenses, they often choose less effective but cheaper

treatments. For example, many new targeted therapy drugs are expensive, causing patients to use older, cheaper drugs instead. (O4)

To save money, some patients would use the same colostomy bag for over half a month. Colostomy bags are meant to be disposable and one-time use only, but doing so allows them to save money. (N8)

Most oncologists stated that older cancer survivors typically have a hard time balancing a part-time job with their cancer treatments. Some participants also mentioned that older cancer survivors try not to burden their adult children too much, attempting to reduce direct and indirect non-medical costs as much as possible. For example, to minimize travel costs, patients would choose to walk to the hospital even if it was far away from home; and they leave in the afternoon and return home past midnight to save on accommodation costs.

There are a lot of patients in our oncology department who are working temporary jobs between treatments. (O3)

Patients live frugally; they would rather be given a hospital bed in the hallway than a regular room since the fee is cheaper than that of the normal beds. (N3)

Some older cancer survivors are discharged late in the day and do not want to spend the night at a hotel. Instead, they ask to stay in the hospital (without a bed) for a night. (N5)

Oncology providers were finding ways to reduce the financial toxicity of cancer patients

Effective communication about the cancer-related costs

Participants emphasized the importance of communication with patients about building active listening skills, as well as the importance of presenting clinical information in an understandable manner. First, patient-oncology providers' communication plays a key role in alleviating the financial toxicity of patients. To better communicate, oncology providers need to understand patient needs and preferences for information about treatment costs. Oncology providers, as the most clinically knowledgeable entity, should initiate these cost discussions, especially those related to medical choices (e.g., treatment plan/times).

We consider their family's economic situation in the whole course of treatment, and the patient is informed of estimates of their cancer care costs. If they have a stressful financial situation, we consider other alternatives, and the family makes the final decision. (O2)

The oncologist talks to patients and family about the costs of the drugs prescribed, cancer treatment plan,

and prognosis, as well as more cost-effective options based on the patient's financial situation. (N1)

Second, it is crucial that oncology providers have the ability to communicate well with other health care team members. Discussing the patient's economic situation with colleagues can help older patients mitigate their financial burdens while still ensuring good clinical outcomes.

We often discuss the financial toxicities of our patients with colleagues and try to recommend a treatment plan that is suitable for the family. (O3)

Improving the professional ability to care for the patient

Participants also mentioned that many medical interventions are invasive, dangerous, and potentially detrimental. Furthermore, medical products can be expensive. To alleviate patient discomfort and conserve medical resources, it is necessary to improve the working standards of medical personnel. Current medicinal practitioners use the Guidelines of the Chinese Society of Clinical Oncology (CSCO) to guide their actions.

First of all, oncologists and nurses should improve their operation level and ability, such as improving their biopsy skills to reduce patients' pain, complications and economic losses caused by repeated treatments as much as possible. (N4)

Cancer education program as a way to reduce knowledge gaps

Participants hope that patients can understand clinical situations thoroughly, including prognostic implications and treatment options. Older patients need accurate information to make informed health care decisions. Therefore, it is particularly important to popularize cancer-related knowledge. Patients with advanced cancer suffer both physically and psychologically. Patients' families have to bear the heavy double burden of the possible death of their loved one and the bear medical expenses. Popularizing the knowledge of palliative treatment to the patients gradually began being advocated in the clinic.

Considering long-term adherence and lowering economic burden, [oncologists] need to create a treatment plan that has lower cost and good efficacy. Therefore, we had to inform patients that certain drugs can produce serious side effects. (O4)

Palliative care is the treatment to relieve, rather than cure, symptoms caused by cancer. Many patients have never heard of palliative care; we educate patients that it is a comprehensive service that relieves suffering in people with cancer. (N6)

The oncologist pointed out that some anticancer drugs are expensive but not very effective, and providing pharmaceutical knowledge is the key to making sound decisions in these scenarios.

Sometimes, I advise patients or their adult children not to believe in myths of imported drugs; some domestic PD-1 inhibitors are better than these imported medicines. (O4)

Clinical empathy as an effective strategy

Participants stated that empathy is increasingly considered a crucial aspect of effective medical care. The reasons are as follows: (1) it establishes trust between oncology providers and patients, facilitating faster and more accurate diagnoses; (2) it encourages patients to adhere to their treatment regimens; and (3) it results in higher patient satisfaction and less patient anxiety. Practicing empathy can effectively improve the hospital as a whole to achieve rational drug use and emphasize patient-centered health care. The current health care system is not prepared to address the clinical empathy needs of older cancer survivors, which are urgent due to physical changes, functional and cognitive frailty, comorbid diseases, increased side effects from anticancer treatments, and a greater need for social support.

It is necessary for [providers] to practice better bedside manners: to cure sometimes, to relieve often, to comfort always. (N2)

Participants encourage patients to take part in clinical trials to obtain free treatment drugs and even apply for subsidies. This is a good method to treat cancer patients who have no choice but to deal with financial toxicity. Oncologists can recommend patients for clinical trials if their physical conditions and treatments are in accordance with inclusion criteria.

If a patient's physical health and clinical diagnosis meets the inclusion criteria of clinical trials, we will recommend trial drugs to the patient so they can receive free treatments. (O3)

Free medication is recommended for economically disadvantaged patients whose health meets clinical trial criteria. (N4)

Discussion

This research used a descriptive qualitative approach to explore the current perspectives and practices of oncology providers regarding financial toxicity among older cancer survivors in China. We found that oncology providers

identified several characteristics of such patients, including increased vulnerability, inadequate social support, and poor treatment outcomes. Moreover, according to patient characteristics, participants also reported on the importance of taking positive measures to alleviate patient financial toxicity.

Our qualitative findings in this paper are similar to published literature on cancer-related financial toxicity in older cancer survivors. Most research suggests that as older adults with cancer transition to survivorship, they face a number of unanticipated challenges, including physical, psychological, and financial change [23]. This could cause impairments to the quality of life of both patients and their families [24], as well as put older adults undergoing cancer care at risk for financial toxicity [25]. Oncology providers have a critical role in addressing financial toxicity as the primary advisor to patients, they feel that it is important to be explicit about the impact of treatment choices on patients' finances, but only about 50% of them do this [26]. However, there are not such written rules about addressing patients' financial toxicity and no specific data on the costs of oncologists-patient communication in China. This indicates that many oncology providers are not able to effectively perceive the severity of the financial toxicities of cancer patients. Therefore, they are not able to help cancer patients in a timely and effective manner. Oncology providers find it difficult to deal with financial issues, especially when it comes to communicating with older cancer survivors. Financial toxicity has been identified as a potential adverse effect of cancer treatment, and discussion on the topic has been identified as a key component of informed decision-making and survivorship care planning [27–30].

China's health insurance system has grown remarkably in recent years. The UEBMI and URRBMI constitute China's basic medical protection network. This system covers the vast majority of the population, and the reimbursement has been extended from inpatient to outpatient services. The government has fully implemented a system of social assistance for patients with major and serious diseases and encouraged social capital to provide public welfare support [31]. Health services have become more accessible for older adults. However, this benefit may be offset by the rapid increase in cancer-related medical expenses. The increasing elderly population poses another challenge to the health insurance system. Because older adults are typically in poorer health than younger adults, this leads to higher cancer-related costs for those who use medical services. In this scenario, basic health insurance plans do little to alleviate OOP expenses. Despite the availability of health insurance, this study found that older cancer survivors do not cope well with financial toxicity. In the meantime, patients with URRBMI are at greater risk of financial toxicity; this is mainly because URRBMI provides a lower reimbursement rate on outpatient and inpatient services than UEBMI

in China [32]. Health care policymakers should consider cancer reimbursement differently from that of other diseases, because cancer also requires chronic intravenous and oral therapy. The World Bank has set an ambitious goal: that, “by 2030, no one should fall into poverty because of OOP health care expenses” [33]. With further research and more effective practices, perhaps this goal can be achieved.

Clinical implications

In this paper, oncology providers listed characteristics that they thought described the financial toxicity of older cancer survivors, and they attempted to alleviate it through a series of measures. Timely assessment of financial toxicity in clinical practice can facilitate conversations about financial well-being. It may also help oncology providers identify patients in the early stages of financial toxicity so that interventions can be initiated earlier. Hospitals can provide continuous geriatric oncology education programs, oncology provider-oriented training on financial toxicity, or expert guidelines on cost effectiveness of cancer therapies. Some anticancer treatments are self-financed, and oncologists need to seek patient agreement before prescription. When cancer is refractory, oncology providers should consider giving palliative care to patients in advanced stages. Nurses also play a critical role in helping patients manage their financial toxicity by increasing awareness of financial toxicity, strengthening emotional support systems, and providing supportive care to prevent and reduce complications. The government should take measures to include developing policies of anticancer drugs, improve the abilities of the pharmaceutical industry, and accelerate the approval process. Similarly, many cancer patients are discharged with medical tubes (e.g., gastric tube and PICC), so community hospitals should follow up and evaluate patients regularly in order to reduce infection and readmission rates. Finally, it is time to intervene in financial toxicity with the help of the appropriate stakeholders (e.g., financial counselors and pharmacists).

Study limitations

There are some limitations to this study. First, some participants were interviewed over the Internet or telephone due to the COVID-19 pandemic; therefore, researchers were unable to capture visual cues such as facial expressions and body language. Second, the results were derived from oncology providers’ self-reports, so there is possible subjectivity and bias in this study, especially when researchers surveyed oncology provider’s perspectives and behaviors.

Conclusions

Oncology providers perceive that older cancer patients’ financial toxicity plays a key role in increasing the negative effects of diagnosis and treatment of cancer and worsening cancer outcomes. The practice of providers on effective cost communication, improving professional abilities in geriatric oncology care, cancer education, and clinical empathy have the potential to mitigate financial toxicity among older cancer survivors. Future studies are needed to evaluate older cancer survivors with financial toxicity during routine medical treatment to better provide effective and long-term treatment for older cancer survivors.

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Data availability The data underlying this article will be shared on reasonable request to the corresponding author.

Declarations

Ethics approval All procedures performed in this study are in accordance with the ethical standards of the Institutional Review Board at the Centre for Health Management and Policy Research at Shandong University (ECSHCMSDU20200901), and with the Declaration of Helsinki.

Consent to participate and publish results Informed consent was obtained from all individual participants included in the study. Additionally, participants consented to having their data published.

Conflict of interest The authors declare no competing interests.

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