



Treatment decision-making for older adults with cancer: A qualitative study

Nursing Ethics I-II
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Abstract

Background: Independent decision-making is one of the basic rights of patients. However, in clinical practice, most older cancer patients' treatment decisions are made by family members.

Objective: This study attempted to analyze the treatment decision-making process and formation mechanism for older cancer patients within the special cultural context of Chinese medical practice.

Method: A qualitative study was conducted. With the sample saturation principle, data collected by in-depth interviews with 17 family members and 12 patients were subjected to thematic analysis.

Ethical considerations: The study was approved by the ethics committees of Sun Yat-sen University. All participants provided verbal informed consent after being told their rights of confidentiality, anonymity, and voluntary participation. They had the right to refuse to answer questions and could withdraw at any time. Results: Three themes emerged: (1) complex process; (2) transformation of family decision-making power; and (3) individual compromise. Family members inevitably had different opinions during the long process of treatment decision-making for older cancer patients. The direction of this process could be regarded as an extension of the family power relationship. The patient usually compromised the decision to survive, which was made by family members.

Conclusion: This study describes the treatment decision-making process of older cancer patients in the context of Chinese culture. The reasons underlying this process are related to the views on life and death and family values. An individual is a part of the family, which is often seen as the minimal interpersonal unit in

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Chinese society. It is significant that while emphasizing patient autonomy in the decision-making process, health professionals should also pay attention to the important roles of culture and family.

Keywords

China, culture, decision-making, older cancer patients, process, values

Introduction

Independent decision-making is a basic patient right. Full implementation and protection of this right can help improve patient satisfaction and outcomes, as well as reduce the cost of care. ^{1–3} To most countries in Europe and the United States, although patients consider suggestions given by family members, the ultimate decision is up to them. ⁴ This is in contrast to East Asian countries such as China, Korea, and Japan. Influenced by Confucian culture, when older cancer patients and family members have different opinions on treatment decisions, patients tend to follow family members' advice, which means relatives make the final decisions. ^{5–8} In addition, according to research in China, the older people, who account for over 60% of cancer patients, are particularly reluctant to participate in decision-making because of incomprehension or unwillingness to accept disease information. ^{9–11} The present study was performed to understand how the mechanism of family-making decision is determined during internal repeated communication. We assessed the types of interactions that family members have in the process of treatment decision-making and examined the underlying cultural and cognitive reasons. These questions were considered under the special cultural context of Chinese medical practice to analyze the treatment decision-making processes and formation mechanism using deep interviews with older cancer patients and their family members.

Many studies concentrated on the participation of cancer patients and their family members in treatment decision-making and reported many influencing reasons. In China, patients' cancer diagnosis are often concealed by family members, which limited decision-making power to some extent. ^{12–14} On one hand, under the influence of Confucian culture, people associate death with pain and fear, and it is taboo to talk about death. ¹³ On the other hand, family members have higher weight in the decision-making process both in countries affected by Confucian culture and highly religious countries like Saudi Arabia. ^{15–17} These cultures hold that patients are not individuals but part of the family, and all family members have an obligation to protect patients from the fear of illness. However, with greater age, aggravation of disease, and increased cognitive impairment, both patients and their family members believe that treatment decision-making should be family oriented for patients who know their conditions. ^{8,18,19}

Although previous studies have focused on the existence and causes of decision-making conflicts between cancer patients and their families, few have assessed how to communicate and coordinate different opinions within the family. At the same time, the importance of cultural factors in decision-making has been confirmed. However, due to the influence of Confucianism in Asia, the importance of family member input during decision-making process cannot be ignored; we will also explore the balance between cancer patients' independent decision-making and family-assisted decision in Chinese culture. Therefore, this study focused on the decision-making process to explore the mechanism of family replacement for older cancer patients.

Methods

Given the limited research into treatment decision-making processes among family members, we chose a thematic analysis approach to explore and understand these complex issues.²³ Semi-structured and

in-depth interviews of patients and their family members were collected face-to-face from June to September in 2017.

Participants

Purposive sampling was used to recruit participants who had been diagnosed with cancer from two first-class tertiary hospitals in Guangzhou, South China. The inclusion criteria of patients included (1) 65 years or older, (2) an established diagnosis of cancer, (3) undergoing or had completed initial treatment, (4) had at least one closely connected family member, (5) ability to speak Mandarin, and (6) willingness to participate in this study. The exclusion criteria of patients included (1) recommended palliative care or had given up treatment, (2) with end-stage cancer or other severe complications, (3) with a medical or psychiatric diagnosis of cognitive or psychiatric disorders. In addition to the patients, we also recruited at least one family member of each patient to better understand the family treatment decision-making process. In addition, the cancer stage was not considered when the patients were recruited. That was because the cancer stage was detected by pathological findings about 2 weeks after surgery, and treatment decisions were often determined before surgery, which meant there was little possibility for patients and family members to consider cancer stage during decision-making process.

Data collection

An initial interview guide was developed on the basis of literature review. 4,24,25 After being reviewed and revised by a cancer nursing specialist and an anthropologist, the final interview guide included (1) How does the patient's (to family members)/your (to patients) cancer affect your life? (2) What's your opinion to the patient's (to family members)/your (to patients) treatment decision? (3) How was the patient's (to family members)/your (to patients) treatment decision decided? (4) What role did family members play in this process? Older cancer patients and their family members received semi-structured interviews individually in mandarin by Q.D. and H.L. Recruitment ended when no new codes emerged, meaning saturation was achieved.

Ethical considerations

The study was approved by a university ethics committee. The interviews were conducted in a separate meeting room, providing a private and quiet environment. It should be emphasized that in line with the family-oriented traditional Chinese Confucian culture, even if patients have decision-making capacities, physicians will disclose the patient's prognosis and alternative options to their family members first and only explain them to the patient with the consent of the relatives. Thus, we first interviewed patients' family members. Patient interviews were conducted only after obtaining family member permission. Before the interview, our study purpose, voluntary participation, and confidentiality were informed to participants. All participants provided informed consents to be recorded by audio after being told their rights of confidentiality, anonymity, and voluntary participation.

Data analysis

The interviews were audio recorded and transcribed verbatim within 24 h after the interview. According to thematic analysis, ²⁶ the analysis and development of coding were performed by two groups of researchers (group 1: Q.D. and Y.Z.; group 2: H.L. and N.G.) to ensure reliability.

All researchers familiarized themselves with the data and generated initial codes related to family decision-making processes. Coding was data driven and was independently performed by groups 1 and 2

Table 1. Description of participants in the study.

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No.	Patients' information				Family members' information	
	Gender	Age	Marital status	Types of cancer	Relation to patients	Age
I	Male	63	Married	Rectal cancer	Son	39
2	Female	66	Married	Rectal cancer	Daughter	43
					Husband	66
3	Male	61	Married	Rectal cancer	Son	34
4	Female	68	Married	Breast cancer	Husband	70
5	Male	74	Widowed	Rectal cancer	Son	48
6	Male	69	Married	Rectal cancer	Daughter	44
					Son	40
7	Female	81	Married	Rectal cancer	Daughter	55
8	Male	73	Married	Rectal cancer	Daughter	44
					Wife	69
9	Male	71	Married	Lung cancer	Son	46
10	Male	86	Married	Lung cancer	Son	61
11	Male	64	Married	Rectal cancer	Wife	63
12	Female	66	Widowed	Breast cancer	Son	40
13	Female	66	Married	Rectal cancer	Daughter	41
14	Male	64	Married	Lung cancer	Wife	65

to identify possible coding units related to the treatment decision-making processes of older cancer patients. This was followed by a team discussion to compare and discuss the coding units of the group transcripts until consensus was reached. We subsequently sorted codes into potential themes, which were reviewed to ensure they met the criteria of internal and external heterogeneity. Finally, we defined and named the themes. Saturation was deemed to have been met when no further subthemes or themes could be identified.

Results

Ultimately, 17 family members and 12 patients completed the interviews (P4 and P10 were not recruited in the interview because they did not know their diagnosis.). The interviews lasted between 33 and 91 min for each participant. Some older cancer patients were in poor physical and mental condition and offered to take a break or have the interview another day. Thus, some interviews were conducted two to three separate times and the longest one lasted 91 min. Table 1 shows the sociodemographic and clinical characteristics of the participants.

From the results of our interviews, the fundamental difference in treatment decisions between patients and their family members was in the selection of aggressive versus conservative treatment. For patients, relatively aggressive treatments such as chemotherapy and surgery may expose them to unbearable physical pain and a long rehabilitation period. Therefore, they tend to choose conservative treatment options but higher quality of life. However, in the opinion of their family members, risky aggressive treatment is expected to result in longer survival time for the patients. Understanding the differences between patients and their family members in treatment decisions improves our understanding of the three themes of the treatment decision process for older cancer patients identified in this study: (1) complex process, (2) transformation of family decision-making power, and (3) individual compromise.

Complex process

The diagnosis of cancer for an older family member profoundly impacted other family members, who needed to spend time, energy, and resources in treatment and care, and therefore actively advise in treatment decisions. When there were differences in multiple opinions (especially intergenerational differences), patient treatment decisions required intra-family communication and coordination to reach agreement. This complex process between family members and patients occurred throughout treatment.

1. A person falls ill, and the whole family is mobilized

The collective concept of family is emphasized in China. The whole family is affected when one person is sick, and those who are hospitalized are accompanied by family members. When an older person suffers from cancer, it is not that he or she is sick alone, but that the entire family is affected, and all members are involved in treatment decisions and care. When we asked participants what impact this illness had on the family members, they said,

My illness involves the whole family and affects their lives, including my son, daughter, daughter-in-law, and they have to ask for leave to take care of me. (P1)

I accompanied her [the patient] during the doctor visit, and two children also came . . . I can't take care of her all by myself. I need more help. (R2, patient's husband)

2. Intergenerational negotiation

The complexity of the treatment decision process for older cancer patients lies in that every family member has their own views on specific treatment modalities, and disagreement is inevitable in the process of mutual coordination and communication between multiple generations.

I support my father's decision not to have the surgery, and I want him to pass away decently. But my mother definitively wants to push him into surgery. She thinks that survival is foremost before anything. (R8, patient's daughter)

My child feels that my father [the patient] should not continue the treatment. It is not only a waste of money, but also that his appetite and mental condition will not be as good as before after chemotherapy. We prefer discharge back home so that he can enjoy some quality time with family... However, in the view of me and my brothers, continuing treatment is our duty as children, and even if there is only a 1 in 10,000 chance of survival, our father must be treated, and giving up treatment is serious violation to filial piety. (R10, patient's eldest son)

How to convince patient's family members to accept the decision becomes a new issue after the family roughly agrees on the treatment decision. Some children suggest a modality to try their best to save their parents at the end of life, which may be contrary to the patient's belief that he or she is at an advanced age and unwilling to undergo surgery, causing discordance.

My father has some very negative thoughts, and he feels that he is old and treatment is meaningless. He is worried that we children take care of him all day long, and the treatment costs us money... But as children, we feel that father with this disease must continue the treatment. The old man has worked hard all his life, and when he is old, we must show filial piety as children, which is also our obligation. (R6, patient's son)

3. Long process

The differences of ideas and opinions within the family make the decision-making processes full of discussion and confrontation, and this is complicated by the universal participation of family members. In

decision-making process, family members constantly weigh the pros and cons of decisions and try to persuade others, which leads to several times of discussion. Therefore, it often takes a long time to repeatedly discuss multiple opinions to reach a final treatment decision. As one family member said,

Our family has been discussing whether to treat or not for more than half a year. (R10, patient's eldest son)

In other families, even if the opinion is unified, the patient is unwilling to comply with the decision. In these cases, the decision process enters the stage of opinion exchange between the family and the patient, and the process of persuading the patient increases the length to reach a final treatment decision.

She was diagnosed with cancer more than a year ago but refused to see a doctor for various reasons, and she won't listen no matter how we try to persuade. (R2, patient's daughter)

Transformation of family decision-making power

Family members may disagree about the choice of treatment modalities. Some people list prolonging life as the first choice and hope for active treatment; others choose conservative treatment to ensure quality of life. In the face of different opinions, the authority of the family members is prominent compared to the patients whose decision-making power is weakened because of the disease, and the final treatment decision for older cancer patients can be regarded as transformation of family decision-making power.

1. Strengthening power of the head of the family

When it is difficult for family members to agree, a single decision maker who gives the final word often appears, and this person is usually the most authoritative—that is, the head of the family.

I'm the eldest son, and I'm obligated to take this responsibility... The whole family has discussed it many times, and it is difficult to form a unified opinion on whether to receive aggressive treatment or not, and finally I gave the final verdict and asked my father to continue chemotherapy and have a try. (R10, patient's eldest son)

Usually my mother and father would discuss any difficult situation they encountered, and my father would mostly compromise and listen to my mother . . . I can say that my mother would usually have the final say when it comes to family matters . . . My father [the patient] told my mother several times before that he wanted to do only chemotherapy and would not receive surgery in the future. But my mother just pretended not to hear it and ignored him. (R7, patient's daughter)

Decide to receive the surgery? I made the decision, and I'm quite sure. She [the patient] doesn't understand this... She always listens to me for the important things at home. (R4, patient's husband)

2. Strengthening power of the family

Although the direction of family treatment decision mirrors the direction of power relationship within the family, when the head of the family becomes ill, his or her discursive power may decrease, and his or her role in the final say is replaced by other members of the family. We present the following two family cases in which patients compromise with family members' decision finally.

Family 2:

Usually at home, I have the final say in making the decision, and others generally listen to me... But this time, they (children) resolutely do not listen to me, and insist on letting me have surgery. (P2)

I think she is very reasonable about the suggestions she previously proposed. But, since she got sick, she's been making trouble out of nothing... She used to be strong at home before, but she could no longer have her way in this matter of health. (R2, patient's daughter)

Family 9:

Usually, there are only two people in my house...I often have the final say when making decisions about important things...But this time I am sick, the decision is made mainly by my wife and our children after discussion. (P9)

My mother and us made the decision about the surgery. We made that decide first, and then tried to convince him and asked for his consent...My father used to be a master in the home, and it was difficult for him for a while to accept others making decisions for him. But, after all, he gets this disease (cancer) and is physically and psychologically afflicted, and he may think too radically, and we feel it is less considerate for him to making this decision. So, we don't want him to worry so much more. (R9)

Individual compromise

"Death" is taboo in traditional Chinese culture, so survival is usually more important than quality of life for many people. ²⁷ It is often not the patient's own will that is prioritized when treatment decisions are made; rather, the goal is to prolong the patient's life. Although palliative and conservative treatment can allow the patient to pass away with more dignity, such treatment is often denied by the patient's family because it does not prolong the patient's life as effectively as active treatment methods like surgery and chemotherapy. Therefore, keeping their sick family member alive as long as possible is often the fundamental principle for making decisions. In the face of family expectations, the patient himself or herself may also tend to give up his or her personal appeal and compromise with family members to reach a common decision.

1. Family members think "survival" is a priority over everything

In the process of making treatment decisions, family members focus on hoping the patient will remain alive, which somewhat ignores their future quality of life. As shown in the case of Family 8, in the patient's opinion,

I don't want that stoma surgery. It's better to die without an anus. (P8)

But in the family members' opinion,

We're pushing my father [the patient] step by step for surgery, especially for my mother, who has been pushing so hard on letting him have surgery. My mother just thinks total resection can save his life, and surviving is the basis for my father to talk about quality of life. (R8, patient's daughter)

In addition, some family members expressed puzzlement about the patient not putting life first:

He [the patient] did not want to have surgery and felt that having chemotherapy and radiotherapy would make his mental status poor...But why doesn't he cherish his life?...Life is not easy in this world, and no one wants to die. If he really gets close to death, life must be saved, and if he can't be saved, let him live as long as he can. (R5, patient's son)

2. The body is not only his or her own but also that of the whole family

In stark contrast to the Western conceptions of responsibility to self, Asians perceive individuals as components of the family, and the interests of the family as a whole supersede those of individuals. ^{9,28} As stated by a patient's family member,

After all, we are family. If he is sick, it is not his own thing, this is also the family's thing. (R14, patient's wife)

In fact, everyone's body is not only their own, but also the family's. Be responsible for your body equals for your family. (R3, patient's son)

3. For the sake of assuring family members

When a patient is sick, treatment and hospitalization require family members to visit and provide care, which means some of them must put aside their life and work. To help reduce family member stress, some patients choose to compromise with the family's decision.

I don't want to suffer this, and hospitalization is bad for me. But my son and daughter certainly don't agree if I don't have surgery. I am afraid that my children will be distracted by my illness, so I compromise. I have no choice but to accept the surgery. (P12)

4. For the sake of making the loved one still have a life partner

In China, older couples usually call each other "old companion," which refers to their mutual companionship and support during old age.²⁹ Therefore, expecting their spouse to accompany them during aging has become an important reason for family members to want the patient to survive.

My wife always says, how can I live without you...I have no choice. She's too old. I can't bear to leave her alone. (P11)

For children, the desire for parental companionship is also an important reason why they want the patient to live, and some patients choose to compromise with their family members to meet this expectation.

My daughter works out of town, and we used to see each other only for the holidays... After she knew I was ill, she said she couldn't bear to let me go and wanted me to stay with her for a few more years... I can only choose to make a stoma, and live a little harder life. (P13)

Discussion

This study describes the complex and long treatment decision processes for older cancer patients, and how this core issue is thoroughly discussed by family members. When older people are diagnosed with cancer, family members' lives are disrupted and revolve around disease treatment. Patients and their family members have different opinions on treatment decisions and communicate and coordinate constantly, which makes decision-making process take a long time. In this process, the direction of decision-making can be seen as an extension of the family power relationship. When patient–family disagreements arise, after consultation, the patient usually compromises with the "survive" decision, and finally the family makes the decision on the patient's behalf. This decision-making process is influenced by profound cultural logic, which can be discussed from two aspects: life/death and family views.

By summarizing the results, it is obvious that in the face of different treatments of terminal illness, patients and their families show two distinct attitudes. For patients, the benefits of radical treatment are far less than those of living their remaining days with quality and dignity, so patients are more likely to choose conservative treatment with less damage to the body and a shorter recovery period. However, in the opinion of the family members, radical, riskier treatment options are worth a shot and offer the possibility of complete cure. In the face of incurable cancer, maximizing life is what family members crave. However, the patient's choice of conservative treatment, gives up the hope of life and entrusts their life to fate, is an outcome the family is reluctant to face. A Chinese folk saying states, "better a living dog than a dead lion." In the opinion of the family, life expectancy is superior to quality of life.²⁷ In the eyes of many family members, death is the worst possible outcome. Different feelings of patients and their families regarding treatment outcome leads to inevitable divergence in treatment decisions.

When disagreement arises between older cancer patients and their families about treatment decisions, family members often choose to use the strength of the family and intervene. Unlike the West, which puts more emphasis on individuals, families are often seen as the minimal interpersonal unit in Chinese society. An individual is a part of the family, and this tradition is deeply engraved in the Chines culture. Integration of the two sides lies in the fact that when an individual in a family becomes ill, the stress due to care and economic cost can be borne by family members. However, treatment decisions also need to be made jointly by all family members in the common interest of the family.

In the disease decision-making process, the head of the family often becomes the spokesperson. They bear the responsibility of bringing happiness to the family, and his or her opinion represents the greatest family benefit, so medical decisions (especially those related to life and death) are usually made by the head of the family.²⁴ However, when the head of the family becomes ill, his or her discursive power may decrease, and his or her role in the final say is replaced by other members, shifting family authority. This differs from previous studies which found that the family head was more likely to involve in treatment decisions.⁹ The family members interviewed in this study believed that suffering from cancer caused patients to lose their decision-making ability or rationality; therefore, family decisions on their behalf were the best option.

In addition, the Chinese have always emphasized that "reunion is a blessing," and "four generations under one roof" is considered the highest familial pursuit. Maintaining family integrity to the greatest possible extent is an important criterion to judge whether a family is happy. This is why, in the process of treatment decisions, the ultimate choice will tend to be aggressive solutions that may prolong the patient's life, even if the chance is slim. Under the mobilization, encouragement, and persuasion of family members, "surviving" becomes a reason why patients find it difficult to reject the aggressive therapy. In summary, although patients need to endure the pain and burden of the disease, because the collective concept of family is deep-rooted and far-reaching in Chinese culture, the final family suggestion is dominant in treatment decisions, and patients eventually choose to compromise.

Limitations

This study has several limitation. First, we only recruited patients and their family members from two tertiary care hospitals in urban south China and did not focus on patients and their families in other regions, hospitals, or communities. Second, based on the convenience sampling method, we only interviewed family members who were at the hospital, which may have led to sampling bias. Third, considering ethical issues, we were unable to assess the views of older cancer patients who were unaware of their diagnosis and treatment decisions.

Conclusion and implications

In summary, despite the many benefits of autonomous decision-making, many family members in China make decisions on the patient's behalf. Influenced by the cultural concept of life and death, older cancer patients often disagree with their families about treatment decisions. This decision is made in a family-centered cultural atmosphere, stifling patient's voice in the family, and finally the patient often chooses to agree with the family's decision. It is suggested that in medical practice, we should pay attention to the influence of the overall sociocultural atmosphere on each individual and family. The development of interventions should also be rooted in culture and family, and nurses should promote communication between family members, considering the important role of the family while advocating autonomous patient decision-making to choose the most suitable treatment plan.

Acknowledgements

We thank the staff of the Cancer Center, and the Sixth Affiliated Hospital of Sun Yat-sen University for assisting in recruiting participants. Our special thanks go to the older cancer patients and their family members who were willing to share their experience.

Conflict of interest

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: This work was supported by two grants from the Ministry of Education of Humanities and Social Sciences Projects (No. 18YJA840022 and No. YJC840013) and one grant from the Medical Scientific Research Foundation of Guangdong Province (No. A2017080).

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