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Special Section: Bioethics Beyond Borders

The Understanding of Death in Terminally Ill Cancer Patients in China

An Initial Study

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Abstract: Patient's needs and rights are the key to delivering state-of-the-art modern nursing care. It is especially challenging to provide proper nursing care for patients who are reaching the end of life (EOL). In Chinese culture nursing practice, the perception and expectations of these EOL patients are not well known. This article explores the feelings and wishes of 16 terminally ill Chinese cancer patients who are going through the dying process. An open-ended questionnaire with eight items was used to interview 16 terminally ill Chinese cancer patients, and was then analyzed by a combined approach employing grounded theory and interpretive phenomenological analysis. Four dimensions were explored: first, patient's attitudes towards death, such as accepting the fact calmly, striving to survive, and the desire for control; second, the care desired during the dying process, including avoiding excessive treatment and dying with dignity; third, the degree of the patient's acceptance of death; and fourth, the consequences of death. This cognitive study offers a fundamental understanding of perceptions of death of terminally ill cancer patients from the Chinese culture. Their attitude toward death was complex. They did not prefer aggressive treatment and most of them had given a great deal of thought to their death.

Keywords: end-of-life; nursing care; Chinese culture; cancer patients; terminal illness; perceptions of death

Introduction

The attitude toward death of terminally ill cancer patients is of great significance for healthcare providers so that they can be able to deliver the appropriate individualized care. However, verbal communication with Chinese patients is perceived as a challenge that could thwart some patient's preferences for end of life (EOL) care.[1] Especially in China, we know very little about the feelings or expectations of death of these patients. Over the past thousands of years, the Chinese attitude toward death has been strongly influenced by Confucianism and Taoism.[2] In Chinese culture, death has been associated with distress, fear, or a mystery, and people rarely talk about death directly or openly. Chinese tend to use such euphemistic expressions such as "go to the heavens," "pass away," or "become old" instead of using the word "death," although we know that dying, as a part of life, should not be a taboo topic. It should be the subject of an open discussion that everyone would be able to face and think about. Honestly addressing the dying process can lead to a better attitude toward death. This right attitude will substantially facilitate the work of healthcare professionals.

In China, family members play an important role in the decisionmaking process about the patient's terminal care.[3] After years of inattention, Chinese society and healthcare providers are reexamining how we approach dying and death. We are questioning if our care of the patients who are at the end of their lives is really

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reflective of the patient's will. Even though many important innovations such as hospice programs and palliative medicine have improved the treatment and care potentially available to terminally ill patients, changes in attitudes and practices have been more limited than has been recognized by researchers. The temptation remains strong to ignore its limits and to evade the uncomfortable and emotionally challenging demands. We believe that as healthcare providers, we can do much more to relieve suffering, respect personal dignity, and provide opportunities for people to find meaning in life's conclusion. We are heartened by a small but growing number of activities that are aimed at reaching these goals.[4,5,6,7]

The importance of understanding terminally ill patients' true feelings in order to provide better end-of-life care is obvious. More research is needed to study the attitudes of different populations, including the Chinese, and especially of the patients themselves, toward death.[8] Research and surveys on death education are attracting mounting attention. Nowadays, Chinese researchers have studied attitudes regarding death of non-cancer patients[9] and cancer patients' relatives,[10] the general public and healthcare providers,[11] and nursing students,[12] among others. However, there has not yet been a study of the cognition of terminally ill cancer inpatients in China. The psychological status of terminally ill cancer patients is very sensitive and complicated. Patients experience physical and psychological misery, which significantly affects their quality of life. Therefore, it is hoped that understanding the attitude toward death of terminally ill cancer patients can allay the patients' pain, help medical staff to better understand and meet their demands, and help them to the end of their lives peacefully and calmly, surrounded by the love of their friends and relatives.

This study was conducted to answer the following questions: (1) what are the essential components of the understanding of death in the minds of terminally ill Chinese cancer patients? (2) What is their real mental status with respect to death during the dying process? (3) Does the cognition of Chinese patients toward death differ from that of the rest of Asians or from that of Westerners? (4) What can we do to provide palliative care consistent with these patients' stated feelings?

To answer these questions, a study was conducted from July to December in 2014 involving 16 inpatients who were terminally ill with cancer in one Grade III A hospital (a gradation level in China reserved for the most specialized hospitals), Permission to conduct the study was approved by the institutional review board at the hospital, and permission was also sought and granted by the department chiefs and nursing managers.

Study Design

The study design consisted of two parts.

Initial Questionnaire

Patients who expressed interest in participating were first given a questionnaire in which they were asked whether their illness was serious or not. Those who did not acknowledge the seriousness of their illness were excluded from the study on the basis that they might not be able to openly discuss EOL. It was also decided not to

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ask potential participants if they were terminally ill, to preclude the possibility that their physicians had not informed them of their situation.

Face-to-Face Interview

Patients who acknowledged awareness of the seriousness of their illness subsequently participated in an open-ended interview aimed at determining their attitudes toward death, wishes regarding care, degree of acceptance, and anticipation of consequences. They were provided with a written consent form, which was signed at the beginning of the interview. Patients were informed that participation was entirely voluntary, and that they could withdraw at any time. Patients were also made aware of their right to ignore any interview questions that they chose not to answer, without jeopardizing their treatment.

Participation Criteria

The inclusion criteria for inpatients were (1) age 18–75 years, (2) being cognitively intact, capable of understanding and responding to the interview, and (3) having estimated median survivals of 6 months or less based on a Karnofsky Performance scale of 50 or less for cancer.[13] The study protocol called for the exclusion of individuals with moderate or severe cognitive impairment, reflected by a score below 24 on the Mini-Mental State Examination (MMSE), who might not be able to provide in-depth descriptions of their experiences.

Characteristics of the Participants

Patients deemed appropriate for the study were diverse in terms of: gender, age, marital status, health insurance type, primary site of cancer, education level, occupation, and religious beliefs as shown in Table 1.

Instrument Development and Implementation

Based on a research-related literature review, the "Death Cognition" interview outline was developed and modified by expert consultation. Before the formal interviews, a pilot survey was conducted with two subjects who met the inclusion criteria for this study (their interviews were not included among the formal interviews). After adjustments were made according to the pilot result and feedback, the interview outline was finalized as shown in Table 2.

The average interview time was 37 minutes (range, 24–49 minutes) and took place in the conference room of the wards. The investigator was well trained and masters-degree educated, and had good communication skills.

The interviews were audiotaped, and respondents' pauses, tone, facial expressions, and other non-language information were also noted at the time. Communication skills such as encouragement, gaze, exploration, clarification, and silence were employed in hopes of obtaining more detailed information. The interview was gradually deepened according to the patient's reaction. If the emotion of a patient was very strong, the interviewer would suspend the interview and provide emotional support to maintain the calmness of the patient.

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Table 1. Characteristics of Participants (n = 16)

Item		Number
Age	18-30	1
	31-50	4
	Above 50	11
Marital status	Married	14
	Divorced	1
	Remarried	1
Insurance type	Medical insurance for urban residents	12
	Employee medical insurance	2
	New rural cooperative medical insurance	1
	None	1
Primary site of cancer	Stomach	4
	Lung	7
	Rectum	2
	Others (cervix of womb, germ cell, Inferior smooth muscle)	3
Educational level	Junior high school	5
	Senior high school	6
	College or above	5
Occupation	Businessperson	2
	Teacher	4
	Workers	5
	freelancers	2
	Other (civil servant 1 peasant 1, information technology staff 1)	1
Religious belief	Yes	1
	No	15

New participants were enrolled until theoretical saturation was reached; that is, until no new themes emerged from answers to the open-ended questions in the interview.

Data Analysis

Participant responses to open-ended questions were transcribed verbatim. Two investigators read the transcribed interviews multiple times to identify emerging themes, developed a list of codes, and then reread and coded the transcripts independently. Next, the coders compared their assignment of codes. Discussion among coders was used to resolve coding discrepancies. The codes and associated passages were entered into a qualitative analysis database.

Within 24 hours after the interview, the participants' original statements were transcribed intact into the computer. The process is very strict and not open to deletions or changes; therefore, the accuracy and integrity of the data are ensured. Grounded theory methods of open and axial coding were utilized to analyze the data.

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Table 2. Interview Outline of Respondents' Cognition of Death

1. Could you tell me a little about your life's special experiences or the most important accomplishment? What do you want your family members to know or remember about them?
2. What lessons do you want to deliver to the people you love (e.g., son, daughter, wife, husband, parent, or other persons) that you have learned from your life? Do you have any hopes and dreams for them?
3. What do you think about the current treatment you are undergoing?
4. How do you think about the process of dying?
5. Do you think you are well prepared to face the dying process?
6. Looking at the totality of life, from beginning to end, what kind of situations and states do you think are the happiest?
7. At the end of life, how do you want to be treated by the medical staff? Would you want them to use heroic measures to sustain your life? Or, would you prefer that they withhold such measures and let nature take its course?
8. For this interview, do you have any other ideas and opinions you want to add/share with me?

After reviewing recorded information, the data were encoded, and theme and subtopics were separated. At the same time, the research memorandum was established for the next interview. The subject analysis process was completed through continuous interview and analysis. Analysis was done by two researchers independently, and then compared; any inconsistencies were resolved by returning to the initial data.

Data Analysis and Results

Attitude Toward Death

Chinese tradition values life; living is happy, and death is taboo. The study found that the majority of patients rationally admitted that death was the end of the normal course of life, but rather than wait for death, they were willing to try different treatments. Those who had a higher educational level or were more satisfied with their life could accept the irreversibility of death more easily and were more willing to receive hospice care or palliative services.

Accepting Death with Equanimity

The study found that 87.5 percent of the patients were able to recognize that death was a part of life. Cases 4, 11, and 13 believed that "life and death was a natural process," "well, everyone has to walk this road until the end, as a natural law," "life and death is a complete circle; if we all live forever, the earth will have to explode (laugh)." Cases 7 and 9 maintained "I have survived and held on for a long time. My condition right now is still ok." Someone else with the same disease died after a long time. "I have lived two years more (than him) and it is enough." Case 8 thought that "since I got sick, I believe in Jesus. Now I believe that death is not terrible, for it is God's call for us and lets us excuse from death." Case 3 said, "All things were done and I could die without regret."

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Striving for Survival

The study found that 75 percent of patients believed that they did not want to wait for their death and wanted to try different treatments. Cases 1, 4, 9, and 14 believed that "Although birth, senility, illness and death are rules, I still have the desire to live. I came to this hospital, because it is the best in the central and southern regions of China. I should strive for a cure. If it fails this time I will give up." "If the chemotherapy this time is unsuccessful, I will go home to try traditional Chinese medicine. If it's not effective I will eat and play and live the rest of my life and not worry about it. Anyway, I tried."

Holding on to Hope

Some patients are always looking forward to a miracle. They hope to live longer or even be cured. Cases 10 and 15 stated "I know cancer treatment nowadays is not perfect, but I still hope to have a new drug that can cure this disease." "I heard that someone found a medicine somewhere that can beat the cancer cells. I have asked my son to find it. Although we have to wait at least three years for the medicine to come to market, I might be able to get it." Cases 11 and 16 expressed, "I have been fighting this disease for several years but it kept coming back. It seems to be undefeatable, but I still hope for miracles." "My neighbor had advanced cancer. He turned to traditional Chinese medicine after the conventional treatment failed to cure the cancer and got better. I believe there is a miracle." Case 2 said "In 1989, I was diagnosed with ovarian cysts. The surgeons said I needed surgery, and I refused, but the result is good. I believe that I have a strong immunity and perhaps this time I will heal on my own again."

Controlling Death

In the interview process, 10 patients mentioned euthanasia. Case 6 stated: "Sometimes I want to buy some sleeping pills and wish I could take them when I want to." Case 8 said: "Euthanasia in some foreign areas is legal, and it would be good if it were also allowed here." Case 14 asked: "Can you give me euthanasia here?" Case 7 said: "I hope to donate my organs after euthanasia before the cancer cells damage my body too much."

Avoiding Excessive Treatment

Cases 3, 7, 12, and 14 said: "I got a lot of chemotherapy and do not want to continue again. I want to rest." "I'm very tired now and feeling terrible with needles. I have had a good talk with my family. I try to avoid nutritional medicines." "My appetite is not so good and nutrient medicine is enough, and I do not want to use other treatments." "I do not need too many infusions."

Dying with Dignity

Patients commonly expressed their hope of a painless and comfortable dying process without excessive treatment, and maintaining dignity in the process; 93.75 percent of patients expressed the desire not to have unnecessary EOL

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cardiopulmonary resuscitation (CPR) or invasive treatment. They expected a comfortable dying process. Case 13 said: "I'm afraid of nothing but pain." Case 6 said: "I had a good friend. I went to see him before his death. He couldn't speak a word with the machines and the tube. His face was swollen…Oh, I don't like this. If there was a kind of medicine that could help me to pass away falling asleep, it would be good for me to take one. I met a patient friend who was gone 10 minutes after he finished his words. Although his family was very uncomfortable, I think this was a great blessing to him." Case 8 admitted: "I once had a surgery with a catheter and tube inserted. That was too painful. I do not want to endure those again. It is better to pass out forever like when I had a hepatic coma last time, instead of waking up again." Case 14 said: "I don't want to have a tracheotomy, and prefer to just lay down without drinking or eating anything. It is not only a waste of resources but also a great suffering to us."

Accepting Death

Case 8 said: "I am very calm to face and accept this matter (death)." Case 6 said: "I have made a testament that was handed over to my spouse." Case 7 said: "My several sets of houses have been allocated and my children also arranged for, so that I have no regrets." Case 13 said: "Funeral affairs have been planned and the tomb in my hometown has been fixed. I told them to invite a few bands to my funeral for decency." Case 3 mentioned: "Now I see, leaving the world earlier is better than suffering from this disease." Case 16 announced: "I have written my will and assigned my legacy. In this way, (death) would not be a terrible thing at all."

Carrying On

Chinese traditional Confucian culture and family-oriented philosophy emphasize the responsibility of each member of the family. These responsibilities should be carried on throughout one's life. These responsibilities do not end with one's life, but rather pass on to one's descendants. Our study found that most patients are not concerned about their children's wealth or fame. Instead, they expect good health, honesty, friendliness, devotion, and a happy family. The patients also hoped that their own death would not bring excessive sadness. Rather, they wanted their loved ones to be strong and move on. In addition, some patients expected to stay with the family forever through a biography, photographs, and other ways.

Keeping Healthy

The study found that 87.5 percent of patients considered family members' health to be all that mattered. Case 1 said: "Money is not as important as good health." Case 3 said: "Before this I just knew how to strive for money; now I realize that life is my own, and other things are just external things. I hope they learn this lesson from me." Case 8 stated: "I used to play Mahjong. There were several heavy smokers around and my family all blamed me for not cherishing my own body. Now I believe they know to cherish their health more." Case 5 said: "I hope my Grandma can live to be a centenarian."

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Maintaining Traditional Virtues

The sweeping majority of patients hoped that their relatives would manifest typical Chinese virtues: to be industrious, steadfast, honest, kind, harmonious, and filial. Case 2 said: "I have two sons; I always tell them not to think about how to make money but to lay a foundation for your business. Respect all the clients and work hard. Do not live in luxury, although the temptation is great in society. Be nice to your wife rather than being fickle." Case 6 said: "I hope he [his son] will be an honest person and work steadfastly." Case 10 said: "they should keep family harmony, for a peaceful family will prosper." Case 13 said: "I tell my children to show kindness; if they see beggars on the roadside they should give them money. Don't be afraid to be cheated; benevolence is the most important." Case 1 said: "My wife has dementia. I took care of her before this (disease). I said to my son, 'if I pass away, take good care of your mother, it is too hard in her lifetime.'"

Hoping for Family Resilience

Case 1 said: "I want my family to enjoy the time with me now and to continue their lives without sadness after my passing (death), so that I will be comfortable." Case 3 said: "I don't want them to be too sad. We should be happy when staying together. When the time comes, my families staying and silently looking at me would be enough; and don't cry." Case 5 said: "I hope my Grandma is staying safe and sound, for she is old and would not be too sad." Case 8: "I hope my husband can be happy and doesn't take into account what people are saying and will find a partner in a short time." Case 12: "They must be sad for my leaving, but I don't want them to be always like this." The study found that most patients had made certain arrangements for their funerals, either publicly or privately.

Arranging for Remembrance

Although the patients were aware that they were reaching EOL, they hoped to be remembered by their loved ones so as to continue their companionship with their family by other means. Case 8: "I would like to sort out my own life now. I plan to write an autobiography as a souvenir, so that my wife and children can read it after my passing. Then, I can depart this life peacefully." Case 6: "My child is in a foreign country and coming back is not easy, so I am taking a lot of photos now and they will all be left to him."

Discussion

The needs of patients are individualized, and proper assistance can help them make their own EOL decisions. In Chinese culture, when someone has a serious illness such as cancer, family members often choose to hide the disease mostly or in part, [14,15] the patients' treatment decisions being made by family members after discussion. Often times, patients do not completely understand their condition, and they are not given the chance to make their own treatment decisions. Many patients receive excessive medical treatment against their will. Many patients admitted that they were not afraid of death itself, but that they were frightened by witnessing the suffering of other patients at the terminal stage, including

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the process of medical rescue. One study revealed that few patients had their expectations of nursing met. For example, the "do not resuscitate" status (DNR) has been promoted worldwide to avoid unnecessary resuscitation in terminally ill cancer patients, but the idea is inconsistent with Chinese culture.[16] In this study, people with more education and those who are married can talk about death frankly, and their level of acceptance of death is relatively high. They hope to avoid unnecessary treatment and rescue. Those patients expected a pain-free and dignified dying process. This result is consistent with other Chinese studies.[17,18] It is important that the responsibility for decisions be recognized in order for nurses to feel supported.[19] We should fully respect the patients' right to know and their decisionmaking power, so that patients can participate in treatment decisions and sustain a high quality of life.

The results of the study support encouraging patients to express their feelings, as a way for health providers to achieve the goal of helping patients overcome the fear of death.

Many researchers recommend that nurses and physicians be closely acquainted with the prevailing traditions and religious beliefs in the communities where they serve.[20] Chinese traditional culture holds that physical death is not the end of the bearing of responsibility, and that experience should be passed down from generation to generation. Our study also showed that the vast majority of patients were worried about their loved ones suffering excessive grief at their death, which could affect their families' lives. What is more, Chinese people tend to have reserved personalities. Men especially are generally reluctant to express their true feelings. Talking about death and dying is socially prohibited among Chinese people, who believe that the dead are judged in the afterlife and punished according to the sins that they have committed in life.[21] However, our study reveals that many patients want to be informed regarding the process of their disease and would be better able to accept the truth. Nurses could help to strengthen and support patient–family relationships, thus paving the way for fewer regrets and a healthier recovery for the family following the patient's death.[22]

The study also indicates that more attention should be paid to implementing grief care for families and gradually extending the role of hospice care services.

At present, Chinese medical service focusing on the treatment and nursing care of patients and bereavement care for family members is insufficient. We are not only caring for patients, we are also involved with their families. Studies indicate that care skills training and providing palliative care can be helpful in reducing the pain and burden of family caregivers of patients with cancer.[23] Our patients voiced their hope that their family would recover from grief and continue to live happy lives. Therefore, to pay attention to and implement grief care for the families can help families come to accept the patients' dying, and in this way contribute to a peaceful dying process for the patient.

Conclusion

For the first time, this study interviewed terminally ill cancer patients in order to explore their feelings and understanding about death with the purpose of providing information for palliative care in China. The acceptance of death, tolerance of bad news, and desire to handle the process and understand their own treatment of the patients in our study are different than our common assumptions based on

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Chinese culture would have led us to expect. This helps us have a better understanding of the feelings and needs of cancer patients in order to properly handle the relationship between traditional Chinese ethics and what they mean in a modern context. We call on Chinese society, policymakers, and medical training to promote EOL education in order to promote better understanding of the true feelings of terminally ill cancer patients, so that, as healthcare providers, we are better able to care for patients and families throughout the dying process.

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