



Ethical Issues in the End of Life Care for Cancer Patients in Iran

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(Received 26 Oct 2012; accepted 09 Jan 2013)

Abstract

Background: In the recent years, advances in medical technologies for end stage cancer patients' care have affected the end-of-life decision-making in clinical practice and exposed oncologists to serious ethical dilemmas. But little is known about oncologists' viewpoints in our country regarding their ethical problems in this mention. We aimed to clarify the ethical dilemmas which Iranian oncologists may face in our health care setting and to determine factors influencing decision-making process.

Methods: In this qualitative study, a phenomenological approach was used. We interviewed 8 cancer specialists in teaching hospitals in Iran and used content analysis to identify codes and categorize themes in the data.

Results: During the process of analysis, three main themes emerged about ethical dilemmas in end of life care for advanced cancer patients: illness factors, socio-cultural context and patient-physician relationship. Cancer specialists identified ethical problems on several main issues, the most important of which were telling the truth in Iranian cultural context, uncertainty in end stage definition, multidisciplinary team working and cost consideration in Iranian health care system.

Conclusion: Health care and insurance system in Iran face to end of life care challenges; therefore, health care providers and policy makers need to allocate appropriate resources and programs to improve quality of care in terminal stages. Appropriate physicians' communication skills training, multidisciplinary team working and supplementary insurance services that provide essential health care can improve the quality of care of patients with end stages of cancer. The findings of this study can help us to provide ethical policies for decision-making in end-of-life care.

Keywords: End-of-life care, Cancer, Ethics, Iran

Introduction

Cancer is the important cause of death in many countries (1), including Iran (2). In fact, cancer, being a life-threatening disease, makes the inevitable need for the implementation of an effective end-of-life care strategy in health care services more than ever (3). Physicians should consider the patients' best interests (4); moreover, the treatment they choose should be beneficial to the pa-

tients and does no more harm. Besides, the treatment should be selected on the basis of the patients and their families' views on end-of-life care and financial costs of terminal care (5). Therefore, on the basis of patients' views and conditions, oncologists sometimes decide to continue curative cancer therapy for terminal patient to improve the survival rate or recommend palliative care to im-

prove the patients' quality of life (6, 7). Oncologists can fairly decide on end-of-life provided that they know patients' and their families' values and preferences (8), and can communicate with them honestly (9). Many physicians avoid informing patients of their survival chance, because they believe that discussing this issue may diminish patients' hope (10). In addition, health care costs are high in many parts of the world and financial discussions on the cost of treatments and care of end stage cancer patients can be of paramount importance (11). Consequently, considering differences of health care services in various cultural backgrounds and social structures, the professionals in service providing face with numerous ethical problems for decision-making (12,13).

Many studies have discussed ethical problems in decision making on end-of-life care (12). In one study, the authors believed that physicians face different ethical problems, the most important of which being uncertainty about treatment, prognosis, quality of life and external factors such as economic and legal issues as well as work environment (14). Another study showed several factors which included patients' characteristics and illness factors, health care provider and health care system agents (15). In another study, researchers reported a considerable difference in Russian, Swedish and German physicians' approach in terms of end-of-life treatment decisions which relies on a large variety on socio-cultural context (16).

Diagnosis of a life-threatening disease like cancer is undoubtedly crushing for the patient (17). The society tends to consider death as a taboo, something in which man cannot interfere. Therefore, death has some cultural and religious aspects (18). Western countries have done great attempts for conceptualization of death, and introduction of end-of-life care (19). Moreover, at present, in many countries improvement of the quality of health care services for the end stage patients has become the main subject of many research and clinical plans at national levels. But the results of studies conducted in other societies cannot be used in the Iranian community. Meanwhile, cancer is one of the three major causes of death in Iran and the burden of this life-threatening condition

have caused many challenging problems for the public health system in our country. Furthermore, some cultural aspects of death and terminal patients' care have not been considered yet in our country and very few researches are carried out regarding death and the end of life care. We should try to pay a great attention to cultural and social aspects because family ties are very strong among Iranian families and usually the whole family is involved in a patient's problems.

In fact, we can provide an appropriate care for cancer patients provided that we understand medical, ethical, legal and economical challenges which may be experienced by physicians and other cancer care providers in our health care system in the special socio-cultural context. These studies can help to provide appropriate guidelines for decision making and educational interventions in terminally ill cancer patients. Accordingly, we conducted a qualitative study on the oncologists' experiences in end-of-life care for end stage cancer patients in Iran to clarify ethical challenges experienced by them in an Islamic Middle Eastern setting.

We aimed to shed light on the ethical dilemmas which Iranian oncologists may face in our health care setting and to determine factors influencing their decision-making process.

Methods

Study Design

The present study is a part of a doctoral thesis project to explore ethical dilemmas in decision-making process in end of life care in Iran. This study was approved by Ethics Committee of Tehran University of Medical Sciences. We conducted a qualitative study using in-depth semi-structured face-to-face interviews. We were particularly interested to know how participants viewed experiences, beliefs and practices regarding ethical dilemmas in decision-making in end of life care of terminal cancer patients. Each participant gave written informed consent and the principal researcher assured all of them that the data would remain confidential. Therefore, the principal re-

searcher would remove any identifying data from transcripts and keep the files separately.

Participants

We used a purposeful sampling method and interviewed certain specialties including adult hematologist-oncologists, radiotherapists, and surgeon oncologists. Physicians from the Department of Oncology and Cancer Institute in a teaching hospital in Tehran, Tehran University of Medical Sciences and the Department of Oncology at a teaching hospital in Kerman, Kerman University of Medical Sciences were contacted by the principal researcher, and after explaining the study, were invited to participate. The aim of this sampling method was to gather the perspectives of a group of specialists who were involved in taking care of terminal patients and providing them and their families with the option of palliative care.

Data Collection

The data collection and analysis process was based on the Phenomenological approach, which is a methodology for exploring the experience of a group of individuals in a certain topic. Interviews were continued until thematic saturation, a point where no new or relevant theme is added to the gathered data, is achieved (20). In our study, thematic saturation occurred after interviewing of eight participants. The interviews were conducted from July to August 2011. All the interviews were recorded and transcribed verbatim. The interviews, ranging in length from 30 to 45 minutes, were conducted by the principal researcher in a quiet environment at participants' office room. The interviews began with questions on the participants' demographic information and were followed by questions on the participants' clinical experiences regarding end-of-life care decision making in cancer patients. A palliative medicine specialist, an expert in qualitative research methodology and a specialist in medical ethics planned the guide of interview questions. Following questions were asked: What are your experiences in end-of-life care of cancer patients? What are your beliefs and ideas about end-of-life care approach for patients with terminal cancer? What

would you do for these patients? Furthermore, the principal researcher used probes to encourage participants to elaborate on their experiences; for example, "What information do you say to patients and patients' families prior to making the decision and how do you communicate with them?; Which factors influence your decision to select curative treatment or palliative treatment?; Which factors are related to diagnosing terminally ill patients?; What ethical challenges you face end-of-life care decision-making?"

Data Analysis

Each interview was transcribed. Besides, the interviewer took detailed comments on the text in the transcript margins. Data analysis using Strauss and Corbin method was proceeded concurrently. Therefore, analysis was done using open-coding process. In this process, the principal researcher reviewed the transcripts line by line several times and broke down, compared, conceptualized and categorized the data. Four members of the research group studied the codes and collaborated in the open-coding process. Then, the codes were categorized and themes were compiled into groups. This process was repeated with more interviews and the codes were amended. New themes were achieved based on the new interviews. To enhance the credibility of the analysis and to determine its dependability and to confirm ability, four steps were completed: 1-Thematic saturation, 2- open-coding process, 3- presentation the summaries of the interviews to three participants to confirm the researcher's perception from content, 4- presentation's preliminary analysis with attached codes to 3 participants to confirm the results. All of them confirmed that the analysis explained these issues adequately.

Results

Three hematologist-oncologists, four radiotherapists and a cancer surgeon were included in the study. Two of the interviewed specialists, were female. The age of interviewees was between 40-60 years. The mean no. year in profession with cancer patients was 17.5 years (8-27 years). They

have visited their patients (mean 30 patients) daily in teaching clinics in their hospitals and their private office too. We distinguished three main themes, according to the oncologists' experiences, beliefs and practices in end stage cancer patients' care. The participants believed that these issues were influential factors in end-of-life care decision-making.

First Theme: Illness factors

1. Assessment of cancer patients: Many cancer specialists emphasized that they assessed their patients on the basis of performance status and their co-morbid conditions. They believed their experiences affect the patients' assessment. Therefore, the specialists not only used formal assessment tools such as the Eastern Cooperative Oncology Group Performance Status (ECOG) and the Karnofsky scale, but also apply their experiences in cancer patients' care. One of the hematologists-oncologists specialists said:

"As we graduated, we thought we have to treat the disease rather than the patient. Gradually, we understand that we should apply special treatments for each patient, similar to what happens in the court. We improve this judgment power by applying our experiences in cancer patients' care, rather than relying only on text book. In fact, the physician with more experience makes better decisions."

2. Uncertainty in End stage definition: Dealing with end stage definition, one of interviewees said: "We cannot determine an individual precise time of death, thus we should assess each patient based on their condition. Our year's long practice show that we can never determine the exact time of death based on probability and statistics. It is hard to accurately define end stage."

"The first question of the patient's relatives is how long our patient will survive. Many factors affect the patients' survival. So we avoid answering this question."

3. The aim of cancer therapy: The physicians explained the aim of treatment for cancer patients well and classified these treatments into two main categories; palliative and curative.

One of the experts said:

"Most of time, we do not treat cancer to increase the patient's survival, but we only treat the patient to improve their quality of life."

"The purpose of Palliative treatments is just to increase patient's life quality. At a stage which we know that the disease is not curable, we resort to palliative treatments.

4. Withdrawal of treatment in cancer patients:

All physicians considered withdrawing a treatment as one of the most difficult decisions in treating cancer patients.

A radiotherapist said:

"I believe that I am not allowed to stop the treatment through interrupting the patient's fluid therapy or extubating them. We don't withdraw the patient's treatment ourselves just because they are end stage patients."

Another oncologist insisted on maintaining the patient's hope and said:

"We have no right to disappoint patients and we should continue the treatment. We don't want that patient think we are leaving them alone to die."

5. Cost consideration (financial issues): The physicians expressed that financial problems and lack of optimal insurance system are one of the most important problems in this regard.

"As many oncology drugs are very expensive, the financial and economical problems can affect our decisions surely."

"The second ethical challenge, which to some extent is related to the same problem of medical decision-makings, is financial problems."

"Doctor's criterion is not medicines' price, but they decide on the basis of scientific issues; when the patient says he can't afford it, we won't deprive him of the treatments."

The second Theme: Socio cultural Context

1. Patients: Physicians believed that cultural background is one of the most important issues in cancer patients' care.

"Social and cultural issues affect the patients' care very much, and they are very important. Based upon our culture, many families do not allow their patients to be aware of the nature and severity of

their disease. Therefore the patient has no active role in decision making.

“In our society, people are strongly religious, and think such beliefs can help them during hard times.”

2. Families: In another part, the physicians stressed that many families ask for the patient being unaware of their disease. Therefore, in the Iranian society, in many cases physicians encounter ethical dilemmas and cannot decide easily, as they are obliged to fulfill the request of patient’s relatives.

One of the physicians said: “We have to tell the truth to the first-degree relatives of patients. Sometimes the treatment isn’t helpful at all. Therefore, patients should be prepared for the outcome. We should give necessary information to the patient's family.”

Another issue presented by the physicians was the patients and their family tendency to take their patient home, and to do end-of-life care at home.

“They want their patient to die at home; they do not like death in hospital at all, this is their family belief.” “Practically, we have no hospice in Iran, end of life care is mostly undertaken by patients’ family; perhaps it is because of eastern culture, not only Iranian culture, we are not happy to leave our patients in hospital.”

The Third Theme: Patient- Physician Relationship

1. Truth-telling: The interviewees emphasized that the cultural background of the society and the families’ requests are the main obstacle for truth-telling. “We cannot directly tell many patients about their serious condition. We cannot inform them clearly and frankly in this regard.” “The problem, with which personally I’m challenging is, that informing the patient about his problem helps him to be prepared to face it.”

“People are always more afraid of what they know nothing about.” “The patient who is looking into your eyes, and he is the one who has the right in this regard, should not be told that “you don't have the disease.” Several oncologists described the experiences in difficult situations. They believed that unawareness and incorrect participa-

tion of patients in treatment planning have forced many physicians to decide autonomously.

One of the oncologist surgeons stated an important point in telling the truth to the patient and said:” In some conditions, there is no other choice for decision-making and treatment but to tell the truth to the patient. Sometimes the patient has a cancer in his hand for example, which needs to cut the hand. This is not something that you just tell the families.”

2. Multidisciplinary team working: The interviewees agreed that advanced cancer patients should be treated in a multidisciplinary approach, and a group of specialists should be involved in treating these patients. They, however, stressed that multidisciplinary approach is not possible in our hospitals because our centers are solely designed for treatment and are not appropriate for providing supportive care.

“We need a team of nutritionists, social workers, etc. to participate. But we don’t have access to all these specialists. So, we should do everything on our own knowledge and experiences, the physicians are responsible for such tasks in our hospital while all of them are not in their job description. Cancer patients’ care is a team working.” “Oncology is a very complicated field, which needs coordination and cooperation among the groups.” “Our oncology hospitals are for treatment of patients, not for end-of- life care.”

3. Physician Training: Moreover, the oncologists believe that another reason, which creates contradictions for them and make them face difficult situations of decision-making, is educational constrains regarding medical care and ethical decision-making in courses of medicine, and even in residency courses that they have passed. “We have also received no education in this field, and it creates conflict itself.” “Education can be very effective; even educating specialists is very important.”

Discussion

Based on the results of the present study, cancer specialists focused more on issues such as telling the truth in our cultural context, uncertainty in

end stage definition, multidisciplinary team working and cost consideration in Iranian health care system that are priorities for end-of-life care cancer patients. Generally the results of our study are consistent with other studies. However, cultural background and health care system structure may lead to certain differences.

One of the most specific issues indicated by our study's participants is telling the truth to end-stage patients. Many families prefer to hide the detailed information from their patients so that not to diminish their patient's hope. Furthermore, sometimes our physicians are obliged to fulfill the families' requests, and they experience more distress.

Recent studies have pointed out the difficulties of truth-telling in terminal patients (21,22). In one study in Iran 5 years ago, the researcher questioned 400 physicians about truth-telling to patients suffering from life threatening diseases. According to this study, 35% of the respondents believed that the patients have the right to be aware of their disease, whereas 6% disagreed with disclosing information to the patients. Furthermore, 59% of the respondents believed that the patient should be informed in special circumstances (23). In some countries such as Japan, China, Greece, Turkey, Spain and Italy, the physicians have not accepted the truth disclosure completely; however, they are more interested to inform the patients than before, but still do not apply it in practice(24,25). Japanese physicians first inform the patients' families and then the families decide whether the patient should be informed or not (26). We can see a similar practice in the Arabic Islamic patriarchal cultural context (27, 28). In one study, the authors reviewed the cultural differences in the understanding of end of life care in seven European countries (29). Hence, the evidence indicated that truth telling issue in health care has a cultural origin and cannot be considered as an ethical dilemma (30).

Our study showed that many physicians are reluctant to tell the truth as they were not ready for such interaction. Our physicians emphasized that they have not been received any formal training in key communication skills, truth-telling and breaking bad news that are very essential for end of life

care. It can be highly satisfying for our physicians and their patients can have better outcomes if they can realize excellent communication skills. Several studies have shown that education about end-of-life care is very important and can improve physicians' practices in this area (31-34). One study introduced a workshop to teach third year medical students three skills in end of life care. They found that many students could apply these skills to patients care by six months and they felt to improve their skills (35).

Meanwhile, our interviewees thought it is not necessary to reveal the whole truth. Thus, the patients should become aware of the required information based on their wishes. So, information about an end stage diagnosis should only be told by patients' relatives in a longer time. They stressed that providing patients with unnecessary information would result in loss of patients' hope but also deviate the treatment plan. Previous studies have indicated that the patients have different interests in seeking the information and most patients prefer to receive information gradually depending on their emotional responses. Physicians should know that total information disclosure is not helpful for all patients at particular times during their illness and they should take patients' needs into account (36).

Oncologists should apply various tools to assess the patients' performance and the results of such this assessment greatly affect the final decisions (6). Our interviewees emphasized that they assess their patients on the basis of patients' performance status and their co-morbid conditions by using formal assessment tools and their personal assessment. Our participants stressed that they were not able to determine the end stage disease certainly and exactly and cannot predict patients' survival rate and may lead they cannot make the decision to shift the treatment or withdrawal of curative treatment. The evidence suggested that uncertainty to define end stage disease and patients' response rate are the most important factors that may influence oncologists' treatment planning (30, 36).

Hence, physicians need to share the information and responsibilities with other professionals to

ensure that they provide appropriate end of life care (36). In our study, the participants expressed their concern regarding their weak collaboration with other professionals such as psychiatrists, nutritionists, social workers, palliative medicine specialties, etc, whereas this cooperation would improve cancer patients' care. Therefore, cancer specialists prefer to only discuss such cases in their tumor boards, and consequently, they experience more distress. Finally, multidisciplinary team-working is a good approach to clarify the general practitioners, specialists and nursing staff role in end of life care. The authors in one study believed that collaboration between primary and specialty physicians' cancer care may improve care for these patients (37). Also, another study showed that cancer specialists prefer to consult their patients' cases with other specialists such as geriatricians (38).

Moreover, oncologists face an underlying moral question raised by expensive treatments in advanced cancer patients as to whether these interventions worth their high cost (11). Of course, in our study, most physicians would choose the standard treatment on the basis of scientific evidence and the high cost of treatment would not change their decisions. So, they may have to discuss with their patients and families about financial issues whereas they cannot avoid effective interventions on the basis of cost and they are responsible to advocate for their patients. Actually, the decision-making in this situation will be very difficult and distressful for our physicians. In one study, researchers demonstrated that financial issues may be problematic factors which can affect physicians' practice in regards with decision making as they cannot tell patients that some treatments are more beneficial but more expensive (39). Furthermore, health care and insurance system in different parts of the world face many challenges in regards with terminal illness and health care providers and planners need appropriate resources and programs to improve the quality of end of life care (1). In Iran's health care structure, the insurance system does not currently pay all of the oncology drugs' costs because the existing insurance coverage is not optimal. Therefore the

patients and their families have to pay out of the pocket to undergo these high expenditures treatments or to deprive themselves of some treatment options. In fact, if our patients can use an appropriate insurance coverage and governmental financial support, they can enjoy better treatment services and our physicians endure less distress.

The qualitative designation of this study is considered as its point of power because this type of study allows the researcher to clarify cancer specialists' perspective in depth. As subjectivity is the main limitation of such studies, we applied certain measures to reduce this risk. So, two researchers read the transcripts and the merging themes were discussed in groups. Another limitation is that we interviewed cancer specialists working in teaching hospitals in Tehran and Kerman. However, a representative sampling is not the aim of a qualitative study and thematic saturation is very important. Finally, the authors interviewed cancer specialists only, while ethical dilemmas in end-of-life care existed in other settings as well.

Conclusion

Uncertainty about the definition of end stage disease for cancer patients causes physicians to be reluctant to shift from curative to palliative treatment. Furthermore the physicians often lack the skills to communicate with patients and their families. This is compounded by difficulties in telling the truth in socio-cultural context. So, the experiences of Iranian physicians indicated that although they would like to communicate with their patients more honestly, they endure more distress for disclosing the truth regarding terminal illness in our socio-cultural context. The other proposed reason for challenges our physicians are faced with is unequal availability of end of life care services and financial problems that exist in Iran health care setting when it is medically indicated. Besides, as our care providers are not involved in teamwork for end of life care, they cannot share information and understand their responsibilities. According to the results of our study, there is a need for good planning in regards with terminal cancer which requires improvement of physicians'

communication skills, provision of appropriate services for end of life care, developing multidisciplinary team working and optimal insurance system. It could be suggested that the mentioned viewpoints are basic concerns in our healthcare system. Finally, the results of the present study can help policymaker to develop a guideline for ethical decision making and set educational priorities for physician working in this field.

Ethical considerations

Ethical issues (Including plagiarism, Informed Consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc) have been completely observed by the authors.

Acknowledgment

The researchers wish to express their deepest gratitude and warmest appreciation to the following people who in any way have contributed and inspired the researchers to the overall success of the undertaking: To Oncologists who have participated in interviews and Dr. Pooneh Salary for her guidance in providing final draft of article. This study was supported by grant (number 91-03-50-19313) from research deputy of Tehran University of Medical Sciences. The authors declare that there is no conflict of interests.

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