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Exploring the ethical decision-making experience of caregivers of end stage cancer patients in Iran: a phenomenological study

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Abstract

Background Ethical decision making is a complex issue because it strongly depends on the religion, beliefs, traditional laws and moral views of each society. The purpose of this study was to explore the experience of Iranian family caregivers of end stage cancer patients about ethical decision making.

Methods This qualitative study is based on van Manen's method of hermeneutic phenomenology. In-depth interviews were carried out to collect data. Participants were 12 caregiver. Audiotapes were transcribed and analyzed for common themes that represented the participants' experiences. Trustworthiness of the findings was established using the Lincoln and Guba's criteria.

Results Three themes reflected the essence of caregivers' lived experience including; fluctuating between hope and despair, wandering dilemma, and ethical decision making. Each of these themes consisted of several subthemes.

Conclusion The present study revealed that, the caregivers of terminally ill cancer patients need different information about prognosis and end of life decision making process. Our perception of how families negotiate ethical issues in their decision-making is still developing. Opportunities should be created to empowering caregivers to talk about their uncertainties and concerns.

Keywords Terminal care, End of life care, Family caregiver, Ethical decision making, Cancer

Background

Ethical decision-making at the end of life for patients such as cancer patients raises a wide range of complex issues that concerns patients, their families and health professionals. Terminally ill patients become increasingly dependent on the care of others and must delegate part of their decision-making to others [1]. Family members play a key role in the care and support of terminally ill cancer patients. They face increasing responsibilities and duties, which include indirect and direct caring tasks such as coordinating care, managing symptoms, providing emotional support, assisting with activities of daily living [2], and helping to search information [3]. Family

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members have a more complete understanding of the patient's beliefs, values, background and expressions of discomfort. To ensure the patient's best interests, a family surrogate is designated to make decisions that genuinely represent the patient's treatment preferences. Adequate understanding of patient's treatment preferences by a family member is particularly important in Iranian cultures [4, 5].

In Iranian culture, family members play a significant role in medical and ethical decision making. There are cultural differences in attitudes toward decision–making styles, truth-telling and life-prolonging styles at the end of life [6].

The patient's autonomy is a concept that values individual's freedom and self-determination. Individuals are the arbiters of their values and the ones who determine their best interests. Making informed choices is viewed as a right, to which, each individual is entitled. These approaches have slowly been adopted by other countries, including Asian countries such as Iran.

In patients in the final stages, their decision-making capacity may be impaired due to the deterioration of their physical condition. In such a situation, in order to exercise autonomy, two procedures can be taken; in one approach, a qualified surrogate decision maker acts in place of the patient. The challenges of determining his/her competence and ensuring that such a person has adequate knowledge of the patient's preferences limit the use of this approach. In another approach, the patient's opinion and preferences regarding end-of-life care areethid predetermined, and this choice will become the decision-making reference in the final stages of his illness [7].

Ethical and medical decision making for patients with life-threatening diseases increasingly entails a balanced consideration of psychosocial, medical, ethical and societal aspects [8]. By providing care that meets the needs of terminally ill patients, we can improve the quality of end of life care [9]. Understanding the ethical decision making experiences of caregivers is essential for the continuous improvement of outcomes for all stakeholders. The present study was conducted with the aim of exploring the experiences of caregivers of terminally ill patients about the end of life ethical decision making process.

Method

Design

A phenomenological approach was employed to explore the care givers' experience of ethical decision-making process for end-stage patients. Van Manen (1990) believed that phenomenology is a systematic attempt to uncover and describe the internal meaning structures of lived experience [10].

Sampling

Purposive sampling techniques were used to recruit participants (from both sexes) that included the family caregivers of terminally ill patients. Caregivers are those who spend a significant amount of time providing unpaid support to family member/s or friend/s [11]. In this study, the family caregiver was defined as the person who plays the most important role in the patient's care and health care decision-making. Creswell (2014) recommended a sample size of 6 to 18 participants for a phenomenological study. This number can be increased until the data saturation is reached [12]. After the tenth interview, the research team agreed that data saturation had been reached. The last two interviews were used to check the level of data saturation and confirmed our conclusion about data saturation, in which no new information was found in the interviews.

Data collection

Data were collected by in-depth and semi-structured individual interviews conducted between October 2020 and March 2021. This study was conducted in a teaching hospital in Tehran, the capital of Iran. The research question was "*How do Iranian family caregivers describe their lived experiences regarding the process of ethical decision-making* at *end of life*"? To answer the research question, participants were asked to describe their experiences in a situation where they had to make a decision for their terminally ill and end-stage family member. The interviews were conducted face-to-face using a prepared interview guide. The guided interview questions were developed based on a thorough review of the literature and the researcher's professional expertise in this field including the following:

1. Please express your experiences on the decisions you made during care for your patient.
2. Please express your experience of deciding on patient life care.
3. How was these decisions made for the patient?

The interview started with an initial open-ended question that was used for the purposes of this study. Follow-up probe questions were also used to encourage the participants, such as: "Please tell me more"; "Can you give an example?" "What happened after that?" (Interview guide in the supplementary file 1).

During the interviews, the researcher also observed the body language and facial expressions of the participant and recorded them in a field note. Each interview continued until the participant reported that he/she had nothing more to share. All interviews were recorded (Sony ICD-PX240 audio recorder) to accurately preserve the participants' statements, including tone and pauses.

Table 1 Caregivers' demographic characteristics

No	Type of cancer	Age of the caregiver	Relationship	Age of the patient	Duration of caring	Duration of cancer
P1	Colorectal Cancer	45	Husband	42	8 month	1 year
P2	Multiple myeloma	34	Wife	35	8 month	8 month
P3	Breast cancer	52	Husband	53	2 year	2 year
P4	Lung Cancer	53	Wife	64	2 year	2 year
P5	Liver Cancer	28	Son (oldest)	61	9 month	1 year
P6	Brain tumor	48	Son (oldest)	70	5 month	15 month
P7	Osteosarcoma	42	Mother	62	8 month	8 month
P8	Melanoma	59	Father	36	6 month	1 year
P9	Gastric cancer	65	Father	34	1 year	14 month
P10	Pancreatic cancer	32	Daughter	63	9 month	13 month
P11	Ovarian cancer	33	Husband	30	2 year	2 year
P12	Liver Cancer	56	Father	23	15 month	2 year

Each interview was given a number and other information such as participants' names, was saved in a separate file. Each interview lasted about 40–60 min and was conducted at a quiet room without clients was allocated in the hospital for the interview.

Data analysis

The data analysis process in this study was based on the following three approaches of textual analysis described by Van Manen (1997):

1) Holistic approach: The researcher read the text holistically to make a general understanding of it.
2) Selection or highlighting approach: The researcher regularly returned to the text in order to underline the phrases within the participants' statements that revealed their experiences. Related statements were then collected and sorted into folders, and re-examined until the hidden themes and subthemes emerged.
3) Detailed line by line approach: The researcher carefully read every line of the text to find out what it reveals about the phenomenon [13].

MAXQDA-10 software was used for data management. Study rigor was attained using the Lincoln and Guba's evaluative criteria which include: credibility, dependability, and transferability and comfirmability [14]. For the accuracy and validity of the study, it was tried to examine the phenomenon from various dimensions such as personal experiences, descriptions of other people's experiences, and experimental descriptions from other sources, as well as the use of phenomenological texts.

Also, in order to increase the accuracy and credibility of the present study, careful selection of qualified participants and their participation in the process of data interpretation, review by the participants, use of the opinions of professors and colleagues in different stages of the study, especially in the extraction of themes and final interpretation done.The study's protocol was approved by the Ethics Committee of Tehran University of Medical Sciences with the number: IR.TUMS.VCR.REC.1396.4580.

Table 2 Theme and subthemes

Theme	Subtheme
Fluctuating between hope and Despair	Emotional distress A dying loved one Caregiver's burden Lack of preparation and support
Wandering Dilemma	Patient is a unique individual Desire to do the right thing Futile care Euthanasia
Ethical decision making	Keeping patient safe Maintaining human dignity Having a peaceful death Patients' best interests Nondisclosure of diagnosis Adherence to tradition and religion

All participants received a full explanation of the study procedure and signed the informed consent form. The participants were assured that they could withdraw from the study at any time without penalty, and were also assured about the confidentiality of their personal information.

Results

The demographic characteristics of caregivers are presented in Table 1.

Three themes were identified to illustrate the ethical decision making experiences of Iranian caregivers (Table 2).

Fluctuating between hope and despair

The dying process creates a patient-caregiver bond and makes them both physically and emotionally close to each other. Fluctuating between hope and despair was reported as the dominant feeling of the participants in this study. This theme consisted of several sub-themes which are described below:

Emotional distress

Caring and decision making for individuals who are dying evokes a range of emotions, such as a sense of running out of patience, losing power, a sense of crisis, anger, denial, shock, fear, anxiety, and endless grief.

P1 shared: *They say there is no hope. They say that we have reached the end stage and we have to start palliative medicine. It's too early for him to go. I have to let his care turn into palliative care so that he dies without pain. Well, I do not want him to die. I do not want to lose him.*

A dying loved one

When the caregivers were informed that their loved one was near death, they reported that, they would miss their loved one greatly. All caregivers stated that, their loved ones no longer have a good quality of life. The participants stated that, they wanted their loved ones to have a natural death.

P10 shared: *I want him to be at home and close to us during the last days. I would like to take after him with all my power. I will do anything for him to die peacefully.*

Lack of preparation and support

The participants shared their perceptions of the lack of all the necessary information and time needed to make an informed decision, leading to undesirable outcomes.

P11 shared: *If I know about the treatment that I choose for my patient, I can consider its advantage and disadvantage, so I'll decide better. We are not given enough information. Not everyone has medical literacy. I wish they could take the enough time to inform people who really need it, so they can make the right decision.*

Caregiver's burden

Caring for someone with a terminal illness or disability can affect as much as the caregiver and care recipient.

P3 shared: *This care and thought make me sick. When a new treatment starts for my patient, I get headache and don't feel well for a while.*

Wandering dilemma

Caregivers described their situation as living in a dilemma. Some caregivers did not believe the test result to be true. Some of them asked for the diagnostic tests to be repeated before they could believe the results. This theme consisted of following subthemes:

Patient is a unique individual

Each family believed that their patient is a unique individual with unique needs.

P12 shared: *Any illness has some needs that may be specific to that illness. As the fingerprints of people are different, their treatment, need, and response to treatment are also different.*

Desire to do the right thing

Families described the conditions in which, they should make the best decision or do the right thing, as an moral situation that they can hardly deal with.

P1 shared: *Sometimes I can make a decision that I know is right. I mean that, I know I've made the best decision with the facilities that I had, but I still have feeling that I could have made a better decision.*

Futile care

Spending time and money on futile care was reported by the caregivers as a major concern.

P8 shared: *I would be scared to say the chemotherapy should continue if it has no benefit for my patient; just hurting him with more nausea, anorexia and trouble.*

Euthanasia

Although most patients do have a pain free death, there are some who do not. Sometimes analgesia is insufficient without side effects such as sedation, nausea and confusion [15]. Euthanasia can also give rise to questions, doubts, and feelings of guilt in family members, possibly resulting in a pathological mourning process.

P2 shared: *I think if we have to call for the treatment termination, it's like we are planning the death of the patient. Death and life are in the God's hand, but with the discontinuation of treatment, we would accelerate the death.*

Ethical decision making

Given the need to weigh benefits, harms, and inconveniences of different options, caregivers are likely to experience personal uncertainty about the best ethical decision and they sure require support to participate in decision making. However, the caregivers in our study tried to make the best decision on their own. This theme contained several subthemes, including:

Keeping patient safe

The end of life period for many families is characterized by existential and practical uncertainty. They seek safety in the middle of insecurity and uncertainty.

P9 shared: *He is too weak, and cannot even get out of the bed. If I don't look after him, it's not clear what would happen to him. We need to be careful he does not to fall from the bed, develop bed ulcer, or anything else happens to him.*

Maintaining human dignity

When the individual's autonomy is conflated with the notion of dignity, the inability to maintain independence while dying may be experienced as a fundamental loss of dignity, undermining the value of life itself.

P12 shared: *He was respected by everyone when he was well. I still like him to be the same and everyone maintain their respect of him. I know that, he wants it too.*

Having a peaceful death

Family members were adamant that they did not want to prolong the dying process or cause undue suffering.

P5 shared: *I know we're going to lose him. Every day he is getting closer to death. The treatments do not affect anymore. I want him to be in peace. I give him everything he likes and enjoys. I want him to be perfectly comfortable.*

Patients' best interests

Some caregivers reported that, they have a some idea about their patients' wishes for the end of life care.

P4 shared: *It is true that some decisions are now our responsibility, but we still ask him for his opinion. We don't want him to think that we are giving him assignments. We explain to him what to do and finally let him make the best decision according to his priorities. He is still alive and still breathing. He was an independent person and this independence should continue and we should respect his decision and interests.*

Nondisclosure of diagnosis

Acceptance comes with growth in personal resilience, which empowers caregivers to cope with the challenges ahead. Honesty is one of the most important factors in making the best decision.

P2 shared: *We told him, his chemotherapy drug was a supplement drug and his bone pain was caused by the cold, so he would do not be afraid. We were lying to him. We were afraid if we say that has bone cancer he may lose his spirit.*

Adherence to tradition and religion

Some caregivers have to face unique challenges that are often influenced by cultural and spiritual beliefs. The majority of caregivers interviewed expressed that they were spiritual and not necessarily religious. Their beliefs were able to provide them with comfort and additional strength to cope with the patient illness.

P5 shared: *They say it is the end of line and you must accept it. I trust in God. If God wants, he will stay alive, and If God does not want, he won't.*

Discussion

Fluctuating between ***Hope and Despair*** for decision making and the reality of imminent death is a communication paradox for family caregivers in the context of cancer. Family caregivers face countless complexities in managing the bright and dark sides of hope. Maintaining hope is complicated in the context of cancer, and patients and their caregivers often have reported different experiences and needs in this regard. For example, Koenig Kellas et al. [16] found that cancer stories cause patients to focus on positivity and hope, so palliative and hospice health providers help families to shift cancer stories from treatment to focus on everyday happiness. In their study, 40% of family caregivers experienced isolated cancer journeys marked by false hope, denial and despair.

Caregivers reported a great level of ***emotional distress*** in this study. The profound social, physical, and psychological effects of caring are well documented in the literature [17, 18]. Thinking about the ***dying of a loved one*** has made all caregivers in this study to experience the feeling of despair. At the end of life, the care ethics emphasize that care does not end with the death and should continue until the family has received support with their grief responses [19]. Nurses need to play a vital role in decreasing the family ***caregivers' burden*** by providing emotional support, assessing their needs, and meeting them. Nurses need to be sensitive towards the caregivers' needs, fears, and uncertainties [20]. ***Lack of preparation and suppor***t from healthcare professionals were reported by the participants in this study. Previous studies have shown that healthcare professionals are often reluctant to discuss death and dying process with patients and their families and do not feel they have the required skills for such difficult conversations [21]. Merrouche et al. reported that approximately 40% of family members were dissatisfied with the information they received concerning their terminally ill cancer patients [22]. Ethical ***dilemmas*** occur in problems for which, there are no clear right or wrong answers. Judgments regarding right and wrong are guided by four basic ethical principles, including autonomy, beneficence and non-maleficence, fidelity and justice [23]. Some of our participants believed that every ***patient is unique*** and decisions made for different patients should not be the same. For any specific stage and type of cancer, no two individuals can experience the disease in exactly the same way because their bodies and minds are unique. This uniqueness (every patient is a unique individual) creates a dilemma in ethical decision making and choosing the right path. A great deal of the interview data reflected these negotiations within the principle of beneficence regarding the weighing of right and wrong decisions. In this study, the caregivers ***desired to do the right thing*** for their loved one's caring process. However, while this care was necessary for the patient, futile care was not beneficial. The caregivers in our study believed that futile treatments should not be provided by the healthcare providers. However, there are different viewpoints about what can be defined as a futile treatment [24] and what cannot. Differences in caregiver's perceptions of futile treatment have created many challenges between the patients' family members and healthcare professionals regarding the continuation or discontinuation of treatments [25]. Sometimes when treatment is futile, it is still offered by the physician as a last chance or resort. In such cases, the motivation is psychological rather than medical, and the decision to discontinue the treatment is being postponed in order to give the patient the time to get used to the fact that the treatment is useless [26]. In practice, patients' caregivers rarely ask for treatment to be stopped. The caregivers in their interviews stated that, the following common moral arguments are involved in futile care and ***Euthanasia***. In most countries, like Iran, physicians are not allowed to grant such a request, although the physician-assisted death is now a topic of debate in many countries [27–29].

Findings of the interviews gave rise to the following question: ***What is the best decision?*** Caregivers believed that, a decision would be a good decision if it protects the dignity, integrity, safety and interests of the patient and also ends the patient's suffering and ensures a good death. Suggestions for providing a good death include; facilitating dying with dignity; not allowing patients to be alone while dying, managing patients' pain and discomfort, knowing and then following ***patients' wishes*** for the end of life care, promoting earlier cessation of treatment or not initiating aggressive treatment, and communicating effectively as a healthcare provider. Educational initiatives for professionals and the public have also been suggested [30]. In this study, not all families had a clear indication of their patient's wishes. Disagreements between patients and families about the goals of end-of-life care and the use of life-sustaining treatments may result in the overridden of patients' preferences at the end of life. Sonnenblick reported that among the patients' children who claimed that they knew the patient's wishes relating to life support or withholding treatment, only 46% subsequently requested for the patient's wishes to be followed [31].

The ***truth telling*** about the diagnosis and treatments of cancer is still considered a problematic issue by the Iranian healthcare professionals. Telling patients and their families the truth about the choices they have to make could be a very difficult issue. Iranian caregivers desire to ***adhere to tradition and religion****when it comes to the illness of their patients*. They believed that, the cancer of their loved ones is the God's will and thus, it cannot be resisted and should only be accepted. Some caregivers stated that, they gain strength from their religious communities and prayer groups, and find support in the sentiments offered by fellow members at their places of worship. They also believed that, the family, friends and community supports are "the God sent". In their view, protection of God is not only applied to the present life, but also to the afterlife. It was a great comfort for them when people said: "I'll pray for you" [32].

Conclusion

The philosophical and methodological lens of phenomenological inquiry is a strength, which enabled the researcher to elucidate the importance of human experience in informing others about the end of life ethical practice. The current study suggests that, the caregivers of terminally ill cancer patients have different needs for information on prognosis and end of life decision making process. Our understanding of how families negotiate the ethical issues in end of life decision-making is still expanding. Opportunities should be created for empowering caregivers to talk about their uncertainties and concerns.

Limitations

This study's limitations included the small sampling size, which can be prevented in future studies by selecting a larger group of samples. Also, due to the nature of qualitative research, the findings of this study may not be fully applicable to other population, or may not be generalized to other locations. Therefore, further qualitative studies in various medical settings are recommended.

Also, this work is empirical on ethically relevant aspects and but does not contain an ethical- normative analysis itself, at the same time, it can be said that this work was a qualitative and phenomenological analysis of an ethical experience of incaregivers. And finally, study of this lived experiences introduced us another world in the field of nursing ethics.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12910-024-01131-y.

Supplementary Material 1

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Author contributions

Study design: SEH, ANN, SJ, NS, MS. Data collection: MS, SEH. Data analysis: ANN, MS, SEH, AA. Study supervision: SEH, ANN, SJ. Manuscript writing: SHE, ANN, AA, SJ, NS, MS. Critical revisions for important intellectual content: SEH, SJ. All authors read and approved the final manuscript.

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Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
To comply with ethical considerations, after explaining the objectives and method of the study to the participants, informed written consent was obtained from them. It should be noted that the principles of the Declaration of Helsinki, including free entry into the research project, no harm to the participants, preservation of the right to withdraw from the study, and confidentiality of information have been observed in this research. In addition, the researchers committed themselves to adhere to the principles of the Committee on Publication Ethics (COPE) established for the publication of the results. This study was approved by the ethics committee of Tehran University of Medical Sciences with the ethics code IR.TUMS.VCR.REC.1396.4580.

Consent for publication
Not required.

Competing interests
The authors declare no competing interests.

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