

Original Article

Barriers to End-of-Life Care Delivery to Home-Dwelling Terminally-Ill Older Patients: A Qualitative Content Analysis

Manijeh Dehi, Kian Norouzi¹, Farahnaz Mohammadi¹, Reza Negarandeh²

Department of Nursing, University of Social Welfare and Rehabilitation Sciences, ¹Department of Nursing, Iranian Research Center on Aging, University of Social Welfare and Rehabilitation Sciences, ²Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

ORCID:

Manijeh Dehi:
0000-0002-5095-6882

Kian Norouzi:
0000-0001-7439-6691

Farahnaz Mohammadi:
0000-0001-8357-0882

Reza Negarandeh:
0000-0002-7597-5094

ABSTRACT

Background: In the last days of life, home-dwelling terminally-ill older patients have complex care needs. End-of-life (EOL) care for these patients is usually delivered at home. However, there is limited information about the barriers to EOL care delivery to home-dwelling terminally-ill older patients. **Objectives:** This study is aimed to explore the barriers to EOL care delivery to home-dwelling terminally-ill older patients. **Methods:** This qualitative study was conducted in 2017–2018. Ten family caregivers and ten health-care providers were purposively selected. The main inclusion criterion was the experience of EOL care delivery to home-dwelling terminally-ill older patients. Data were collected through semi-structured interviews and were analyzed through conventional content analysis. In total, 23 interviews were held with twenty participants. **Results:** The barriers to EOL care delivery to home-dwelling terminally-ill older patients were categorized into the following three main categories and ten subcategories: inappropriate community-based healthcare context (subcategories: lack of public home care services, lack of palliative/hospice care services, legal/ethical dilemmas, and wrong cultural beliefs leading to wrong EOL care), unsupportive healthcare providers (subcategories: limited preparation for EOL care delivery, negligence towards appropriate home care delivery, and indifference to patients' and their families' rights), and inappropriate family conditions (subcategories: families' lack of care-related knowledge and skills, families' poor financial status, and tension in families). **Conclusion:** There are different familial, financial, professional, organizational, and social barriers to EOL care delivery to home-dwelling terminally-ill older patients. Culturally-appropriate policies and strategies are needed for operationalizing EOL care, integrating it into the public health-care system, and preparing healthcare providers and family caregivers for its delivery.

KEYWORDS: Aged, Death, Palliative care, Qualitative research, Terminal care

INTRODUCTION

Older adults have different complex needs in the last years of their lives.^[1] Effective fulfillment of their needs requires a unique approach to care delivery^[2] called end-of-life (EOL) care.^[3] EOL care refers to care services delivered to terminally-ill patients who are predicted to die in 6–12 months.^[4] EOL care is provided through hospice care or palliative care in home or clinical settings. Hospice care is provided to patients with untreatable conditions.^[5,6] Although most

terminally-ill older patients experience death in hospital settings, the process of predeath care delivery mainly takes place in home settings.^[1] Studies showed that in the latest days of their lives, most older adults prefer to


Address for correspondence: Dr. Kian Norouzi, University of Social Welfare and Rehabilitation Sciences, Kodakyar Ave., Daneshjo Blvd., Evin, Tehran, Iran.
E-mail: dr.kian_nourozi@yahoo.com

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

Submitted: 26-Nov-2019 **Revised:** 01-Jan-2020 **Accepted:** 21-Jun-2020
Published: 20-Apr-2021

How to cite this article: Dehi M, Norouzi K, Mohammadi F, Negarandeh R. Barriers to end-of-life care delivery to home-dwelling terminally-ill older patients: A qualitative content analysis. *Nurs Midwifery Stud* 2021;10:121-9.

Access this article online	
Quick Response Code: 	Website: www.nmsjournal.com
	DOI: 10.4103/nms.nms_108_19

be at their homes with their family members.^[7] However, quality EOL care delivery at home is a major challenge for families and health-care systems.^[8]

Despite the importance of EOL care, it is not appropriately designed and delivered in most countries,^[9] and there is no comprehensive plan to facilitate patients' and family members' access to EOL care.^[10,11] The International Organization of EOL care reported that only 19.2% of countries have integrated palliative care services into their formal healthcare systems.^[12] Therefore, most older adults receive inappropriate and low-quality EOL care.^[13,14]

Recently, several training initiatives were created in developed countries to improve EOL care delivery.^[15,16] One of these initiatives is the Six-Step to Success program developed by the consortia of cancer and EOL care networks in the North West of England. This program addresses the main stages of EOL care delivery in a cycle with the following six steps: (1) discussions as EOL approaches; (2) assessment, care planning, and review; (3) coordination of care; (4) delivery of high-quality care; (5) care in the last days of life; and (6) care after death.^[17]

The formal EOL care system in Iran is rather new and is limited to only some large cities.^[18,19] Most EOL care services in Iran are delivered by family members or laypeople without any professional support.^[20] However, families that need to provide EOL care to their older adults face many different challenges and barriers which may negatively affect quality EOL care delivery and impair their functions and roles.^[21]

The first step to the improvement of EOL care delivery is to identify its barriers.^[22,23] Such identification requires further studies in different countries.^[24] This study was conducted to address this gap.

Objectives

The aim of this study was to explore the barriers to EOL care delivery to home-dwelling terminally-ill older patients.

METHODS

Design and participants

This qualitative study was conducted in 2017–2018 using the qualitative content analysis approach. Participants were ten family caregivers and ten health-care providers (including five nurses, one nurse assistant, and four physicians) who had the experience of EOL care delivery to home-dwelling terminally-ill older patients. They were recruited from homes, home care institutes, and Imam Reza, Madani, and Ghazi Tabatabaei hospitals, Tabriz, Iran. Sampling

was performed purposively with maximum variation concerning participants' gender, work experience, educational level, socioeconomic status, and kinship with older adults as well as older patients' age, gender, and underlying conditions. For sampling, we initially referred to home care institutes, where there were few eligible caregivers for the study. Therefore, we referred to the different wards of the abovementioned hospitals for sampling. Eligibility criteria were age over sixteen, the experience of EOL care delivery to home-dwelling terminally-ill older patients, ability to share experiences, and agreement for participation.

Data collection

Data were collected through in-depth semi-structured face-to-face interviews held by the first author. Firstly, the family caregivers and secondly for fulfilling of data, the professional caregivers were interviewed. Interviews were guided using broad, open-ended questions about the barriers to EOL care delivery [Table 1]. Then, probing questions were used to ask participants to provide more detailed data about their experiences. The time and the place of the interviews were arranged according to participants' preferences. Health-care providers were interviewed at their workplace, while family caregivers were interviewed either at their homes (nine interviews) or at their workplace, the first author's workplace, or parks (four interviews). Three family caregivers were re-interviewed after the death of their patients to obtain more in-depth data about their experiences. The length of the interviews was 30–70 min. Except for two interviews with two family caregivers, all other interviews were digitally audio-recorded. Those two interviews were documented through written notes because interviewees did not consent for the digital audio-recording of their interviews. Data collection was continued up to data saturation.

Data analysis

The conventional content analysis approach proposed by Graneheim and Lundman was used for data analysis.^[25] Interviews were transcribed verbatim and carefully read for several times to achieve a general understanding of their content. The sentences related to the research topic were identified as meaning units, and initial codes were extracted. The extracted codes were classified in conceptual categories based on similarities and differences. We then generated more abstracted concepts by systematically comparing the different primary conceptual categories. The MAXQDA software (v. 10 R250412, Verbi® Verbi, Berlin, Germany) was used to manage the data. Table 2 shows an example of data analysis.

Table 1: Interview guide

Questions for family caregivers	Questions for professional caregivers
May you please explain your father's/mother's disease and condition	May you please explain your experiences of EOL care delivery to older patients with terminal conditions
How do you care for your father/mother?	What challenges/difficulties have you experienced when delivering care to your older patients?
What kinds of care have you given to your patient?	Did your care services and treatments improve the patient's overall health and conditions?
What challenges/difficulties have you experienced when giving care to your patient?	In your opinion, how should these patients be cared for?
Were there any other barriers or challenges?	Were there any other barriers or challenges?

Table 2: An example of data analysis

Meaning units	Condensed meaning units	Codes	Subcategories
The law says that patients' medications should not be reduced or discontinued in no way. The doctor says the medication no longer helps the patient. I also know that the medication is not effective for the patient anymore. The family also doesn't know whether medications need to be given to the patient. I don't know what to do	Having the challenge to act according to the law or physicians', nurses', patients' or family members' preferences	Challenge of selecting the best choice	Legal/ethical dilemma
The doctor said the patient didn't need cardiopulmonary resuscitation; but when the patient experienced cardiac arrest, I couldn't avoid doing resuscitation and I began it	The doctor says one thing and the nurse does another thing	Contradiction between doctor's and nurse's opinions	

Trustworthiness

Lincoln and Guba criteria were used to establishing trustworthiness. These criteria are credibility, dependability, confirmability, and transferability.^[26] To ensure credibility, we had prolonged engagement with the data and triangulated the data source through interviewing both family caregivers and different health-care providers. The first author also had the experience of working with older patients, particularly those with terminal conditions, for at least 8 years. Coauthors also had the experience of working with older patients with severe chronic conditions. Peer debriefing and member checking were also used to ensure credibility. In peer debriefing, two qualitative researchers assessed the soundness of data analysis. In member checking, some participants approved the congruence between the study findings and their experiences. For transferability, clear explanations were provided about the different aspects of the study, including sampling, data collection, and setting. To ensure dependability, all documents related to the study were kept so that others can cross-check the process of the study. Moreover, excerpts from the data were independently analyzed by two of the authors, which both achieved the same findings. Direct and verbatim quotations of participants' interviews were presented to ensure confirmability.

Ethical considerations

This study has the approval of the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences, Tehran, Iran (code: IR.USWR.REC.1396.265). Participants

were ensured that their participation in the study would be completely voluntary, and their data would be managed confidentially. They were informed about the study aim, and written informed consent was obtained from them. Interviews were anonymized using numerical codes.

RESULTS

Participants were ten family caregivers and ten healthcare providers. Three family caregivers were interviewed twice, once during caregiving to their terminally-ill older patients and once a few months after their patients' death. Accordingly, 23 interviews were held with twenty participants. Table 3 shows participants' characteristics.

Barriers to EOL care delivery to home-dwelling terminally-ill older patients were grouped into three main categories, namely inappropriate community-based health-care context, unsupportive health-care providers, and inappropriate family conditions [Table 4].

Inappropriate community-based health-care context

The health-care system of Iran does not integrate community health medicine and nursing, EOL care, and palliative care, and hence, terminally-ill patients may not receive effective care for pain relief and comfortable death. This main category had four subcategories.

Lack of public home care services

As EOL care services for older adults are very complex, family members need professional support

Table 3: Participants' characteristics

n	Older patient			Family caregiver						
	Age (years)	Gender	Diagnosis	Age (years)	Gender	Caregiving duration (months)	Occupation	Educational level	Marital status	Kinship with patient
1	62	Female	Leukemia	26	Female	5	Housewife	Diploma	Married	Daughter-in-law
2	65	Female	Lung cancer	58	Female	3	Housewife	Illiterate	Married	Spouse
3	76	Male	Heart failure	44	Male	5	Employee	Bachelor's	Married	Son
4 ^a	72	Female	Gastric cancer	37	Female	4	Housewife	Diploma	Single	Daughter
5	84	Male	Pulmonary fibrosis	68	Female	8	Housewife	Illiterate	Married	Spouse
6	85	Male	Prostate cancer	45	Female	7	Housewife	Diploma	Married	Daughter-in-law
7 ^a	74	Female	Heart failure	39	Female	4	Carpet weaver	Secondary	Single	Daughter
8	75	Female	Liver failure	48	Female	5	Employee	Bachelor's	Married	Daughter-in-law
9	86	Male	COPD†	26	Female	10	Housewife	Bachelor's	Married	Daughter-in-law
10 ^a	70	Male	Brain tumor	40	Male	14	Self-employed	Master's	Single	Son

Healthcare providers			
n	Occupation	Age (years)	Educational level
11	Nurse	36	Bachelor's
12	Nurse	40	Bachelor's
13	Nurse	34	Bachelor's
14	Nurse	28	Bachelor's
15	Nurse	35	Master's
16	Nurse assistant	58	Diploma
17	Physician	50	Internal medicine specialist
18	Physician	48	Cardiac specialist
29	Physician	55	Oncology subspecialist
20	Physician	60	Pain and palliative subspecialist

^aParticipants who were interviewed twice. COPD: Chronic obstructive pulmonary disease

for home care from the public health-care centers. However, after the discharge of their patients from health-care centers, family caregivers do not receive any professional support. On the other hand, home care delivery institutes are independent from the health-care system, and there is neither close supervision nor organizational support for their services. Moreover, most of their services are not covered by insurance, and family members may not afford them. Consequently, most families may choose not to receive care services from these centers.

A wife with 8 months of caregiving stated: *"We didn't have enough money to buy an oxygen cylinder. We referred to different centers such as hospitals to borrow a cylinder; but, none of them gave us any. Finally, the Red Crescent Organization rented us a cylinder. Now, there is no one to help us learn how to use it appropriately"* (P. 5).

One of the nurses also reported: *"Most home care institutes don't have necessary legal permissions for*

practice from the Ministry of Health and there is no supervision on their practice" (P. 15).

Lack of palliative/hospice care services

The current health-care system of Iran does not include any EOL, palliative, or hospice care program. There are only a handful of private and palliative care centers in some large cities that provide nonspecialized services without receiving any official support from the public health-care system. These centers do not provide their services in home settings, while most older adults cannot be transferred to these centers due to their physical conditions or financial problems. Moreover, most of these centers and their services are unknown to the public, so that most participants were unfamiliar with them.

A nurse mentioned: *"There are only few palliative care centers in some cities of Iran. Most of our colleagues are unaware of the availability of these centers. Nobody values palliative care in our system"* (P. 13).

Table 4: Sample codes, subcategories, and main categories of the study

Categories	Subcategories	Sample codes
Inappropriate community-based health care context	Lack of public home care services	Illegal activity of most home care institutes No insurance coverage for home care services
	Lack of palliative/hospice care services	Private nonspecialized palliative care centers Inaccessibility of palliative care services for most patients
	Legal/ethical dilemmas	Lack of ethical guidelines for EOL issues Lack of clear legal guidelines for EOL decision making
	Wrong cultural beliefs leading to wrong EOL care	Death as a socially unacceptable phenomenon Negative public attitude towards palliative care
Unsupportive healthcare professionals	Limited preparation for EOL care delivery	Shortage of trained staff for EOL care Disease-centeredness instead of patient-centeredness
	Negligence towards appropriate home care delivery	Lack of necessary infrastructures for EOL care delivery Employing lay people for home care delivery
	Indifference to patients' and their families' rights	Not involving families and patients in clinical decision making Delivering futile therapeutic interventions for the interests of people other than patients and their family members
Inappropriate family conditions	Families' lack of care-related knowledge and skills	Lack of reliable sources of care-related information for families Lack of knowledge as a main source of stress for families
	Families' poor financial status	Financial problems as the main barrier to care delivery Selling family possessions to afford care-related costs
	Tension in families	Family members' mental fatigue Family disputes

EOL: End-of-life

Legal/ethical dilemmas

Health-care providers in the present study complained of the inattentiveness of the public health-care system in Iran to the legal and ethical issues of EOL care and noted that the lack of clear legal guidelines and ethical codes for EOL care had led to many challenges and dilemmas in care delivery. The most important dilemma was related to the lack of legal guidelines for nonresuscitation of patients with terminal conditions. This dilemma caused health-care providers to decide on either unrealistic or fake resuscitation or avoidance from resuscitation without informing families and seeking their opinions. Besides, most of the current regulations do not support patients. For instance, strict regulations on opioid analgesics deprive most patients of these analgesics.

A nurse said: *"Some patients don't respond to resuscitation due to their terminal conditions; however, they (i.e., authorities) have required us to perform resuscitation in a fake way due to the ethical and legal issues related to resuscitation"* (P. 13).

Also, a physician commented: *"Here, there are very strict regulations on using opioid analgesics. For example, regulations require us to just receive these analgesics from university authorities and don't allow physicians to prescribe them"* (P. 17).

Wrong cultural beliefs leading to wrong end-of-life care

According to the participants, there is great fear over talking about death in the Iranian culture so that it is

difficult for health-care providers to inform patients of their terminal conditions. Consequently, older patients with terminal conditions have limited participation, if any, in EOL decision-making. Moreover, longer life despite great suffering is preferred over a shorter life with better quality. However, in the last days of patient life, family members usually want their patients to have no pain and comfortable death, though dominant beliefs in the Iranian culture consider pain and suffering as inseparable parts of aging and death. Some participants noted that pain and suffering can purify patients of their sins and hence, are necessary for meeting God with a purified heart. Both health-care providers and family caregivers noted that Iranian families value therapeutic interventions more than palliative care. Two Physicians commented:

"At first, families urge treatments rather than pain relief; but with the aggravation of their patients' conditions, they get tired of ineffective treatment and prefer pain relief over it" (P. 20).

"Our people have negative attitudes towards informing patients of the possibility of a near death. Families are very sensitive to such informing and hence, ask physicians and nurses not to inform their patients of their death" (P. 17).

Unsupportive health-care providers

The second main barrier to EOL care delivery was unsupportive health-care providers. This category

included three subcategories, namely limited preparation for EOL care delivery, negligence toward appropriate home care delivery, and indifference to patients' and their families' rights.

Limited preparation for end-of-life care delivery

According to the participants, health-care providers do not receive any comprehensive and specialized education about EOL care during their university and in-service education and do not have adequate knowledge and skills for managing complex EOL situations. They frequently highlighted health-care providers' inability to effectively use their knowledge in practice, manage terminally-ill older patients' symptoms, and establish effective communication with patients and their families.

A physician described: *"Staff who work with these patients haven't received any in-service education about EOL care and have either forgotten or not applied what they learned during their university education"* (P. 18).

A similar experience was remarked by a nurse: *"We don't have the necessary skills for establishing appropriate relationships with terminally-ill patients"* (P. 11).

Negligence toward appropriate home care delivery

Participants noted that health-care providers have limited motivation for quality home care delivery due to many different problems. These problems included the lack of a definite status for home care in health-care system, the lack of necessary requirements, security issues related to care delivery at home, the costs of traveling to patients' homes, issues related to care delivery by same-gender health-care providers, staff shortage, limited insurance coverage of home care services, and physicians' limited interest in home care delivery. Moreover, home care institutes usually employ nonprofessional individuals for care delivery, and nurses engage in home care delivery as their second job and deliver it with low quality. Physicians also consider home visit futile or time-wasting and hence, either refuse to do it, request high fees for it, or write medical prescriptions without any actual patient visit.

A nurse expressed: *"Home care centers usually convince nonnurse individuals to work for them with low salaries. These centers employ people who even don't have secondary education and assign them nursing tasks"* (P. 12).

As well, a family caregiver added: *"One day, he was terribly ill. His doctor initially refused to visit him at home and said that he couldn't do anything for him at home. We insisted a lot until he accepted to visit him at home for a fee of 700000 Tomans [the superunit of the official currency of Iran]. He visited*

my patient, examined him, and said that he couldn't do anything" (P. 3).

Indifference to patients' and their families' rights

Participants noted that as older patients and their family members do not have good emotional status and necessary competencies for decision-making, health-care providers usually do not actively involve them in clinical decision making and treat their requests with indifference. Participating family caregivers highlighted that due to health-care providers' indifference to their requests and rights, they could not appropriately express their opinions, ask their questions, and show disagreement. Moreover, health-care providers' use of medical terms, older patients' inability to hear and understand conversations and physicians' nonempathetic conduct towards patients and family members had caused confusion for patients and family caregivers.

A doctor declared: *"I make decisions alone and don't inform families. In my opinion, families don't have the necessary competence for decision making"* (P. 19).

Likewise, a nurse disclosed: *"Some physicians are stockholders in private hospitals and hence, refer their patients to some certain pharmacies and hospitals. Families have no option but to obey their orders"* (P. 14).

Inappropriate family conditions

The third main barrier to EOL care delivery to home-dwelling terminally-ill older patients was their inappropriate family conditions. The three subcategories of this category were families' lack of care-related knowledge and skills, families' poor financial status, and tension in families.

Families' lack of care-related knowledge and skills

Most family caregivers complained about their lack of knowledge and skills for patient care and about the lack of reliable sources for acquiring care-related information. Health-care providers also highlighted that health-care providers do not greatly value patient and family education, have limited time for it due to their heavy workload and are unaware of patients' and family members' educational needs. Family caregivers' lack of care-related knowledge and skills causes them severe stress and causes their patients great suffering.

A family caregiver commented: *"There is no one to tell us what we should do. They don't care whether we can give care to our patients. Only a nurse mentioned something at the time of hospital discharge which I didn't understand"* (P. 1).

Furthermore, a nurse said: *"I went to a patient's home. His daughter even couldn't speak due to her severe*

stress. She told that she was frightened and didn't know how she should give care to her patient. Family members have limited information and can't care for their patients and hence, experience high levels of stress" (P. 15).

Families' poor financial status

Most participants referred to financial problems and the necessity of full-time care as two main barriers to EOL care delivery. Before older patients reach terminal conditions, their families have already spent a lot on their treatments and hence, may not be able to afford the costs of their terminal conditions and EOL care. Sometimes, the high costs of caregiving to older patients with terminal conditions may require their families to borrow money or sell their possessions.

A family caregiver said: "It's for 2 years that we have spent money on her illness. We have worked throughout our life to save money for our children's marriage. But, all our saving was wiped out and we have borrowed a lot so far" (P. 2).

Tension in families

Huge care-related needs of terminally-ill older patients, their imminent death, and their family members' loneliness in caregiving lead to serious physical, mental, and emotional tension in families. Family caregivers in the present study frequently referred to problems such as aggression, fatigue, and stress due to their inability to manage their patients' conditions. Because of the worsening conditions of their patients and their limited perceived support, family members may eventually consider patient death as the only solution to their patients' suffering and may request health-care providers to hasten death.

A family caregiver said: "I become very tired and angry. I shout at everybody and unduly hit the children. When the strain is too much, I even hit myself and curse" (P. 7).

Related to this issue, a doctor also declared: "I visited a seriously-ill patient at his home. One day, his daughter cried and said that she didn't want her father to experience such great suffering and asked me to inject a drug to end his suffering" (P. 17).

DISCUSSION

The main barriers to EOL care delivery to home-dwelling terminally-ill older patients were inappropriate community-based health care context, unsupportive health care providers, and inappropriate family conditions.

Inappropriate community-based health-care context seemed to be the most important barrier to EOL care

delivery to home-dwelling terminally-ill older patients. Despite older adults' great need for care, there are neither formal geriatric care services nor formal home care services and official support for them and their families in Iran. Home care in Iran was first introduced in 1999. However, most insurance companies still do not cover home care services, and hence, these services are not widespread and easily accessible in Iran.^[27] Contrarily, these services are widely accessible in most developed countries.^[28]

Findings also showed the lack of palliative/hospice care as a barrier to EOL care delivery to older adults. Home care is a rather new concept in Iran, and limited efforts have so far been made for its development.^[19] Similarly, a worldwide study conducted by the International Organization of EOL care reported that palliative care services are not widely and systematically delivered.^[12] Therefore, more efforts are still needed to promote palliative care delivery and integrate it into public health-care systems.

Another contextual barrier to EOL care delivery in the present study was legal/ethical dilemmas. There are many dilemmas and issues related to EOL care delivery in Iran, which include the greater importance of prolonging the lives of terminally-ill patients using machines and medications as well as the lack of legal regulations about EOL care such as the "Do not resuscitate" order.^[29] A significant factor contributing to these issues and dilemmas is the fact that while Islam is the dominant religion in Iran, there are limited clear juridical guidelines for treating terminally-ill patients in the country. Jurisprudence related to EOL care is still in its infancy, and none of the Islamic countries have still developed clear guidelines in this area.^[30] Another factor contributing to legal/ethical dilemmas in the area of EOL care delivery in Iran is related to strict regulations on opioid analgesic use. Current regulations restrict its prescription and administration, and hence, many patients with pain have limited access to these analgesics.

Wrong cultural beliefs were the fourth contextual barrier to EOL care delivery in the present study. In line with this finding, a study on patients from different nationalities in the United States reported cultural barriers as the main barrier to EOL care delivery.^[6] Another study also showed that culture has significant effects on EOL care delivery.^[31] Our findings revealed death as a taboo in the Iranian culture so that instead of effective pain management and palliative care services, terminally-ill patients mainly receive therapeutic services. Similarly, a former study showed that the social taboo of death has become more widespread in recent

years, and hence, people have currently greater fear over facing death. That study recommended strategies such as cultural changes and educational interventions for facilitating death-related talks as well as promoting the acceptance of death as the final stage of life and a way to terminate pain and suffering.^[32]

The second main category of the barriers to EOL care in the present study was unsupportive health-care providers. EOL care is a new concept in Iran, and no serious efforts have yet been made for its operationalization and education.^[21] Accordingly, health-care providers in Iran, particularly physicians, have limited preparation for EOL care delivery. A study showed that more than half of the medical specialists in Iran had no accurate understanding of EOL care.^[33] A systematic review also confirmed the lack of quality education for health-care providers as the most important barrier to EOL care delivery and recommended improvements in education for promoting EOL care delivery.^[34]

We also found health-care providers' negligence towards appropriate home care delivery and their indifference to patients' and their families' rights as main barriers to EOL care delivery. Home care in Iran is delivered without any careful formal supervision and coherent structure. Consequently, health-care providers are inattentive to quality home care delivery and are indifferent to patients' and their families' rights. Our findings showed that health-care providers did not involve patients and their family members in clinical decision making. Although EOL decisions should be made in collaboration with patients, families, nurses, and physicians, there is no clear guideline in Iran for assessing patients' and family members' preferences, and most EOL decisions are made mainly by physicians.^[11]

The third main category of the barriers to EOL care delivery was inappropriate family conditions. Findings showed that due to the lack of professional support and limited access to medical equipment, family caregivers experienced different physical, mental, emotional, financial, knowledge-related, and skill-related problems in EOL care delivery to their terminally-ill older adults. In line with this finding, a study reported that families face different challenges and problems in EOL care delivery to their older members.^[35] EOL care is complex and necessitates an individualized approach.^[36] Therefore, without receiving adequate support from the public health-care system, family caregivers may experience different challenges in EOL care delivery.^[37]

Our findings also showed that most families in Iran cannot easily accept the death of their older members and attempt to postpone it at any cost. However, with the

aggravation of patients' conditions and the impossibility of effectively managing symptoms and problems, families develop a positive attitude toward death and may even request health-care providers to hasten it. Islam greatly values life and rejects any intervention for hastening patients' death even in case of great pain and suffering and requires health-care providers to do their bests to prevent premature death.^[38]

Because of limited time and human sources, this study was conducted in one city, and hence, its results may not be generalizable to family caregivers and health-care providers in other cities. Moreover, due to the lack of palliative care centers in our country, none of the health-care providers in the present study had the experience of working in palliative/hospice care settings. In addition, we just explored the barriers to EOL care delivery and did not address its facilitators. Given the limitations of the present study, it is recommended that more studies should be carried out in other cities, especially in the ones with the end of life care delivery facilities, to achieve more valid and deep knowledge about barriers and also facilitators of EOL care for elderly.

CONCLUSION

This study suggests that there are many different barriers to EOL care delivery to home-dwelling older patients, including lack of specialized community-based palliative care centers, incongruent cultural beliefs with EOL care, ethical and legal problems, inadequate insurance coverage of home-based EOL care services, lack of competent health-care providers for EOL care delivery, families' inability to afford EOL care, and their limited knowledge and skills for EOL care delivery. Instead of extensive ineffective and costly therapeutic services, palliative care services should be developed and used for terminally-ill older adults. Moreover, palliative care should be integrated into the academic curriculum of medical science fields, particularly nursing. Adequate insurance should also be provided for palliative care services to reduce families' financial burden. Finally, families should be educated for and actively involved in palliative care delivery.

Acknowledgment

This study was part of the first author's PhD dissertation supported by the University of Social Welfare and Rehabilitation Sciences, Tehran, Iran. The authors would like to thank the Research Administration of the university for supporting this study.

Financial support and sponsorship

This study is sponsored by Tehran University of Social Welfare and Rehabilitation Sciences (USWR).

Conflicts of interest

There are no conflicts of interest.

REFERENCES

- Schou-Andersen M, Ullersted MP, Jensen AB, Neergaard MA. Factors associated with preference for dying at home among terminally ill patients with cancer. *Scand J Caring Sci* 2016;30:466-76.
- Romano AM, Gade KE, Nielsen G, Havard R, Harrison JH, Barclay J, *et al.* Early palliative care reduces end-of-life intensive care unit (ICU) use but not ICU course in patients with advanced cancer. *Oncologist* 2017;22:318-23.
- Balducci L. Geriatric oncology, spirituality, and palliative care. *J Pain Symptom Manage* 2019;57:171-5.
- Salins N, Gursahani R, Mathur R, Iyer S, Macaden S, Simha N, *et al.* Definition of terms used in limitation of treatment and providing palliative care at the end of life: The Indian council of medical research commission report. *Indian J Crit Care Med* 2018;22:249-62.
- Wienczek C, Coyne P. Palliative care delivery models. *Semin Oncol Nurs* 2014;30:227-33.
- Kenny PM, Hall JP, Zapart S, Davis PR. Informal care and home-based palliative care: The health-related quality of life of carers. *J Pain Symptom Manage* 2010;40:35-48.
- Shepperd S, Gonçalves-Bradley DC, Straus SE, Wee B. Hospital at home: Home-based end-of-life care. *Cochrane Database Syst Rev* 2011;7:CD009231.
- Ohmachi I, Arima K, Abe Y, Nishimura T, Goto H, Aoyagi K. Factors influencing the preferred place of death in community-dwelling elderly people in Japan. *Int J Gerontol* 2015;9:24-8.
- Gray BH. England's approach to improving end-of-life care: A strategy for honoring patients' choices. *Issue Brief (Commonw Fund)* 2011;15:1-5.
- Levasseur M, Desrosiers J, Whiteneck G. Accomplishment level and satisfaction with social participation of older adults: Association with quality of life and best correlates. *Qual Life Res* 2010;19:665-75.
- Jabbari H, Piri R, Bakhshian F, Mohit B, Naghavi-Behzad M, Mohammadi S, *et al.* End-of-life Care: Beliefs, attitudes, and experiences of Iranian physicians. *Indian J Palliat Care* 2018;24:431-5.
- Lynch T, Connor S, Clark D. Mapping levels of palliative care development: A global update. *J Pain Symptom Manage* 2013;45:1094-106.
- Bolt EE, Pasman HR, Willems D, Onwuteaka-Philipsen BD. Appropriate and inappropriate care in the last phase of life: An explorative study among patients and relatives. *BMC Health Serv Res* 2016;16:655.
- Chakraborty R, El-Jawahri AR, Litzow MR, Syrjala KL, Parnes AD, Hashmi SK. A systematic review of religious beliefs about major end-of-life issues in the five major world religions. *Palliat Support Care* 2017;15:609-22.
- Gandy R. Economic appraisal of an end-of-life care training initiative for care homes with dementia patients. *J Care Serv Manag* 2010;4:321-30.
- Regan A, Tapley M, Jolley D. Improving end of life care for people with dementia. *Nurs Stand* 2014;28:37-43.
- O'Brien M, Kirton J, Knighting K, Roe B, Jack B. Improving end of life care in care homes; an evaluation of the six steps to success programme. *BMC Palliat Care* 2016;15:53.
- Ghaljeh M, Iranmanesh S, Nayeri N, Tirgari B. Organizational challenges: A major obstacle at end of life care in Iran. *Br J Med Res* 2016;16:1-12.
- Rassouli M, Sajjadi M. Palliative care in Iran: Moving toward the development of palliative care for cancer. *Am J Hosp Palliat Care* 2016;33:240-4.
- Aghdam AM, Aghaei MH, Hassankhani H, Rahmani A. Awareness and attitude of nurses in regard to providing hospice care. *Asian Pac J Cancer Prev* 2015;16:6941-5.
- Kisorio LC, Langley GC. End-of-life care in intensive care unit: Family experiences. *Intensive Crit Care Nurs* 2016;35:57-65.
- Lee JE, Goo AJ, Cho BL. The current status of end-of-life care in Korea and legislation of well-dying act. *J Korean Geriatr Soc* 2016;20:65-70.
- Wright AA, Keating NL, Ayanian JZ, Chrischilles EA, Kahn KL, Ritchie CS, *et al.* Family perspectives on aggressive cancer care near the end of life. *JAMA* 2016;315:284-92.
- Woo J, Cheng JO, Lee J, Lo R, Hui E, Lum CM, *et al.* Evaluation of a continuous quality improvement initiative for end-of-life care for older noncancer patients. *J Am Med Dir Assoc* 2011;12:105-13.
- Graneheim UH, Lundman B. Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24:105-12.
- Lincoln YS, Guba EG. *Naturalistic Enquiry*. Sage; 1985.
- Moradian ST, Nourozi K, Ebadi A, Khankeh HR. Barriers against providing home health care delivery to ventilator-dependent patients: A qualitative content analysis. *Trauma Mon* 2017;22:207-15.
- Cardona-Morrell M, Kim JCH, Brabrand M, Gallego-Luxan B, Hillman K. What is inappropriate hospital use for elderly people near the end of life? A systematic review. *Eur J Intern Med* 2017;42:39-50.
- Assarroudi A, Nabavi F, Ebadi A, Esmaily H. Do-not-resuscitate order: The experiences of Iranian cardiopulmonary resuscitation team members. *Indian J Palliat Care* 2017;23:88-92.
- Gouda A, Al-Jabbary A, Fong L. Compliance with DNR policy in a tertiary care center in Saudi Arabia. *Intensive Care Med* 2010;36:2149-53.
- Innes A, Ashraf F, Ismail L, Mackenzie J. The importance of cultural competence in dementia care. *J Dement Care* 2001;9:26-8.
- Lakasing E. Death's worsening taboo: Is hampering the provision of high quality palliative care. *Br J Gen Pract* 2014;64:243.
- Asadi-Lari M, Madjd Z, Akbari ME. The need for palliative care services in Iran; an introductory commentary. *Iran J Cancer Prev* 2008;1:1-4.
- Anstey S, Powell T, Coles B, Hale R, Gould D. Education and training to enhance end-of-life care for nursing home staff: A systematic literature review. *BMJ Support Palliat Care* 2016;6:353-61.
- Given BA, Reinhard SC. Caregiving at the end of life: The challenges for family caregivers. *Generations* 2017;41:50-7.
- Mitchell G. Rapidly increasing end-of-life care needs: A timely warning. *BMC Med* 2017;15:126.
- Kale MS, Ornstein KA, Smith CB, Kelley AS. End-of-life discussions with older adults. *J Am Geriatr Soc* 2016;64:1962-7.
- Chamsi-Pasha H, Albar MA. Ethical dilemmas at the end of life: Islamic perspective. *J Relig Health* 2017;56:400-10.