

Process Challenges in Palliative Care for Cancer Patients: A Qualitative Study

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Abstract

Background: Quality assessment and service delivery processes for cancer patients are the major components of palliative care. This study intends to explore stakeholder's perceptions of palliative care process challenges for cancer patients in Iran.

Method: In this qualitative study, we conducted 22 semi-structured interviews from February 2016 to August 2017 in hospitals located in Tehran, Iran. Participants were selected through purposive sampling and included cancer patients, their family caregivers, healthcare providers, and policy-makers. The interviews were analyzed by qualitative directed content analysis based on the Donabedian model. In order to assess the accuracy and validity of the study, we used Lincoln and Guba's four criteria.

Results: After analysis of the interviews, we categorized the codes into a main category, "process", and three identified subcategories – "weakness of stakeholders' engagement policies", "standardized care", and "applying educational and research approaches".

Conclusion: Palliative care in Iran is a recent discipline. The results have shown that the process of providing services requires the attention of the health system to the standard models for providing palliative care services. In addition, it is necessary to train human resources in generalist and specialist palliative care groups, design palliative medicine curricula, inform general public about cancer, and empower patients and caregivers.

Keywords: Palliative care, Neoplasm, Process assessment (health care), Quality of health care, Donabedian model

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Introduction

Cancer, one of the main causes of death worldwide,¹ is attributed to more than 70% of deaths in developing countries.² This disease is the third leading cause of death in Iran,³ with 90000 new cases reported annually.⁴ Cancer patients endure a significant burden of symptoms and side effects associated with this disease and its treatment, which makes their quality of life undergo undesirable changes.⁵

In response to the decline in patient quality of life, the WHO introduced palliative care with the aim to manage symptoms, reduce treatment-related side effects, and improve quality of life for people with life-threatening diseases such as cancer.⁶ Palliative care is one of the major cancer control programs,⁷ which addresses the needs of patients by developing structures in the form of various processes. The most important processes include the provision of proper and standard services; use of instructions and clinical guidelines;⁸ provision of general and specialized training for caregivers; perform research and increase the awareness of health care workers and society.⁹

Iranian health policy makers considered expert opinions at the Program of Action for Cancer Therapy (PACT) of the International Atomic Energy Agency¹⁰ and WHO's recommendations on the necessity for palliative care services at various levels⁷ to design a palliative care system.¹¹ Health policy makers in Iran should identify challenges in the process of providing services in Iran's nascent palliative care system, play an important role in overcoming these challenges, and create proper processes for the palliative care system.

Palliative care is relatively new in Iran and only a few centers provide this service.¹² Therefore, the process for providing these services is not well-known and, in most cases, faces many challenges. Services for cancer patients in Iran include hospitalizations or outpatient services as proposed by public and private health centers. These services consist of common diagnostic and general or specialized medical care services, as

well as limited information that patients receive from the time of their discharge until the next treatment stage. These patients do not receive any types of care services, information, or counseling related to their physical, mental, spiritual, and social needs.¹³ Due to their lack of knowledge about the symptom management process, patients inevitably experience frequent emergencies and hospitalizations in Special Care Units. However, only 16% of cancer patients need special services for symptom management and approximately 84% can manage their problems with primary care and education.¹⁴ Examining the process is an acceptable method used by caregivers to assess quality of care.¹⁵

The Donabedian model, a well-known model in this field, is used as the conceptual framework for this research. This model defines "process" as offering and receiving services.¹⁶ In the present study, we have assessed health care providers' performances, how to communicate with patients and act according to guidelines, in addition to standards and educational strategies.¹⁷ Each country has a different opinion of palliative care services based on its health care system.¹⁸ Thus, the current processes and challenges associated with palliative care are unique for every system. This study aims to explore stakeholders' perceptions of challenges in the process of providing palliative care for cancer patients.

Materials and Methods

We used the directed content analysis approach in this qualitative study. The goal of this approach was to validate or conceptually extend a theoretical framework or theory. An existing theory or research could help to focus on the research question.¹⁹ In this study, categories have been determined on the basis of the Donabedian model.²⁰ Quality healthcare is a multi-dimensional concept. Donabedian proposed the triad structures, processes, and outcomes as a framework for assessing quality of care. This study has focused on process measures as defined within the Donabedian model and excluded structural and outcome measures. The process focuses on aspects

of delivering care and is related to interactions within and between practitioners and patients.²⁰

In qualitative research, there is no set criterion to determine the number of participants prior to the study.²¹ We have conducted face-to-face, semi-structured, and in-depth interviews for data collection until data saturation. Purposive sampling was used with 22 participants that included cancer patients and their caregivers as well as healthcare providers, and health policy-makers active in the cancer field. The patients included in this study received a definitive diagnosis of cancer by a specialist. At least six months had passed since their diagnosis and they were under treatment or in the follow-up stage of treatment. The criteria for enrolling family caregivers included direct involvement in the care of a cancer patient for more than six months. Inclusion criteria for the healthcare providers were more than one year of experience in working with cancer patients. Cancer experts and policy-makers also participated in this study. We conducted this study from February 2016 to August 2017 at the Oncology Departments and Clinics of Imam Khomeini and Shohada-ye-Tajrish Hospitals, and the Cancer Research Center, affiliated with Tehran University of Medical Sciences and Shahid Beheshti University of Medical Sciences, as the main referral centers in Iran.

Participants provided written informed consent prior to the participation. Participation in the study was completely voluntary. Participants were informed of their right to withdraw from the study at any stage and the confidentiality of their data. The researcher explained the purpose of the study and participants selected the interview place and time.

We began the interviews with the following questions for patients. “Please talk about when you first learned about your disease. What were the services you needed during your care? What was your experience of receiving care?”

Health care providers were asked the following questions. “What is your experience with providing standard care to patients? For what

Table 1. Study participants’ demographic characteristics.

Patients	
Age (years)	Mean ± SD
	47.58 ± 13.81
Gender	N (%)
Male	3 (43.00)
Female	4 (57.00)
Duration of illness	N (%)
<1 year	3 (42.85)
1-3 years	4 (57.14)
Caregiver	
Age (years)	Mean ± SD
	41.50 ± 19.09
Length of caregiving	N
<1 year	2
Health care providers	
	N
Nurse	2
General physician	2
Psychologist	1
Social worker	1
Duration of professional experience	N
1-5 years	3
>5 years	3
Policy makers	
	N
Surgeon	1
Health policy maker	1
Cancer epidemiologist	1
Nursing faculty member	1
Insurance officer	1
Duration of professional experience	N (%)
>10 years	5 (100)

reasons could you not offer services to your patients?”

Policy makers were asked the following question. “What are the requirements of caring system processes?”

Subsequent questions were determined according to participants’ prior responses. “What do you mean by that? What did you feel then? What happened next?” and so on. The researcher recorded all of the interviews. The duration of each interview was between 30-45 min.

Data analysis was carried out in accordance with the recommended steps by Graneheim and Lundman.²² Once recorded, the researchers repeatedly listened to interview, and then typed the interview verbatim in Microsoft Word. The

Table 2. Main categories, subcategories, and secondary categories.

Main category	Subcategory	Secondary category
	Weakness of stakeholders engagement policies	Influence of intersectoral relations Ambiguity of job descriptions
Process	Standardized care	Preparing service packages Preparing guidelines
	Applying educational and research approaches	Academic planning Workforce training Research and technology Increased public awareness Empowerment of patients and caregivers

transcribed text was read in its entirety for familization with the content and then coded. The codes were merged and summarized, and we identified similar codes. In this manner, we obtained the primary classifications of the data. Finally, the subcategories were grouped into a main category according to the Donabedian model. Data collection and analysis were simultaneously performed with MAXQDA 10 software.

In this study, we used four supporting processes of trustworthiness – conformability, dependability, credibility, and transferability.²³ We chose various participants and performed a peer review on the process of the work and research finding to validate conformability. Dependability was established by detailed, descriptive data analysis, and direct reference to individual professional experiences. We investigated credibility by selecting the appropriate data collection method of the interviews and considered both prolonged engagement and persistent observation with the research participants. In order to improve transferability of the research, we included an extensive description of details regarding the methodology and context.

Shahid Beheshti University of Medical Sciences approved this study (code number: IR.SBMU.RAM.REC.1395.70).

Results

Overall, we interviewed 22 participants. Table 1 lists the participants' demographic characteristics. Analysis of the interviews led to the formation of 546 initial codes. After we removed the repeated codes and merged similar codes according to the

Donabedian model, we categorized the codes into main categories (process), 3 subcategories, and 9 secondary categories (Table 2).

Weakness of stakeholders' engagement policies

The participants acknowledged that engagement and communication with other people and groups could result in improvement in the care-giving process. The most important components of this sub-category were: "influence of intersectional relations" and "ambiguity in job descriptions".

Influence of intersectoral relations

Participants referred to different paths in coordinating the activities and plans of the health care process, and its effects on the stakeholders' participation. "Important steps in the process of service delivery include cross-organizational collaborations and the creation of an appropriate platform for collaboration and interaction with the other sector" (Physician).

Another participant believed that the health care process required the development of multilateral relations and collaborations with public and private organizations and institutions, and the "Providing people's health needs in an organization requires the use of more stakeholders and their resources and experiences; this helps us to reach our organization's goals and increases satisfaction" (Nurse).

Ambiguity in job descriptions

Palliative care offers a variety of services in terms of type and model(s). Depending on each

of these models, the duties and tasks of each individual should be defined. “A cancer patient needs a series of general and sometimes special services. This will make nurses take multiple roles, both general and specialized” (Nurse).

Another participant, based on his experience, mentioned: “The functions of individuals and job descriptions must be specified in this system. Job descriptions might sometimes seem ambiguous and, in some cases, similar to those of other units. For those functions, descriptions must be codified. In my opinion, one of these cases is the manner of providing services. By which means and how you do want to provide the service? What is your duty in the field of palliative care? These are the items that must be defined by the system” (Policy maker).

Standardized care

Participants referred to promote standardized actions, clinical guidelines, and updating health care services, which consisted of developing service packages and guidelines.

Developing service packages

The process of providing services necessitates the design of service packs considering the types and complexity of cancer. These packages may include an explanation of how the services are provided at various levels of care for different types of cancers and information about insurance tariffs for different patients.

“We almost have tariffs for defined insurance services such as visits, medicines, hospitalization, imaging, laboratory, etc. I think that we need to develop proper tariffs and policies for services such as home care and psychological services. Defining services for insurance is a correct path in this field” (Policy maker).

Developing guidelines

Participants felt the need for a systematic and credible set of scientific evidences in clinical encounters with patients. “Patients most often have to interact with nurses. So, we have to provide a single guideline for our services to avoid confusion” (Nurse).

When asked about her experiences in dealing with cancer patients, a nurse with more than 7 years of experience in cancer care stated: “Our patients seek good and proper services. As a nurse, I should be familiar with the latest standards of care giving. Two nurses that work on different shifts in one department deal with the same patient. (They) need to share the same, accurate information.”

Applying educational and research approaches

Participants considered educational and research approaches as factors that influenced the palliative care policy making process. This subcategory referred to five components: “academic planning”, “workforce training”, “increasing public awareness”, “research and technology”, and “empowerment of patients and caregivers”.

Academic planning

Participants in this study considered the lack of palliative care curriculum and educational content in accordance with cancer-related disciplines as barriers to the provision of palliative care. “It's ok to teach cancer along with other noncommunicable diseases and I think that it should be included in the curricula but more comprehensive, in the form of a specialized discipline such as an MSc, PhD, or a complementary course” (Health policy-maker).

It appeared that the standard educational contents on palliative care in universities, familiarization of nursing and medical students with palliative care, and related disciplines to the basic principles of palliative care were of great importance. In this regard, a health care provider stated: “(In the) universities, there is a need for a defined cancer-specific content, at least at the undergraduate level. We don't really want to act as specialized as they do in other countries, but it's necessary for us to have standard curriculum in the related disciplines.”

Workforce training

Continuous and multidisciplinary training of human resources in order to develop and improve various skills was one of the effective factors in

providing care for patients. Multi-discipline and team management were the most popular factors with the participants. “Because of the complex nature of cancer, patients need a comprehensive care team. The care team should see all the aspects of the disease and the patient. It is not just about the disease. There are also mental and social aspects, and the coordination between them” (Health policy-maker).

“Our scientific basis is good, but being up-to-date increases our job satisfaction. On the other hand, it helps patient recovery and improves the system”, stated a nurse with five years of experience in patient care.

Research and technology

Participants indicated the lack of research in palliative care and emphasized the role of research and technology in the educational process. They affirmed the positive effects of research on improving the care provision process. Efficient education is not possible without doing scientific research. “Research in our educational and medical environment helps us to improve our educational programs.” (Health care provider)

The remarkable improvement in information technology worldwide has led to its use to improve care services. “Setting up a notification system that consists of service packages, guidelines, answering general and specialized questions, communicating with other healthcare settings, and organizing this care process will result in the effectiveness of services” (Nurse).

Increasing public awareness

Public awareness and the necessity of attracting people’s attention to information sources have been considered important by the stakeholders. Participants referred to increasing people’s knowledge of advanced care, their willingness to access valid information sources, and the need to change society’s attitude towards diseases, which are hard to treat such as cancer.

“People are looking for a healthy life, they like to plan for their future. With the present number of information sources, people's knowledge has increased, even about specialized care. On the

other hand, they are looking for reliable sources” (Family caregiver).

Empowerment of patients and caregivers

The findings of this research showed that, more than anything else, training both patients and caregivers would lead to their empowerment. Having continuous training from the time of a patient’s admission until discharge, was more important for both patients and caregivers.

“When trainings are continuous along with follow-ups by the hospital, we will have more confidence in the care procedure and recover sooner” (Patient).

Given the importance of home care and the needs of patients with cancer and their families in the process of care giving, the willingness of this group towards home care provides a good opportunity to empower patients and their families. “The best place for training is the patient’s home, called home-care, which can be supported by outpatient services in specialized departments” (Policy maker).

“Cancer has a long-term treatment procedure and there is a great need for training. Therefore, if it is possible for some care services and even trainings to be offered at the patient's home...” stated a patient in support of the above statements.

Discussion

We conducted this study to explore the stakeholders’ perceptions of challenges in the process of palliative care for patients with cancer. The findings showed that these palliative care challenges in Iran could be evaluated in three subcategories: “weakness of stakeholder engagement policies”, “standardized care”, and “applying research and educational approaches”.

Participants in the study referred to “weakness of stakeholder engagement policies” as a challenge ahead of the palliative care provision process. Analysis of their comments led to the discovery of two challenges – “influence of intersectional relations” and “ambiguity of job descriptions”. The results of similar studies in Iran showed a lack of clarity in job descriptions.²⁴ Hence, the importance

of participation by different organizations in provision of palliative care services, ambiguity in responsibilities, and lack of awareness in this field^{25, 26} were barriers to providing the aforementioned services. This issue is still ignored. The solutions we have presented in this research that include strengthening mutual and interdisciplinary cooperation²⁷ and communicating with other organizations²⁸ have yet been taken seriously. Policies, many of which relate to sectors outside the organization such as insurance agencies, private sectors, the Ministry of Education, and the media, should be supported by appropriate mechanisms to provide a platform for their participation. One of these measures is the improvement of organizational culture, which can lead to the cooperation of groups within an organization with other groups as a key factor.²⁹

The research has shown that health care providers fulfill their duties when they are aware of their job descriptions. Therefore, preparing health care providers and having assurance of performing their duties correctly require solutions such as forming committees to determine staff roles, continuous and periodic assessments of their performance, and the development of plans to correct their weaknesses.

Palliative care requires the provision of high-quality physical, spiritual, psychological, and social care to the patients and their families;³⁰ thus, providing comprehensive standard care is the prerequisite for achieving this goal. Developing service packages and related guidelines is necessary to provide consistent, integrated, and high-quality services. This has been mentioned by participants as a challenge in the provision of palliative care. Limited measures have been taken or are being taken in Iran.³¹ Some university clinics use clinical guidelines for the management of fatigue, nausea, loss of appetite, anxiety and depression, exhaustion, dry mouth, lymph edema, diarrhea and vomiting. These guidelines have been mainly derived from the American Society of Clinical Oncology (2016) guidelines, which have been translated into Persian and validated for use in Iran. They are used by the palliative care

team at the Palliative Care Clinic of the SBMU Cancer Research Center.^{32, 33} In response to this need, the topic of localizing the guidelines is proposed with systematic considerations on existing guidelines in order to find the most congruous one with regards to the conditions of patients in Iran. These guidelines should be integrated with the cultural and regional requirements of the target population, while considering the resources, facilities, and infrastructure of the health care process.

Another challenge mentioned by participants while proceeding with the palliative care provision process was "applying educational and research approaches". As a principle, academic educational planning should be in consistent with changes in the health care process and the society's health needs. According to the public health model,³⁴ it is of tremendous importance to provide education at the university, health center, and community levels.^{35, 36} The lack of this type of education is a major challenge in providing services.^{24, 37, 38} In order to remove obstacles such as the lack of a curriculum for palliative care and lack of appropriate educational content for cancer-related disciplines, which are among the findings of this study, integration of a palliative care curriculum into medical education appears to be a proper solution for developing curricula and educational contents, as is experienced in pioneer countries in this field.³⁹ Ignoring palliative care as an independent discipline as a result of scholars' lack of awareness in this field and the absence of palliative care settings can also be regarded as obstacles to provide services. Therefore, palliative care training has been included in medical school's curriculum worldwide as an essential element.⁴⁰

One of the educational challenges mentioned in this study was the necessity of training health care staff. According to the findings of this study and similar cases in Iran, health centers face a shortage of specialized and trained staff, as well as lack of specialized and team management.²⁴ In line with these findings and those of other studies, nurses and doctors feel that they are not adequately trained when they begin to work in palliative care

centers.⁴¹ They seek training in symptom management, communication, and psychological counseling.³⁶ On the other hand, considering the shortage of nursing staff in Iran, authorities tend to focus their efforts on training the general workforce to compensate for this shortage. Training specialized nurses in this field is thus neglected.⁴² Among the measures taken in response to these needs in Iran, we can refer to the design of an interdisciplinary curriculum for palliative care while analyzing the conditions of cancer patients and specialized staff⁴³ and fellowship courses.⁴⁴ Medical and nursing conferences, online trainings, the use of modern teaching techniques along with consistent and short-term retraining courses for human resource training can be helpful.

Participants' experiences have shown that research and technology are considered important elements in providing palliative care. In recent years, the number of articles published in Iran on palliative care has increased. This has resulted in effective steps to identify obstacles to palliative care education.⁴⁵ Among the major challenges in conducting researches in this field, we can refer to the weaknesses in the educational and academic system, as well as financial and organizational barriers. Universities are the most important setting for society's development; therefore, removing administrative obstacles in research activities and the use of research findings in practice and at the community level are of particular importance.⁴⁶ It seems that establishing the appropriate research platform, conducting courses on research methodology, setting research priorities in this field, and providing financial resources for researches can help to overcome this deficiency to some extent. On the other hand, education and research in medical sciences requires a diverse range of knowledge on health and diseases; therefore, planners are required to respond to the health needs of the community in the light of technological advances. Although rapid technological development is a global challenge, the main issue is to apply this technology in line with the health organization's

goals and missions and to integrate it into the educational system.⁴⁷

"Increasing public awareness" of palliative care is one of the recommendations of the WHO.⁴⁸ In this study, lack of public awareness and the need to draw attention to information sources is considered worthy of attention by stakeholders and has come under the category title of "increasing public awareness". In the current study and other similar studies, nursing staff have associated cancer and its related care services with death and end-of-life care for patients. The caregivers' misconceptions as well as the misunderstanding of patients and their families regarding this concept has been reported as a barrier to the care provision process.^{38, 49}

Although the general attitude towards palliative and end-of-life care is complex and ambiguous,⁵⁰ changing people's attitudes towards palliative care is essential to increase knowledge, achieve the goals of care services, and the community's participation in palliative and the end-of-life care.⁴⁹ Overcoming this challenge is possible through valid and proper training in the form of social trends and awareness posters, community-based free discussions by health care staff and caregivers, and the development of various settings to provide palliative care services for those in need in order to increase public awareness.⁵¹

The last challenge mentioned in the study was classified as the subcategory of "empowerment of patients and caregivers". The study showed that the need for care by family members, the willingness to receive home care services, and lack of consistency in educational services significantly affected the care provision process. This finding has been reported in similar studies.^{52, 53} The findings showed that most health care expenditures in Iran were associated with health care services.⁵³ In line with these results, the WHO report also indicated that a tremendous part of a country's health costs belong to treatment procedures, while prevention and health promotion could reduce the financial burden of diseases up to 70%.⁵⁴ Therefore, the application of educational strategies for patients and caregivers to empower them

during disease could be considered one of the methods for prevention and health promotion. In response to these needs, it seems that planners of palliative care systems should pay special attention to home care services. According to the government planning, one of the goals of health policymakers is to establish home care services,⁵⁵ which requires considering resources and multiple infrastructures, cultural and social issues in Iran, training human resources, volunteering at the community level, and utilizing the experiences of developed countries.

The current study is one of the few studies that deals with exploring process challenges of palliative care stakeholders in Iran. Palliative care is a new discipline in Iran. Understanding the mentioned needs would be the basis for further research in this field; however, obtaining extensive information about these needs may require quantitative studies. Of note, this was a qualitative study that was conducted on a small number of participants. Thus, it is of narrow generalizability.

Conclusion

Currently, palliative care is regarded as one of the essential elements of each country's health care system. The results of this study have shown that Iran's nascent palliative care faces numerous challenges in the process of providing palliative care services for adult cancer patients. Overcoming these challenges requires the attention of health policy makers to beneficiaries' participation; standardization of care service provision in physical, psychological, spiritual and social aspects based on guidelines; and training human resources specialized in palliative care, research and high public awareness.

Acknowledgements

This study is part of a doctoral nursing dissertation of Shahid Beheshti University of Medical Sciences (grant no. 7989). The researcher would like to give her special thanks to the authorities of the university and those at the Center for Religion and Health Studies, in addition to all the study participants and authorities at the related

hospitals.

Conflicts of Interest

None declared.

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