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Investigating the challenges and barriers of palliative care delivery in Iran and the World: A systematic review study

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Abstract:

Palliative care and terminal patients care centers have an important role in improving the physical and psychological state of the patient and their families and increasing their satisfaction and care providers. A literature search of online databases (PubMed, Scopus, Web of science, Cochrane library, and Google Scholar) was searched from January 1, 2000, to the end of April 2019, by using the appropriate English keywords. Furthermore, IranMedex, Barkat, and Magiran databases were searched for the Persian articles. We used Standards for Reporting Qualitative Research checklist to evaluate the articles quality. From 1328 articles, 166 were reviewed in depth with 13 satisfying our inclusion criteria. The findings of this study revealed a wide range of barriers and challenges to palliative care delivery. The identified barriers were: Cultural, social and organizational barriers, lack of resources, equipment and financing, attitudes and cultures, barriers related to the patient and the patient's family, related barriers providers, time and money, education, communication challenges, policies, insurance problems, safety, and crisis management. The results of the studies showed that there are various barriers and challenges such as economic, cultural, social, organizational, and communication related to palliative care. Given the identified barriers and challenges, it is suggested that to improve the delivery of palliative care, the health system policy-makers and planners consider a resource-appropriate and culturally appropriate framework for palliative care delivery.

Keywords:

End-of-life care, palliative care, supportive care, systematic review

Introduction

Illness is an integral part of human life, and it is important to respect patients' rights. Every patient has the right to receive adequate health care at the level of human dignity, justly, under cultural and religious standards, without any gender and racial discrimination, at all stages including prevention, diagnosis, treatment, and rehabilitation.^[1] In the past few decades, providing health care to patients has changed from an inactive and ineffective

traditional system to a more active and dynamic system.^[2] On the other hand, due to issues such as population aging and changing disease patterns to chronic diseases, the need for special care has become inevitable.^[3]

According to the World Health Organization (WHO), heart disease, cancer, and diabetes are the leading causes of elderly mortality in the World.^[4] Undoubtedly, incurable diseases such as cancer, AIDS, dementia, and advanced heart disease require special supportive and palliative care. However, according to the WHO,

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only 14% of people under the special care receives these services.^[5]

According to the WHO in 2000, palliative care is a set of measures aimed at improving the quality of life in patients and their families. Furthermore, this care aims to solve the problems and difficulties of terminal and life-threatening illnesses through early diagnosis, complete diagnosis, and treatment of pain and other psychopsychological and physiological problems.^[6] Palliative care and terminal patients care centers play an important role in improving the physical and psychological well-being of the patient and their families, as well as increasing their satisfaction and care providers.^[7] Palliative care was initially provided in traditional forms, but since the 1960s, it has taken on a new form and has become a comprehensive physical, mental, psychological, and social care since the early 1980s. According to various studies, >90% of patients with fatal and incurable diseases wish for a quiet death in a home-like environment.^[8]

It is anticipated that many such patients will inevitably go to specialized and super specialty centers and will be hospitalized for the emergency department or intensive care unit of these hospitals for hours and days to relieve their symptoms and pain. Costly tests are imposed on this hospital, and in some cases, unnecessary therapeutic measures are taken.^[9,10] Statistics show that 20.4 million people in the world need palliative care annually, of which 19 million are adults and 34% are cancer patients.^[11] However, not all people who need supportive and palliative care are necessarily cancer-free and need special supportive and palliative care.^[12]

Despite increased access to palliative care services in recent years, there are major differences in developed, developing, and undeveloped countries, with only 24 countries being primarily developed, including the United States, Japan, and... have earned scores on palliative care services based on the Quality of Death Index.^[13] However, in some Middle Eastern countries, such care is at a lower level. Some countries, such as Yemen lacking a palliative care system, Palestine and Oman in the early stages of palliative care center establishment, Egypt, Iraq, Iran, Pakistan, Saudi Arabia, the United Arab Emirates, Morocco with a nonintegrated services system, Lebanon, Turkey, and Cyprus have a centralized care system, and only Israel has a comprehensive care system for providing services to patients with terminal illnesses.^[14]

One of the most important challenges in the field of emergency care is to choose how to provide care to the patients with terminal illnesses. In countries where a comprehensive system is in place to care for such patients, they use hospital services, special centers for

terminal patients, daily clinics and home care, depending on the severity of the illness and the patient's need. This group of countries falls into the category of developed countries or the advanced integration care system, according to the International observatory on end-of-life care.^[15]

Although the health system has made remarkable progress in providing medical care to terminal patients over the last century, it still faces significant barriers, including the medical culture that governs societies and attention to purely physical and mental health issues.^[16] Death at home is not the only wish for terminal patients with a cure. Many of the needs of patients with chronic illnesses who have long been challenged by their untreatable disease are ignored. The need for these patients to support, comfort, and strengthen them to cope with the problems associated with their illness is far greater than their need to receive treatment for their illness. End-of-life care for patients on the brink of death provides the opportunity that in addition to receiving nursing services, nutritional, psychological, psychological, and pharmaceutical counseling, and patients should have the necessary psychological support and their relatives have the necessary psychological support. Such care is provided by a group of nurses, family doctors, family members, volunteers, psychiatric counselors, and other counselors.^[17]

Nowadays, it is important to meet the needs of the terminal patients, to establish and develop the system of care of terminal patients on the brink of death in the country. Identify the barriers and challenges of palliative care delivery in the different areas of the system, including trusteeship, facilities, equipment and human force, explain service delivery processes, precisely determine insurance and payment systems for service providers, management practices and monitoring indicators, measuring and evaluating services are a necessity. Therefore, considering the importance and role of palliative care delivery, this study aimed to investigate the challenges and barriers of palliative care delivery in Iran and worldwide.

Materials and Methods

Literature search

For the purpose of this study, a literature search was conducted in PubMed, Scopus, Web of science, Cochrane library and Magiran, Iranmedex, SID databases for Persian articles from January 1, 2000, to early April 2019. The appropriate English keywords such as "Hospice Care," "Palliative Care," "Palliative Treatments," "Supportive Care," "Terminal Care," "End-of-Life Care," "end stage," and other similar keywords were used to search the articles in the databases. Furthermore, we

hand-searched the bibliographies of all the included studies, relevant review articles, and the Internet to identify any remaining studies. The full search strategy is available in the appendix.

Inclusion and exclusion criteria

Review and meta-analyses articles; proceeding articles; and policy articles, editorials, and letters – news articles, the poster, case reports, case series studies, conference articles, chapter in books, and any studies that did not have access to the full text and were duplicate excluded from our study.

Data extraction

Data extractions were done by all authors (PR, SAA, SMH, NR, and MSA). After screening articles by three authors (PR, NR, and SAA) based on the titles and abstracts, the full text of remain articles given to two trained authors (MSA and SMH) to evaluate and appraise the results of the searches and extract require data. The relevant extract data are summarized in Table 1. The table included the authors' name, year of publication, country, purpose, study population, and main findings of the study. Any disagreement between the three authors over the eligibility of particular studies was resolved through discussions with a fourth and fifth authors (NR, SMH). Furthermore, to evaluate the quality of articles, the Standards for Reporting Qualitative Research (SRQR) checklist was applied. This checklist contains 21 items that each quality article should have.

Results

The results of the initial search of databases yielded 1328 articles, of which 35 articles were excluded since they were considered as duplicate. Furthermore, by screening articles by title and abstract 1127 articles were excluded because they were not relevant. After reviewing the full text of the 166 articles, 133 articles were excluded due to lack of relevance to the challenges and barriers of palliative and supportive care, and 20 articles were excluded due to nonrelevance to the research topic. Finally, after quality assessment, 13 articles were selected for the final review. Figure 1 shows the flow of the systematic literature search.

Both researchers according to the inclusion and exclusion criteria to obtain a list of the articles used in this regular review evaluated the titles and abstracts of the articles obtained by searching the databases.

SRQR checklist was used to evaluate the quality of the articles.^[18] Both researchers using a quality scoreboard scored articles independently. Finally, no articles were deleted at this stage.

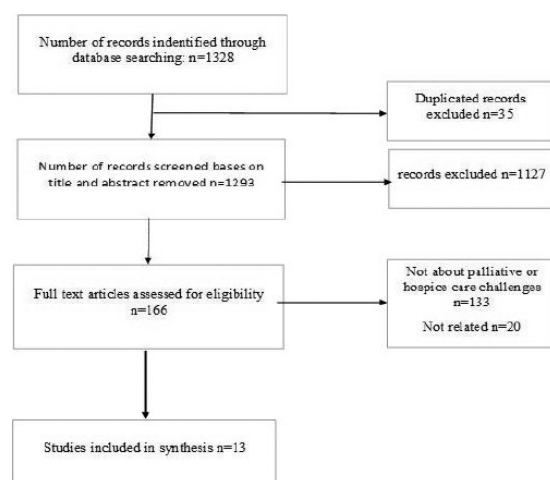


Figure 1: Study selection process

The findings of the present studies showed that there are various barriers and challenges in supportive and palliative care delivery. The lack of time and skills, lack of education, patient and patient's family expectations, attitudes and safety and crisis management, dying and end-of-life problems, lack of patient insurance coverage, financial supplies and structures, patient's noncooperation, lack or shortage of facilities, patient's family resistance, current health system policies and practices, organizational and social barriers, patient community knowledge and culture, communication challenges including patient-doctor communication, lack of understanding the role and importance of palliative and supportive care and treatment-oriented of the health system, educated human forces, and available resources were the most important barriers and challenges in this field [Table 1].

Discussion

This study aimed to investigate the challenges and barriers of palliative care delivery. The findings of this study revealed major challenges and barriers to palliative care delivery, including cultural, social and organizational barriers, lack of resources, equipment and funding, attitudes and cultures, barriers related to patients and their families, provider-related barriers, time and skill, education, communication challenges, policy makings, insurance problems, safety, and crisis management.

The findings of the present study showed that a lack of resources and financial structure are the important barriers and challenges in palliative care delivery. The results of studies by den Herder-van der Eerden *et al.* in the Netherlands, Esmaili *et al.* in Tanzania, and Gardiner *et al.* in the UK indicated that inadequate structure and funding and lack of resources were one of the most important barriers to supportive and palliative care delivery to patients in health-care centers.^[18,23,25,29]

Table 1: The summary results of studies

Author/reference	Publish	Country	Aim	Participants/n	Main findings
Stajduhar <i>et al.</i> ^[19]	2019	Canada	Identify barriers to accessing care among structurally vulnerable people at EOL	Multiplea (n=25)	Five significant barriers to accessing care at EOL: (1) The survival imperative; (2) The normalization of dying; (3) The problem of identification; (4) Professional risk and safety management; and (5) The cracks of a “silo-ed” care system
Esmaili <i>et al.</i> ^[18]	2018	Tanzania	Barriers to providing EOL care	Multiple (n=34)	Barriers to palliative care: financial, infrastructure, knowledge and cultural (including perceptions of pediatric pain), and communication challenges
Brooks <i>et al.</i> ^[20]	2017	Australia	Barriers, enablers and challenges to initiating EOL care in an Australian ICU context	Physicians and nurses (n=28)	Barriers include conflict between the ICU physicians and external medical teams, the availability of education and training, and environmental limitations and challenges include communication and decision making, and expectations of the family
Kilcullen and Ireland ^[21]	2017	Australia	Explored perceptions of neonatal nurses about facilitators and barriers to delivery of palliative care and the impact of the regional location of the unit	Nurses (n=8)	Staff perceived education, lack of privacy, isolation, staff characteristics and systemic (policy, and procedure) factors to impact upon palliative care provision
den Herder-van der Eerden <i>et al.</i> ^[22]	2017	Netherlands	Describe the experiences of IPC leaders in seven European countries regarding core elements, facilitators and barriers of IPC implementation	Multiple (n=34)	Identified barriers included lack of knowledge about when to start palliative care, lack of collaboration and financial structures
Rhodes <i>et al.</i> ^[23]	2015	USA	Barriers to EOL care for African Americans from the providers' perspective	Multiple (n=24)	Barriers identified included: Lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance
Horlait <i>et al.</i> ^[24]	2016	Belgium	Medical oncologists identifying the barriers they experience to introduce palliative care to their patients with advanced cancer	Medical oncologists (n=15)	Oncologist-related barriers, patient-related barriers, family-related barriers, barriers relating to the physician referring the patient to the medical oncologist, barriers relating to disease or treatment, institutional/organizational barriers and societal/policy barriers
Azami-Aghdash <i>et al.</i> ^[25]	2015	Iran	Perspective of patients, patients' families, and healthcare providers towards designing and delivering hospice care services in a middle income Country	Multiple (n=65)	Barriers included financial issues, cultural-religious beliefs, patient and family-related obstacles, and barriers related to healthcare system
Keall <i>et al.</i> ^[26]	2014	Australia	Facilitators, barriers and strategies that Australian palliative care	Nurses (n=20)	Barriers identified as follows: Lack of time, skills, privacy and fear of what you may uncover, unresolved symptoms and differences in culture or belief
Yoshida <i>et al.</i> ^[27]	2014	USA	Barriers of healthcare providers against EOL discussions with pediatric cancer patients	Healthcare providers (n=10)	These barriers were classified as follows: Healthcare provider factors, patient factors, parent factors and institutional or cultural factors
Johnson <i>et al.</i> ^[28]	2011	Australia	Australian palliative care providers' perceptions and experiences of the barriers and facilitators to palliative care provision	Multiple (n=45)	Results Thematic analysis revealed that palliative care, providers consistently view palliative care as a broad holistic approach to care benchmarked on good symptom management. Whilst participants themselves perceived SPC as aiming to maximize the quality of life of the patient and family across all domains of care

Contd...

Table 1: Contd...

Author/reference	Publish	Country	Aim	Participants/n	Main findings
Gardiner <i>et al.</i> ^[29]	2011	UK	To explore the perspectives of health professionals regarding barriers to optimal palliative care for older people in acute hospitals	Health professionals (n=58)	Various barriers was included: including attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources
Turner <i>et al.</i> ^[30]	2007	Australia	Oncology nurses' perceptions of their supportive care for parents with advanced cancer	Oncology nurses (n=24)	Nurses identified the emotional burden of the supportive care role as a key challenge, along with health-care systems that were not attuned to the needs of families

^aMore than a group participating, including physicians, nurses, and service providers. ICU=Intensive care unit, SPC=Specialized palliative care, EOL=End-of-life, IPC=Integrated palliative care

On the other hand, due to the lack of insurance coverage for some patients, they did not receive full or optimal palliative care.^[23,28]

Furthermore, in a study conducted by Azami-Aghdash *et al.*, barriers included financial issues, patient and family-related obstacles, cultural-religious beliefs, and barriers related to health-care system were the most important barriers to such services.^[25]

Furthermore, staff training and awareness were identified as other barriers to palliative care delivery in this study. Employee knowledge, skills, and appropriate training are as currently key challenges and barriers in supportive and palliative care delivery to dying and cancer patients in some developed countries, including Australia, United States, Netherlands, and Belgium.^[20,22-24]

Low attention to palliative care and lack of attention to these cares in university and clinical education is one of the important reasons for these challenges. Finally, it can be stated that education is one of the basic principles in delivering desirable and effective palliative care. In addition, palliative and supportive care delivery requires appropriate skills and training. In a study conducted in Australia, the results revealed that the lack of skills was one of the challenges of palliative care delivery.^[26]

Differences in the providers and recipients culture and attitude of palliative care are another identified barrier in this study. The attitude of patients and staff in providing palliative care can have an effective role in providing desirable care. Patients with different attitudes and cultures have revealed different attitudes toward the provided care. Attitudes and cultural differences were identified as the significant barriers and challenges in about half of the studies evaluated.^[19,26,27,29] Furthermore, the inadequate provided care to the different patient and patient's family expectations can lead to the resistance of patients and their families to receive palliative care and ultimately refuse to receive such cares.^[20,24,25] In this regard, to minimize cultural

barriers, it is recommended that programs and care should be provided according to the culture and environment of each region. Furthermore, apply the necessary training to change patients' attitudes is recommended.

Communication and privacy barriers were also identified as the other important barriers to palliative care delivery. Patients who qualify for receive palliative care are more specific and sensitive than other hospitalized patients, and this may be due to the chronicity and severity of the disease at this stage and may also be in the final stages of their lives. For this reason, lack of privacy and confidentiality of patients' information are one of the challenges and barrier in providing this care.^[18,20,22,24] Therefore, proper education and training of staff as well as localization and acculturation palliative care services can lead to improved communication and privacy of patients.^[19,23,26]

Finally, several other challenges and barriers, including organizational, social, political, and treatment-oriented barriers to care provided, were revealed as the major challenges in the evaluated studies. Too much focus on treating patients will neglect these vulnerable groups in need of supportive care and will make supportive and palliative care delivery not a priority for health-care providers.^[18,24,29] Palliative care is a set of measures aimed at improving the quality of life of patients and their families to solve the problems and difficulties of terminal and life-threatening illnesses through early diagnosis, complete diagnosis, and treatment of pain and other psychopsychological and physiological problems.^[6] It should be noted that most studies have been investigated the view of nurses and doctors.

Conclusion

Therefore, it is imperative that health-care policy-makers and planners adopt policies to create an appropriate framework with providing resources and according to indigenous, the culture of patients to provide

effective palliative care for dying and chronic patients. Furthermore, training can be used as a solution to reducing barriers and challenges related to communication, knowledge, and attitude and also reducing people's resistance. It is necessary for universities to be more sensitive about the teaching of palliative care and its role and importance to medical graduates and to make the training more academic and logical.

Limitation

Similar to other studies, the present study also had limitations. The present study only reviewed articles published in Persian or English. Therefore, studies may have been published in other languages that were not included due to language limitations in the present study and missed.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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Conflicts of interest

There are no conflicts of interest.

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