

Original Article

Bridging the gap and developing a home-based palliative care model for cancer patients

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ABSTRACT

Objective: Early integration of palliative care into home health care services is essential for cancer patients to improve their Quality of Life and reduce their health care costs. Thus, this study aimed to develop a home-based palliative care model for adult cancer patients in Iran.

Methods: This is a health policy and systems research based on the World Health Organization guide. It consists of four phases; an integrative review, a qualitative study through individual semi-structured interviews ($n = 37$), and one focus group interview ($n = 8$), integrating these results in the third phase and generating model indicators. In the last phase, the evaluation of the importance of the indicators and the validation of the model were carried out during four classic Delphi rounds.

Results: Barriers to home-based palliative care were extracted from the first phase, and then 22 categories in eight pillars emerged from the qualitative phase. The indicators created for the model from two phases were integrated in the third phase ($n = 118$). After the four-round of the Delphi, a conceptual model for home-based palliative care in cancer patients, including 92 indicators within eight pillars was created.

Conclusions: Although this model was designed for our society, it can be utilized as a useful guide in other similar societies to design practical models and innovative programs to provide home-based palliative care in cancer patients. The application of the model in predicting different outcomes should be investigated in future trials.

Introduction

Cancer is one of the world's most challenging diseases of the current century.¹ In Asia, the number of new cases of all cancers in both sexes between the ages of 0 and 85 years is estimated to be 16,162,830 between the years 2022 and 2045.² Cancer control and early detection of are among the priorities of the health programs of the World Health Organization (WHO). A comprehensive cancer control program includes screening, early detection, cancer survivorship and palliative care.³ Evidence shows that early integration of palliative care into the care management of patients with life-threatening diseases can improve patients' and their families' Quality of Life (QoL) and reduce healthcare costs.⁴⁻⁶

According to the WHO report, palliative care is most efficient when it is applied in the early stages of the disease. Early palliative care not only improves patients' QoL, but also decreases unnecessary admissions at hospitals, and reduces the utilization of healthcare services.⁷

Furthermore, the assessment of healthcare systems in different countries shows that currently there are various programs and models to provide palliative care services for patients with cancer or other life-threatening diseases. These services can be delivered in different models such as hospice care, hospital-based palliative care, palliative care at home or in outpatient clinics, consultation services, community-based palliative care, spiritual care in palliative care, early palliative care and pediatric palliative care.^{8,9} Since, the development of palliative

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care programs and services varies in different countries, a classification has been made for access to services. Mapping the development of palliative care based on levels of hospice palliative care shows that there are four categories in different countries: “no known hospice-palliative care activity (Group 1 countries), capacity building activity (Group 2 countries), localized hospice-palliative care provision (Group 3 countries), and countries where hospice-palliative care services were reaching a measure of integration with the mainstream healthcare system (Group 4 countries).”¹⁰

While improving QoL is one of the important goals of palliative care, current evidence shows that home care services are associated with beneficial outcomes. Home care as a community-based care method is one of the best methods of delivering palliative care services. Different home-based palliative care programs or models have been developed in different countries to provide high quality care for patients at home. One of these programs is the @HOME Support Program for advanced disease management in Detroit, Michigan.¹¹ This novel interdisciplinary program reduced care costs and at the same time provided high quality care for patients and their caregivers.¹² Another home-based palliative care program is the Kaiser Permanente Palliative Care program in southern California. It was a multidisciplinary care management method for the care and treatment of patients at the end of life at home.¹³ Also, a successful home-based palliative care model is developed by CanSupport; a nongovernmental organization, in India. It was a reliable and cost-effective model for end of life patients or patients with chronic illness.¹⁴ All these programs or models are context-based and include different components. A rapid review of palliative care models showed there are seven major elements for quality of services: “(1) inter-sectoral and inter-professional cooperation, (2) trust and safety, (3) holistic management, (4) non-academic palliative care, (5) spiritual care, (6) support to caregivers, and (7) funding and financial support.”¹⁵ Trend evaluation of the models and programs shows that they are rapidly expanding and moving in an innovative direction with balanced care design to create better and more cost-effective care for critically ill patients.¹⁶

A review of the literature on the effectiveness of home-based palliative care services showed interesting results. The findings of a study by Molassiotis et al. revealed that after providing home care services, the symptoms of the treatments such as mouth ulcers, diarrhea, constipation, nausea, pain and fatigue reduced, and this improved the patients' condition.¹⁷ The findings of another study showed that providing palliative care services at home decreased healthcare costs for patients and their families. Moreover, patients' awareness of and access to healthcare services increased.¹⁸ Cancer patients need access to supportive care in order to control their symptoms and to improve their QoL. Delivering palliative care services at home can provide this care for patients and their families.¹⁹ Evidence shows that home-based palliative care is one of the fastest growing medical services in the world.²⁰ Moreover, various models or programs of home-based palliative care have been presented mainly in developed countries. They are based on the demographics, culture and structure of their healthcare system.²¹

Today's situation in Iran shows that like in many countries in the world, Iran is facing the challenges of an aging population and an increase in chronic diseases. In Iran, healthcare services are provided through the Primary Health Care (PHC) network which was established in 1985. The private sector is mostly involved with patients' treatment.²² Home care centers are developing in the country and they are set up and managed by the private sector.²³ Healthcare services are presented in three levels of the PHC network from the rural to the urban areas with a referral system. The structure of this network includes health houses, rural and urban comprehensive health centers, district health centers, district general hospitals, district health networks, university of medical sciences and university hospitals. The Ministry of Health and Medical Education (MOHME) is located in the highest level of the network.²² Despite the fact that home care services are one of the essential components of the healthcare systems, they are governed by the private sector in our healthcare system. They all have many different challenges in

terms of structure, management and working processes.²³ Home-based palliative care was identified as a missing link in the healthcare system of Iran in a study in 2018. The authors of the article mentioned that this issue has increased the admission of more patients in hospitals.²⁴ Moreover, evaluation of home care centers shows that they have numerous challenges during patient's admission due to the lack of a referral system between hospitals and these centers, improper management and poor quality of healthcare services.^{25,26}

Generally, a review of the history of palliative care in Iran shows that the national comprehensive program of supportive and palliative care for cancer was planned by the MOHME in 2013. In this plan, the service delivery levels of supportive and palliative care services were defined as hospital units, counseling teams, palliative care clinics and home care teams.²⁷ Mapping the development of palliative care in the world shows that Iran is in the third group (countries with local palliative care provision). Current conditions of the country based on society needs show that there is no coherent and organized framework to provide general and specialized palliative care services at home for cancer patients. Also, patients usually do not have access to all necessary physical, psychological, social and spiritual services.²⁸ In the current state of the country, some university hospitals and a limited number of non-governmental organizations (NGO) provide home-based palliative care services for cancer patients with different approaches. Given that there is still no organized infrastructure within the healthcare system to deliver patient-centered home-based palliative care with high quality, we conducted this study with the aim of developing a home-based palliative care model for adult cancer patients within the healthcare system of Iran.

Methods

Study design

This is a health policy and systems research.²⁹ It was conducted from October 2019 to January 2022 in four phases: (1) Integrative review, (2) Qualitative study, (3) Data integration and (4) Delphi study.

To decide where to start, a panel was held with five members of the research team, two external referees (a palliative care physician and a faculty member with doctoral degree in nursing) and two internal referees (two faculty members with doctoral degree in nursing and healthcare services management) before starting the project. Based on discussion on the results of a literature review of the existing models and programs of home-based palliative care which was implemented by members of the research team (the results were published elsewhere³⁰) and experiences of referees, it was decided to start with a review on barriers to home-based palliative care to produce a comprehensive integrative model into the healthcare system by applying the palliative care guide of the WHO. Based on the guide, an integrated approach requires to take into account the barriers and gaps in delivering healthcare services.³¹

The palliative care guide of the WHO consists of six categories: policy making (planning strategies for palliative care development), healthcare financing (allocated costs for palliative care development), service delivery (hospital, home care, etc.), workforce development (educational programs), access to medicines (rules and level of access to the medicines, especially narcotics), and information and research (assessor information system and multidisciplinary research).³¹

Phase one

In this phase, an integrative review was conducted to find the barriers to home-based palliative care for cancer patients. To be able to know the current conditions with the best available and accessible health care services for every cancer patient in need, and later transform this conceptual model into an operational model, barriers to home-based palliative care were extracted. They were extracted based on the WHO palliative care guide.³¹

This integrative review was based on a modified framework presented by Whittemore and Knafl.³² We followed the five steps of the

framework, including: (1) Problem identification, (2) Literature search, (3) Data evaluation, (4) Data analysis and (5) Presentation of the results. This review was implemented through an extensive search in both national and international databases of Web of Science, PubMed, Scopus, Embase, Google Scholar, SID (Scientific Information Database), Magiran and Iran Doc without time limitation up to the end of October 2020. The keywords of “Home based palliative care,” “Home care,” “Cancer,” and “Obstacle or barrier” were used through Boolean expressions (AND, OR, NOT). As we found only a few studies in the first step, in the next search “Chronic disease” was added to the keywords list and a new search was run. The selection of studies was based on the inclusion and exclusion criteria. The inclusion criteria included all original articles in English and Persian languages with various designs focusing on the barriers of home-based palliative care services for cancer patients and/or patients with chronic diseases at home and/or home care centers. Studies that were not related to the topic or had different participants or did not meet the inclusion criteria were excluded. The first author and an expert librarian separately screened the titles and abstracts of all studies, and extracted data from the selected studies. A data extraction form was developed in the research team to record the characteristics of the studies such as the author's name, publication year, country, objective of the study, type of study, sample size and description as well as overall results. Any discrepancies were resolved through discussion with a third person as an expert. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses - 2009) flow diagram³³ of selected studies is shown in Fig. 1. Later, through the results of this phase, a number of indicators of the model was created in the research team.

Phase two

In this phase, a descriptive qualitative study was conducted through directed content analysis method on individual semi-structured interviews and a focus group interview to explore the participants'

experiences about the needs of cancer patients and their families, the structural requirements of the system, and the existing gaps to receive and/or deliver palliative care services at home.

To run individual semi-structured interviews, 37 participants (10 cancer patients, seven family and non-family caregivers, two oncologists, one palliative care physician, one general practitioner, four home care nurses with bachelor degree, two home care nurses with master and doctoral degrees, one psychologist, one physiotherapist, one social worker and one specialist in spirituality-religious issues, three health policy makers and three faculty members of nursing schools) were selected by purposive sampling from three major universities, one university hospital, the MOHME and MACSA (A private cancer control center) in Tehran, Iran.

Inclusion criteria for patient selection consisted of having a cancer diagnosis for at least one year and receiving home care services for 6 months as a minimum. The family and non-family caregivers were selected, if they were directly involved in the patients' home care. The inclusion criteria for the selection of the specialized participants were: having experience and expertise for delivering palliative cancer care services at home, planning and/or teaching in the field of palliative and home care for cancer patients at least for five years. The exclusion criteria of the study were: unwillingness to participate in the study and not to meet the inclusion criteria of the study. All individual qualitative interviews were conducted by the first author in a quiet environment and continued up to the data saturation. The time of the interviews was between 20 and 60 minutes.

A 90-minute online focus group was held through Skyroom following individual interviews in order to enrich the results of individual interviews and increase the strength of the collected information. After individual interviews, we found eight experts/specialists in the field of home-based palliative and cancer care with rich information (one oncologist, one general practitioner as a head of a home healthcare center, one university faculty member, one health policy maker, one

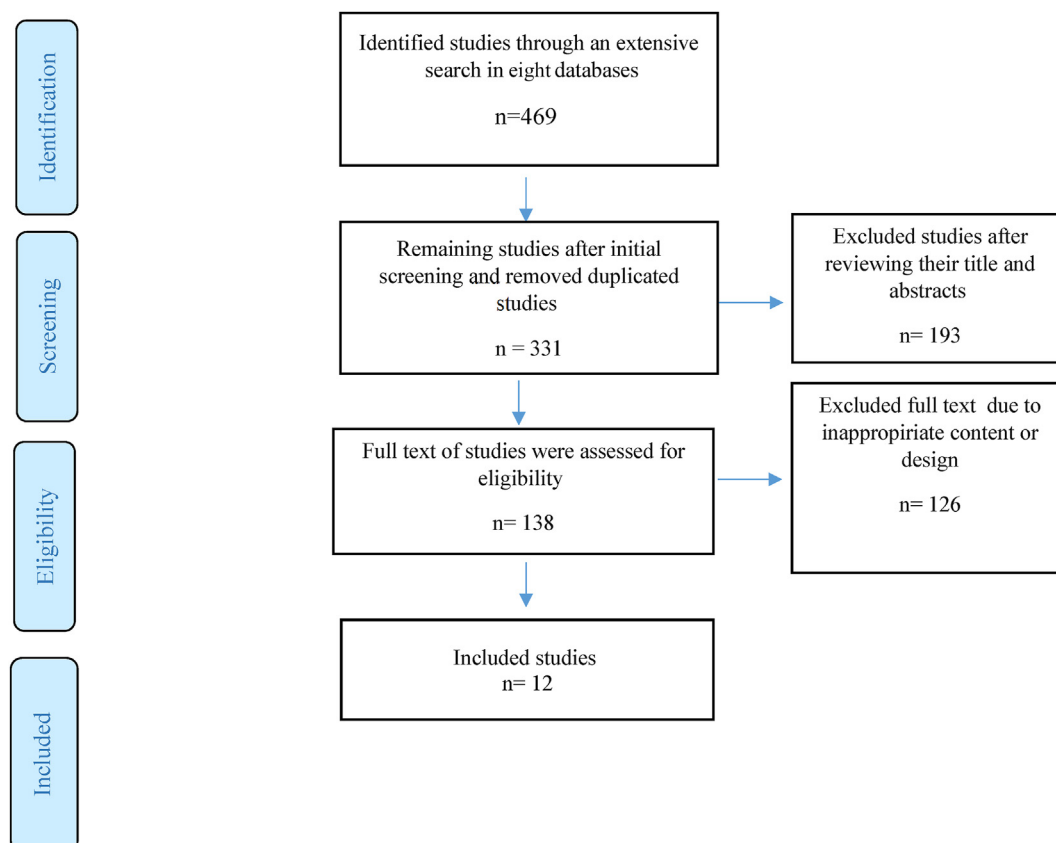


Fig. 1. PRISMA flow diagram of selected studies. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

psychologist and three home care nurses), thus we decided to conduct a focus group interview with them to access to rich information. It was started with the same aim and similar questions such as individual interviews, but based on the discussions, it was guided by the group leader (the first author).

Before beginning the individual and focus group interviews, the first author described the purpose of the study and obtained written informed consent and permission for running interviews and recording. Interviews were conducted with an interview guide.

To ensure trustworthiness of the results, the four-dimensional criteria of Lincoln and Guba, known as credibility, dependability, confirmability and transferability, were examined.³⁴ Credibility of the data was provided through prolonged engagement with the data and spending enough time to collect and analyze them. In order to increase the dependability of the data, the extracted codes were given to the four participants to confirm the accuracy. Moreover, data analysis was checked by five external reviewers, including two faculty members and three doctoral students in three nursing schools. To achieve confirmability, all the stages of analysis, were reviewed and written in detail. Through variation in the participants' selection, the transferability of the data has been accomplished.

Data analysis was done with the directed content analysis approach based on Hsieh and Shannon's method³⁵ through the WHO guide³¹ by MAXQDA-10 software. Later, through the results of this phase, a number of indicators of the model was created in the research team.

Phase three

In this phase, a series of research team meetings was conducted in order to determine the pillars and indicators of the home-based palliative care model for cancer patients. The results of the integrative review and qualitative study were integrated together in the research team, consisting of two university faculty members with the specialties of cancer and community health nursing, and two health policy makers in the MOHME with the specialties of cancer and palliative care as well as a doctoral student in nursing with the specialty of medical-surgical nursing. After that, to specify the importance of indicators in each pillar, the results of data integration were prepared in the form of a questionnaire with a three-point Likert scale for the next phase of the study.

Phase four

In this phase, a classic four-round Delphi study³⁶ was conducted to determine the importance of the model indicators to create the initial draft of the model and to validate it. Delphi was started with 23 experts in home-based palliative and cancer care (two palliative care physicians, two oncologists, three health policy makers, seven university faculty members in nursing, eight home care nurses and one head of a home health care center) but, in the last round only 12 experts stayed in the study (one palliative care physician, one oncologist, one health policy maker, one head of a home health care center, four university faculty members in nursing and four home care nurses).

Two different questionnaires containing model indicators in eight pillars on a three-point Likert scale (low, moderate and high, scores: 1 to 3) along with demographic information questions were sent to the experts in the Delphi rounds by e-mail. All data from the four Delphi rounds were analyzed using the Excel software and the mean and the standard deviation of each indicator and each pillar were calculated. Considering the 75% quartile, for both questionnaires the range of agreement for each indicator was a score of 2.5 or higher. In addition, in the first two-round the experts were asked to record their suggestions regarding the content of the indicators, and in the second two-round about the structure and the content of the model, in addition to the indicators.

Ethical considerations

This study obtained an ethical research code from the Research Ethics Committee of the Shahid Beheshti University of Medical Sciences

(IR.SBMU.PHARMACY.REC.1397.096). All participants were given verbal and written information about the study, and written informed consent was obtained from all of them. The researcher declared voluntariness and the right to withdraw at any stage of the study.

Results

The results of the integrative review

At this phase, out of 469 extracted articles, 138 duplicates were removed and 331 articles remained in the study. After screening the title and abstract of the remaining articles, 193 studies were excluded, and the number of studies decreased to 138. The full text of these studies was evaluated, and 126 studies were excluded due to inconsistency with the inclusion criteria (investigation of barriers to palliative care at home in children, lack of focus on barriers to palliative care at home and studies with a different language other than English and Persian), and finally 12 articles remained in the study. After that, barriers to access to home-based palliative care were extracted from 12 selected studies, according to the WHO guide in the six pillars of "policy making," "health care financing," "service delivery," "workforce development," "access to medicines" and "information and research." But at the beginning of data extraction, based on the data in the selected studies, "ethical and legal issues" was also added to the six pillars of the WHO. Characteristics of the selected studies and the extracted data from them are shown in [Supplementary Files 1 and 2](#).

From the results of this phase, 52 indicators in seven pillars were created in the research team (policy making = 11, health care financing = 5, service delivery = 12, workforce development = 11, access to medicines = 5, information and research = 6, in addition to ethical and legal issues = 2).

The results of the qualitative study

The results of 37 individual interviews and one focus group interview were analyzed. The mean age of the participants in individual interviews was 45.40 ± 7.63 years. Also, 48.6% of participants ($n = 18$) were male and 51.4% were female ($n = 19$). After directed content analysis of the interviews, a total of 546 codes, 22 subcategories and eight categories/pillars were extracted. "Family empowerment" was extracted as a new category/pillar during qualitative data analysis and added to the WHO pillars. All categories, subcategories and a sample of participants' quotations are shown in [Table 1](#). From the results of this phase, 79 indicators in eight pillars were created in the research team (policy making = 10, health care financing = 6, service delivery = 22, workforce development = 5, access to medicines = 5, information and research = 2, ethical and legal issues = 21 and family empowerment = 8).

The results of the data integration

In this phase, the results of the integrative review (52 indicators) and the qualitative study (79 indicators) were integrated in the four research team meetings, and the indicators of each pillar of the home-based palliative care model were produced ($n = 131$ indicators). Next, after removing 13 duplications, 118 indicators remained within eight pillars in the study (policy making = 17, health care financing = 11, service delivery = 29, workforce development = 12, access to medicines = 10, information and research = 8, ethical and legal issues = 23 and family empowerment = 8), and then prepared in the form of a questionnaire for the next phase.

The results of the Delphi study

Thirteen female (56.5%) and 10 male (43.5%) experts participated in the first round of the Delphi. In the first round, an electronic questionnaire, containing the assessment of the degree of the importance of 118

Table 1

The results of the qualitative analysis, consisting of categories, subcategories and participants' quotations.

Categories	Subcategories	Participants' quotations
Policy making	The participation of the executives involved in the home-based palliative care program	"Establishing a program in a healthcare organization depends on the strengthening the organization's relationships and its interactions with other departments and organizations." (University faculty member, p.10)
	Infrastructure management	"Developing a home-based palliative care system requires continuous attention to multiple infrastructures and structural factors. For providing the needs of cancer patients in the form of a systematic care approach, it is necessary that planning is done in advance, policies are formulated, and the activities of different groups are determined." (Policymaker, p. 2)
	Standardization of care	"Actions based on standards, such as educational service packages and clinical guidelines, lead to the improvement of the quality of services provided. The existence of a systematic and valid collection of scientific evidence in clinical settings, can be a good guide for providing standard care for cancer patients at home." (Home palliative care nurse, p.18)
	Feasibility in the health policy dimension	"Health is one of the first priorities of the country and following that, the healthcare system transformation plan seeks to reduce the payment of treatment costs from people's pockets, better access to healthcare services and the development of healthcare and treatment infrastructure." (Physician, p.14)
	Structural barriers to home- based palliative care	"There are many obstacles in the infrastructure for setting up such centers ... not being enough facilities, enough budget allocation, proper training, trained personnel, sufficient space, appropriate policy, and not good access to narcotics medicine at home, in addition to new planning for insurance coverage for this type of services at home and many other issues that can prevent the implementation of palliative care at home." (Policymaker, p. 1)
	Professional barriers in the home palliative care service provider team	"Not having professional solidarity and not enough transfer of experiences and sharing of information among the members of the palliative care team at home is one of the important obstacles in providing palliative care to patients." (Home palliative care nurse, p. 5)
Health care financing	Management and provision of financial resources	"One of the most important goals of the healthcare system in cancer control as a chronic disease, is to manage and provide financial resources to provide healthcare services. Being covered by insurance for healthcare services at home, clear tariffs for home care services, specifying the manner and amount of payment of employees' salaries, cost of establishment and the effectiveness of services are among the things that should be taken into account in the design of a home-based palliative care system." (Focus group interview)
	The family's financial burden	"Cancer patients and their family members, face high costs such as medication treatments, chemotherapy, re-hospitalization of patients, provision of equipment at home such as oxygen, wavy mattress, laboratory tests, and even travel costs to hospitals and/or medical centers." (Family member, p. 3)
Service delivery	Use of telemedicine service in the care system	"The existence of a 24-h response system with the possibility of accessing medical documents of cancer patients by nurses or other experienced healthcare personnel, is an important step in reducing the patients care needs." (Home care unit manager, p. 16)
	Providing integrated services at different levels of health care network	"Healthcare service delivery systems are responsible for providing healthcare services to people in the community and they should include the entire range of care from case identification and disease prevention to diagnostic, rehabilitation and palliative care. Also, they should pay attention to all levels of service delivery, in order to provide universal coverage of integrated healthcare services." (Policymaker, p. 2)
	Providing holistic care	"It is necessary that patients receive a comprehensive care based on their needs and a specific care plan. Also, healthcare services should be provided in different dimensions for cancer patients." (University faculty member, p. 12)
Workforce development	Human resources management	"The use of human resources is to achieve the goals of the healthcare organization, and the training and employment of specialized healthcare providers, is one of its components for home-based palliative care, we need specialized personnel. Training community health nurses who are given specialized training for home care, can be very helpful. But, they are currently working in hospitals or clinics in the healthcare system. Why are they not used at the community level"? (University faculty member, p. 4)
	Training of palliative care service providers	"Palliative care team members need a general and specialized education for delivering cancer care services at home. Professional training of this group, is the solution to improve their skills. In this regard, a national professional training center should be established, which will provide skill and professional training according to the needs of healthcare providers in different regions of the country. Attention should also be paid to the provision of this education in curriculum planning of healthcare students in different stages of education at universities." (Policy maker, p. 1)
Access to medicines	Challenges of prescribing medicine at home	"Nurses in Iran face many challenges for applying medications at home, for example, not having nurse prescribing rule in the country, lack of medication prescription guide, lack of rules and regulations for administering medications at home by nurses, limitations of administering narcotic medications at home. In this line, I can say that the necessity of regulations for administration of medications at home as a roadmap for pharmaceutical policies in the country, is necessary." (Researcher in the field of home care, p.16)
	The necessity of pain relief for patients at home	"Pain management in cancer patients is one of the significant issues in the palliative care system. Ineffective pain management, reduces the patient's QoL and functions, but there are many obstacles and challenges in this path, such as no produce and no access

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Table 1 (continued)

Categories	Subcategories	Participants' quotations
Information and research	Supportive and regulatory requirements for prescribing medicine	to oral morphine in the healthcare system and lack of a national program to access to narcoticsAlso, not enough training of doctors about administration of painkillers at home and no acceptance of narcotics use at home by public due to ignorance and strict laws and weakness of the Ministry of Health and Medical Education for establishing rules to prescribe and consume narcotics at home." (Home palliative care physician, p. 6)
	Developing a quality care plan based on available information	"Cancer patients need to take medications for a long time. Therefore, monitoring and support programs, such as insurance coverage for buying of medications, monitoring the distribution and prescription of medications, especially narcotics, are necessary." (Home palliative care physician, p. 14)
	Research in the field of palliative care at home	"The final goal of home-based palliative care is to increase the QoL of cancer patients, which requires comprehensive care planning based on the needs of the patients and their families at home in the community, they live in along with continuous evaluation ... systematic monitoring and accreditation of home care centers is also an important factor, in order to continuously improve the quality of palliative care services in line with standards." (Policymaker, p. 2)
Ethical and legal issues	The necessity of maintaining safety and security at home	"The importance and position of research in the field of palliative care lead to the development of this field. Research is an important factor in creating change with the aim of improving quality of care." (University faculty member, p. 12)
	Transparency of rules	"Maintaining the safety and security of patients and healthcare providers in patients' homes is essential. Therefore, a series of rules and regulations should be developed to protect the safety and interests of patients and healthcare providers." (Home palliative care nurse, p. 18)
Family empowerment	Education to the patient and family	"The existence of rules and regulations for the care of cancer patients at home determine the roadmap in the palliative care system and also provide the conditions for individuals' accountabilityfor example: what healthcare services can a cancer patient receive from home care centers, what kind of care is the responsibility of the cancer patients family, by which criteria can patients and their families use the healthcare services at home care centers and by which criteria can they be discharged, in case of the patient's death at home, it is also important how the death certificate is issued, and there should be rules and regulations and guidelines for all these cases by establishing laws, there is also the possibility of accountability." (Physician, p. 8)
	Implementation of the palliative care process based on the needs of the patient and family	"Education plays an important role in empowering the patient and his/her family. Being attentive to the patient and family's ability to care, patient-centered care, level of family education, are essential. Also, ability to have a good communication with the patient and his/her family at the beginning of the care program, providing care based on the needs and abilities of the patient and his/her family with the aim of symptoms control and increasing independence and self-care, are important factors in empowerment of the family with cancer patient." (Focus group interview)
		"When caring for cancer patients, the needs of the patients and their family should also be considered, because family members play an important role in improving the patients' Quality of Life. Needs assessment is an important phase in determining appropriate support services, providing high-quality care, and achieving satisfaction with care." (Home palliative care nurse, p. 5)

p: participant.

indicators in eight pillars was sent to 23 experts by e-mail. Only 13 experts completed the questionnaire and returned it by e-mail. The indicators with mean score of ≥ 2.5 were kept in the model and entered to the second round, and the rest were removed. Thus, after removal and/or integration of indicators ($n = 26$), a new version with 92 indicators in 8 pillars was produced (policy making = 13, health care financing = 4, service delivery = 28, workforce development = 5, access to medicines = 10, information and research = 4, ethical and legal issues = 23, and family empowerment = 5). It was sent to the 13 experts who had completed the first round, and they approved them. After the two first-round, a draft diagram of the home-based palliative care model for cancer patients was created in the research team. In the third round, for evaluation of the validity (scientific acceptability and feasibility) of the model and its 92 indicators, they were sent in the form of a questionnaire to the 13 experts from the last round. But, only 12 experts completed the questionnaire and returned it by e-mail. The results showed that the scientific acceptability and feasibility of the model and its indicators were satisfactory (Table 2). After the third round, small suggested changes were applied to the model, and then the model was approved in the fourth round. With this change, one arrow including "Focusing on the integrity of care principle" was added around the model. Also, the item "Developing a monitoring and accreditation program for ambulatory palliative care clinics" was added to the "information and research pillar." After the fourth round of the Delphi, the validity

of the final home-based palliative care model for cancer patients with 92 indicators in eight pillars was approved by 12 experts in the healthcare system of Iran.

The model is shown in Fig. 2. At the beginning of the model, there is a step for examination of the patients' needs and their families and their level of access to the available resources in the healthcare system. Providing integrated palliative care services, symptom management and improving the QoL of cancer patients and their families are the output of the model. The foundations of this model are shown in its components: Establishing and setting up a systematic home-based palliative care system with an electronic platform for cancer patients with the aim of continuing care and support for patients and their families from hospital to home at the community level, continuous training of home healthcare providers, teamwork and creating a cultural and social foundation in the community to accept home healthcare services. Focusing on the principles of "integrity of care" and "access to the electronic platform" at all stages of the model is crucial.

Discussion

This health policy and systems research was conducted in four phases to develop a conceptual model of home-based palliative care for cancer patients in the healthcare system of Iran. This model provides an objective scientific base for integrated care and patient-centered services for

cancer patients at home within the existing healthcare infrastructure. From the final results of the four phases, a conceptual model with eight pillars and 92 indicators was created based on the WHO guide for delivering the healthcare services to cancer patients at home.

Evaluation of the healthcare systems of other countries shows that there are different models of palliative care that fit the healthcare system of the countries as well as the needs of the patients in those societies.³⁷ We tried therefore to produce a model that fits our context and the needs of our patients. It is certain that new models are moving in the direction of providing high quality care and increasing the QoL of patients with serious diseases.³⁷ There are five service delivery models of specialist palliative care: outpatient palliative care clinics (stand-alone or embedded), inpatient palliative care consultation teams, acute palliative care units, community-based palliative care at home or facilities and hospice care at home. They complement each other to provide comprehensive and supportive cancer care from the time of diagnosis to the end of life.⁹ Moreover, new care models for patients with advanced cancer are grouped by prognosis, level of care, or goals of care.³⁸ In our model we used the embedded (embedded outpatient clinics in the oncology departments at hospitals) and/or stand-alone outpatient palliative care clinics based on the cancer patients' needs in our healthcare system.

A glance at our model shows that the model is started with a patient and family needs' assessment and resource availability. During the development of our model, we focused on the two essential principles which were shown around the model: the integration of care and access to an efficient and extensive electronic platform for delivering person-centered and high quality healthcare services to cancer patients. An earlier study shows that the integration of palliative care services into the healthcare system links different levels of the healthcare system to deliver comprehensive care to the patients.³⁹

For creating a coherent home-based palliative care, a step-by-step approach of the WHO guide for palliative care³¹ was used. Evidence-based guide by the WHO in 2016 suggest that these steps should cover the six categories of policy making, healthcare financing, service delivery, workforce development, access to medicines and information and research.³¹ After an integrated review and a qualitative study, we added also two extra categories of "ethical and legal issues," and "family empowerment" to this list.

During the integration of healthcare services from hospital to home, providing reliable resources such as human and financial resources, equipment, and medications are critical issues throughout the creation of the model.⁴⁰ In order to have integrative palliative care services the recommendation of the WHO is to train both general and specialized healthcare providers to implement palliative care services at all levels of the healthcare network in the community. There should be appropriate policies to design the healthcare services as well as access to medications.⁴¹

The evaluation of the model's pillars shows that one of the important issues in the "policy making," is to give priority to palliative care services at home over healthcare services in hospitals and to create new healthcare policies in this area. Based on our participants' experiences, paying attention to the palliative care services at home is new in the country, and it is accompanied by challenges and obstacles. The integration of these healthcare services into the healthcare system of Iran is very challenging. The results of a study in this field show that there is a need for a strong and comprehensive healthcare policy, appropriate healthcare infrastructure, use of all necessary healthcare resources, and governmental support for the private sector.⁴²

Paying attention to the pillar of the "healthcare financing" shows that the use of available healthcare resources and access to universal home healthcare insurance coverage to receive healthcare services at home are important factors that contribute significantly to the establishment of the model. In this context, the WHO has also emphasized the need for universal healthcare insurance coverage at home and reducing the out-of-pocket payments by patients.⁴³ Therefore, the insurance coverage of healthcare services at home and the determination of service tariffs as well as the use of the facilities of charitable institutions by cancer patients

can create more motivation in the society to benefit from these services.

Results of earlier studies show that the establishment of a home-based palliative care model requires the integration of the supportive and palliative care system within the healthcare system and the adoption of national healthcare policies.^{44,45} Our model demonstrated the capacity to integrate palliative care services into the healthcare system. Results of integration of services from hospital to home and vice versa in three phases and six protocols have been published elsewhere.^{30,46} The integration of the palliative healthcare services at the community level can lead to the optimal use of these services and improve patients' outcomes and experiences of caregivers.⁴⁷

Holistic care together with the management of complications and patients' symptoms is another important area which was noticed during the design of the model. The use of national and international guidelines and standards for the management of cancer symptoms and complications and the provision of quality care along with the training of healthcare providers can be very helpful.⁴⁸

Furthermore, in the current model, the use of a skilled and cohesive palliative care team has been emphasized. Recruiting and employing human resources, is one of the important challenges that should be considered in the home palliative care models.⁴⁹ In home healthcare programs, home healthcare services are provided by a healthcare team consisting of physicians, nurses, pharmacists, psychologists, and other staff who need to work together with the patient and family.⁵⁰ A codified in-service training programs for home palliative care providers can be helpful. In this regard, in our healthcare system, a short-term professional home care course has been developed in the MOHME.⁴⁷

Another important area for discussion in our model is related to prescription and application of the medicines at home, specially opioids. In the healthcare system of Iran, there is only access to injectable opioids not oral ones for pain control. Also, in public opinion, the use of opioids has a cultural stigma, and sometimes the insufficient knowledge of the healthcare team members complicates the situation.⁵¹ Prescribing medicine at home is very important, but nurses are not allowed to prescribe medicine at home. Therefore, one of the most important challenges in our society, is to remove this restriction and allow nurses to prescribe medicine at home. Current regulations of nursing care and healthcare centers in Iran enforce that a physician must be present to prescribe medications.⁵²

Safety and quality of care are also noted as important priorities in our home-based palliative care model. Continuous accreditation can improve the quality of home care services and ensure patient safety.⁵³ Developed countries have documented programs to improve the quality of home healthcare services. In countries such as Norway, Sweden and England, the quality control of home healthcare services is carried out with regular and comprehensive monitoring, the use of protocols and continuous reviews.⁵⁴ Therefore, it is imperative that health policy makers consider codifying programs for ongoing accreditation of home healthcare services.

The current model prioritizes a comprehensive care plan based on the needs of the patients and their families, and the revision of the plan based on changes in the patient's condition. The findings of one study in the US showed that after admission of the patient, a complete care plan, including the type of healthcare services and necessary medical equipment, the frequency of home visits, movement restrictions, range of allowed activities, nutritional requirements, necessary medications, and the client's safety need to be determined. This plan is monitored and revised every two months by the decisions of the physician, nurse, and other healthcare providers in the home healthcare team based on changes in the patient's physical condition and needs.⁵⁵ In Sweden, the patient's condition is monitored every few months based on a regular program.⁵⁶ In England, the delivering healthcare services are evaluated after 6 weeks, and the care plan is updated every six months.⁵⁷ In our model, patients and their family can receive comprehensive healthcare services at home based on their needs through coherent palliative care teams, and the care plan is updated within the team based on the patient's needs and family. The details of different care plans and protocols were published elsewhere.^{30,46} However, advantages of this model for

Table 2

A summary of the results of the third round of the Delphi for scientific acceptability and feasibility of the eight pillars of the home-based palliative care model in cancer patients.

Pillar	Number of indicators	Scientific acceptability (Mean \pm SD) ^a	Feasibility (Mean \pm SD) ^a
Policy making	13	2.90 \pm 0.20	2.71 \pm 0.42
Health care financing	4	3.00 \pm 0.00	3.00 \pm 0.00
Service delivery	28	2.94 \pm 0.16	2.66 \pm 0.49
Workforce development	5	3.00 \pm 0.00	3.00 \pm 0.00
Access to medicines	10	2.98 \pm 0.05	2.53 \pm 0.11
Information and research	4	2.93 \pm 0.18	2.91 \pm 0.21
Ethical and legal issues	23	3.00 \pm 0.00	3.00 \pm 0.00
Family empowerment	5	3.00 \pm 0.00	3.00 \pm 0.00

^a Mean score \geq 2.5 is satisfactory.

reducing unnecessary re-hospitalizations of cancer patients, increasing the patients' self-efficacy and QoL as well as empowering their families, should be tested in future trials.

On top of that, the current situation of our healthcare system showed that it is necessary to have palliative care tele-medicine to deliver comprehensive and flexible healthcare services to cancer patients during routine care or crises such as the COVID-19 pandemic.⁵¹ Thus, an integrated electronic platform was considered in our model in order to register patients' records at the time of hospital discharge, patients' triage for requiring home healthcare, and access to telephone consultations when they are at home. In the telephone consultation system, queries

raised by the patients and their families are answered during 24 hours/7 days a week by a skilled nurse. In this platform, the patient's record is accessible for referral to the different levels of the healthcare system and planning for home visits.⁵⁸

In addition, we considered cultural and social factors in our model. Based on previous studies, cancer control includes identifying and removing cultural and social barriers, planning to modify attitudes and beliefs in adopting health behaviors, and health education at the first level of the healthcare service delivery system.^{33,38} Improving one's belief and attitude requires the use of national strategies, including public and media education, education in schools, educational support and effective care as well as supporting cancer patients and their families.

Implications nursing practice and research

This model can be a useful guide for health policy makers to plan for providing comprehensive, flexible, accessible and integrated palliative care services at home for cancer patients in the healthcare system of the country. Although this model was designed for our society, it can be generalized to fit similar societies with similar healthcare systems. Furthermore, this conceptual model can be useful for designing practical models and innovative programs for providing home-based palliative care for cancer patients and integrating hospital healthcare services to the home. We hope that the use of this model leads to a reduction in unnecessary hospitalizations of patients and an increase in the quality of care and satisfaction of patients and their families with the provided services. However, it will require further research in the future.

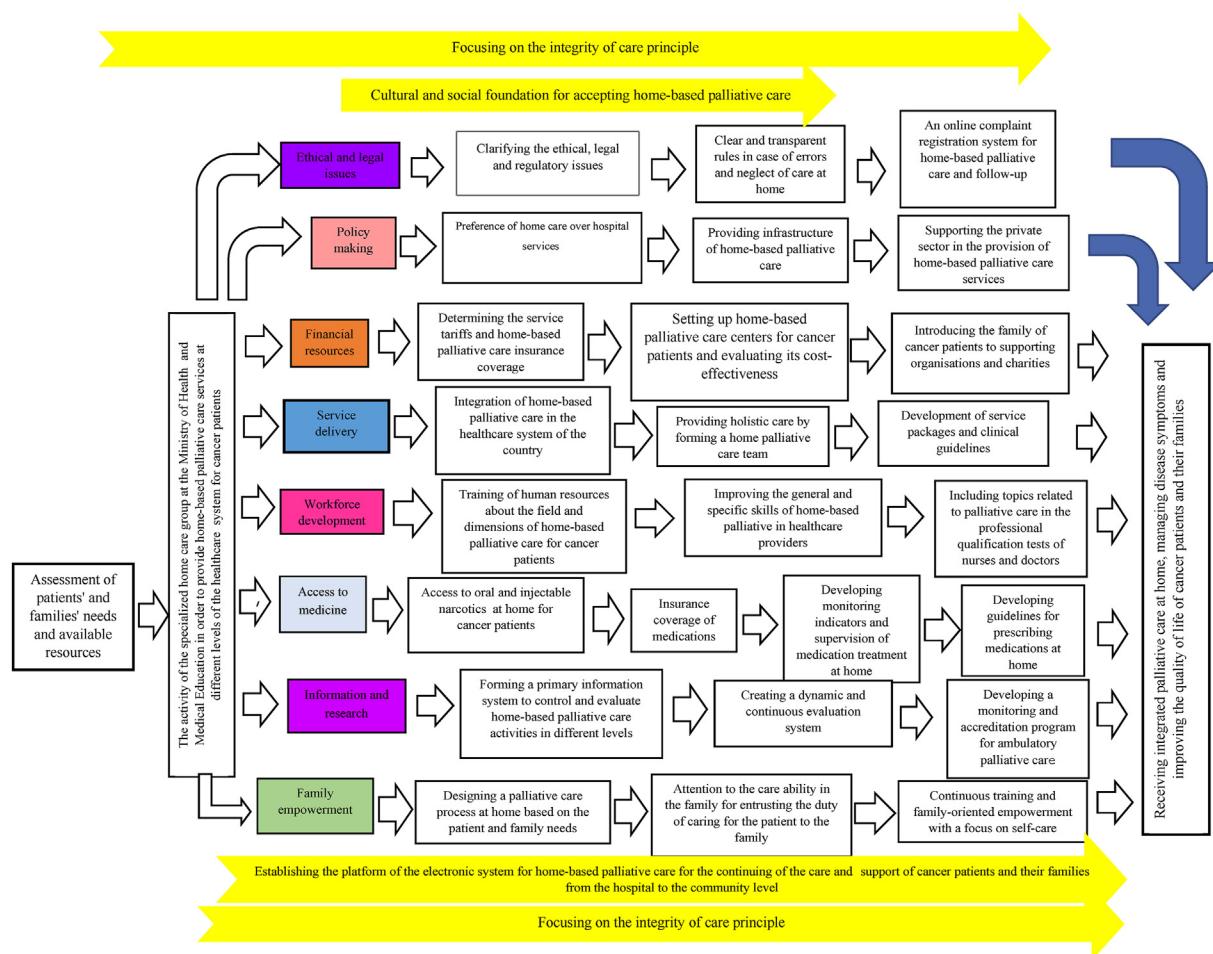


Fig. 2. Home-based palliative care model for cancer patients.

Strengths and limitations

To the best of our knowledge, our conceptual model is unique. Application of different research methods within the phases of the study, is one of the strengths of the study. Another strength is the flexibility of the conceptual model for routine care and/or critical situations such as the COVID-19 pandemic. One of the limitations of this study was limited access to specialized and experienced participants in the field of home-based palliative care, since these services are relatively new in our country. Perhaps, the evolving infrastructure of home care centers in our society and the coverage of these centers by the private sector can justify this limitation.

Conclusions

Based on the WHO guide, a home-based palliative care model for cancer patients was created with 92 indicators in eight pillars; “policy making,” health care financing,” “service delivery,” “workforce development,” “access to medicines,” “information and research,” “ethical and legal issues” and “family empowerment.” This conceptual model is compatible with the healthcare system of Iran, however it can be useful for designing practical models and innovative programs in countries with similar healthcare system. This model has been developed for policy making, planning and implementation of palliative care at home for cancer patients in our healthcare system, but it can be applicable in similar societies, too. Furthermore, this model can be a strategic planning guide for integrating palliative care from hospital to home and vice versa for cancer patients, as well as the integration of these services into the healthcare network of the country by overcoming existing challenges.

CRediT authorship contribution statement

Zahra Alizadeh: Conceptualization, Methodology, Data collection, Data analysis and interpretation, Writing the original draft, Review of the manuscript and editing. **Camelia Rohani:** Conceptualization, Methodology, Data analysis and interpretation, Writing the original draft, Critical revisions of the manuscript and editing, Supervision of the project. **Maryam Rassouli:** Methodology, Review of the process of data analysis. **Mahnaz Ilkhani:** Methodology, Review of the process of data analysis. **Maryam Hazrati:** Methodology, Review of the process of data analysis. All authors read and approved the final manuscript. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the decision to submit for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Ethics statement

This study was approved by the Research Ethics Committee of the Shahid Beheshti University of Medical Sciences (IR.SBMU.PHARMACY.REC.1397.096). All participants provided written informed consent.

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Data availability statement

The data that support the findings of this study are available from the corresponding author (Camelia Rohani) upon reasonable request. The data are not publicly available due to their containing information that could compromise the privacy of our participants.

Declaration of generative AI and AI-assisted technologies in the writing process

No AI or AI aids were used in the writing process.

Declaration of competing interest

The authors declare no conflict of interest. The 3rd author, Professor Maryam Rassouli, serves as a member of the editorial board of the *Asia-Pacific Journal of Oncology Nursing*. The article underwent standard review procedures of the journal, with peer review conducted independently of Professor Rassouli and their research groups.

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Appendix A. Supplementary data

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