Integration of Palliative Care into the Primary Health Care of Iran: A Document Analysis

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Abstract

Background: Providing palliative care (PC) is increasing by the increase in the number of people with life-threatening diseases and determined the benefits of these services in the community. Access to palliative care is a patient's rights and ethical responsibility. Thus it is necessary to integrate into all level of the health system, including the primary health care. This study was conducted to assess the requirements for the integration of PC into the primary health care.

Method: It was a document analysis, carried out through conventional content analysis and 10 national documents on PC, released by governmental organizations from 2010. The 4-step Scott method was used for the data validity and the coding process was done utilizing MAXQDA 10 software.

Results: Base on the data analysis, we identified the "requirements of the integration of PC into the primary health care", was of 4 main categories and 12 sub-categories. The categories include "principles and basics", "legislation and policy-making", "the establishment of PC system" and "the need for civil support", which were extracted by reviewing the documents.

Conclusion: PC is believed to be in its early stages in the Iranian health system. Therefore, universal access to these services requires their provision at the community level. Thus, it is recommended that the principles and basics of PC in the country be explained and then, the necessary infrastructures of this integration be provided with the cooperation of governmental organizations, NGOs, and charities, through proper policy making.

Keywords: Palliative care, Primary health care, Policy making, Integration, Iran

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MEJC
Middle East Journal of Cancer

Introduction

Primary Health Care (PHC) development is known as a global strategy to reduce the costs of health services and improve their quality, which is necessary in every country according to the definition of PHC essential and basic health actions, and should be available to all individuals and families.[1] Thus, the health system of Iran was revised in 2005, and the family physician program was added to the PHC, and was reformed in 2015 under the health system evolution plan.[2]

Moreover, in 2013, using various resources and expert opinions, the Iranian Ministry of Health and Medical Education set up a palliative care (PC) task force and designed the relevant system as a dimension of universal health coverage (UHC), with the aim of integrating PC into the health system.[3]

As one of the aspects of universal health coverage, PC is an approach that improves the quality of life in patients and their families in the presence of life-threatening illnesses, through pain relief and prevention based on early diagnosis, assessment and treatment of pain and other physical, psychological, social and spiritual problems.[4] PC is provided once the disease is diagnosed in settings such as hospices, homes, specialized service centers, community and hospitals, in order to support patients, care-givers and patients' families.[5] According to UHC's goals,[6] the location of providing PC for terminal patients needs to be consistent with their desires and preferences. In this regard, studies have shown that most of them prefer home care or outpatient clinics. This requires the integration of PC into the PHC, which itself requires the establishment of proper infrastructures.[7]

The European Union has considered end-of-life and PC at the PHC level as a part of its current plans. In addition, several countries including Canada, Spain, and recently Brazil, have implemented PC in PHC[8] Saito and Zoboli noted that with the growth in the elderly population, the incidence of chronic diseases has increased, reflecting the need for different levels of PC in the primary health care.[9] This has been accompanied by certain advantages, such as not occupying hospital beds, patient preference for home care,[10] and reduced hospitalization and length of stay.[11]

According to the classification of services and the referral system,[12] in the structure of Iranian PHC, the only community-based cares are preventive, diagnostic and therapeutic care for non-communicable diseases, for instance vaccination, mental health, and so forth.[13] Therefore, the majority of people, particularly those living in less privileged areas, do not receive PC.[14]

Despite the policy of the Ministry of Health to enhance the quality of care, reduce the costs of services in community-based care,[15] and improve the PHC program in Iran, there is still no developed programs for providing patients and their families with coherent PC, especially integrated into the PHC.[16] In order to establish such a relationship, it is primarily necessary to identify the requirements of this integration. Therefore, the present study investigated the requirements of integrating PC into the PHC analyzing the national documents of the health system in the Islamic Republic of Iran.

Method

The analysis in this document was conducted from September 2018 to February 2019 employing a conventional content analysis and it reviewed, the national documents associated with PC. In order to extract the national documents of the health system, the keywords "PC", "end-of-life care", "community care", "home care", "PHC" and "national document" were investigated in the websites affiliated to the Ministry of Health and Medical Education, the Islamic Parliament Research Center of the Islamic Republic of Iran, the medical sciences universities, Cancer Institute and other relevant organizations. Based on Krippendorff's approach guidelines, directives and policies can be analyzed in a five-step approach including access to documents, validity of documents, comprehending the documents, analyzing the data and applying the information. Regarding the access to document, the websites of parliament, the Ministry of Health, universities

of medical sciences, and research centers were reviewed. To assess the validity of documents, the main websites of these organizations were searched. Subsequently, the document was read several times in order to reach a general comprehension. Utilizing MAX-Q Data software 10, the document analysis and coding process was performed and theme and categories were extracted (Figure 1).[17] Rigor process including authenticity, credibility, representativeness, and meaningfulness of data was conducted using 4-steps Scott method. Verification of selected documents by parliament, the ministry of Health, universities of medical sciences, and research centers was conducted in the authenticity step. To implement the second step, not having conflict of interest were assessed so that no name of the persons was mentioned in the content analysis. Afterwards, the documents with the two mentioned criteria were utilized. Exhibiting general policies and/or determined keywords according to the research purpose was used for the representativeness step. Being clear and com-prehensiveness of the selected documents was applied as the fourth step.[18] In total, national 10 documents were studied, which were published by governmental organizations after 2000. Eight documents related to PC were extracted from these w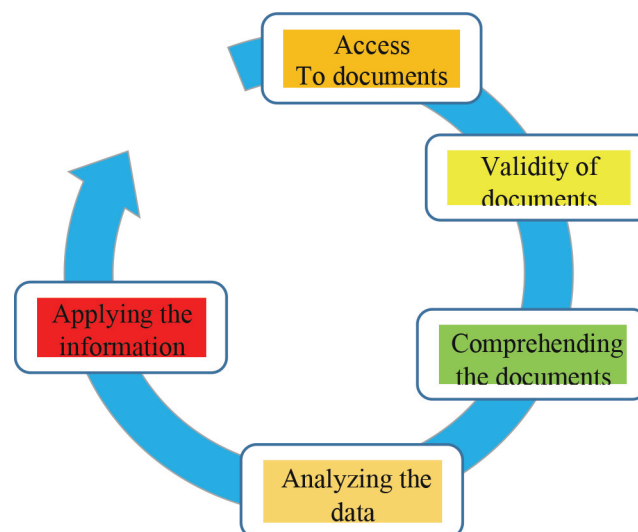ebsites, while two other documents were manually included. The articles and documents published by private organizations were not included in the study. The process of coding was carried out using MAXQDA 10 software. In the analysis of the documents, no Iranian politicians, policy makers or executive managers were mentioned. The ethics approval for the research was obtained from Baqiyatallah University of Medical Sciences under the code IR.BMSU.REC.1397.

Results

In the present study, 10 national documents were analyzed (Table 1) and 498 codes were extracted from the analysis of the documents. In the process of document analysis, after removing duplicate codes and merging similar ones, the theme "the requirements for the integrating PC into the PHC" was classified into four main categories, including "principles and basics", "legislation and policy-making", "the establishment of PC system" and "the need for civil support" (Table 2).

The requirements for the integration of PC into PHC

According to our findings, in order to integrate PC in the PHC properly, it is necessary that in the first step, policy makers and health service providers take action for the systematic

Figure 1. Krippendorff Criteria for Document Analysis

Table 1. Document included in the study and its characteristics

No.	Document	Type	Sources	Audience target	Legislation date
1	The Health System Reform Plan of the Islamic Republic of Iran	Roadmap	Parliament	Ministry of Health	2015
2	The National Plan for Cancer Supportive and Palliative Care	National Plan	the National Cancer Research Network	Cancer/ palliative care	2013
3	Executive Instructions for the Family Doctor Program and Rural Insurance	Regulation	Ministry of Health	health system	2006
4	National Document for the Prevention and Control of Non-Communicable Diseases and Related Risk Factors, in the Islamic Republic of Iran in the Period between 2015 and 2025	National doc.	Ministry of Health	Ministry of Health	2016
5	National Ethical Guidelines in the Field of Palliative and Supportive Care in End-of-life Patients	Guideline	Ministry of Health	End of life/ palliative care	2019
6	Regulations for the Establishment of a Counseling and Nursing Home Care Center	Regulation	Ministry of Health/ Deputy of Nursing	Nursing/ home care	2017
7	The Law on the Sixth 5-Year Development Plan	Law	Parliament	Government	2018
8	Iran's 2025 National Vision Document	National doc.	Parliament	Government/ parliament and others	2006
9	The Comprehensive Scientific Health Plan	Roadmap	Ministry of Health/ Deputy of Education	University of Medical Sciences/ Ministry of Health	2011
10	Clinical Practice Guideline for the Provision of Spiritual Care for Cancer Patients	Guideline	Ministry of Health	Cancer/ end of life / palliative care	2018

establishment of PC in the health system, after being familiarized with the principles and basics, policy-making and concentrated legislation and presenting it to other centers and institutions. The need for social support is another requirement of this integration.

The principles and basics of PC

These services are not only limited to the physical aspects of patients' health, but also they always consider psychological and spiritual aspects. Therefore, it is necessary to examine the scope, definition, and dimensions of these services.

PC's scope

In the objectives of document No. 2, it was mentioned that "It is necessary to organize the status of service provision to various groups of patients with the aim of reducing the burden shouldered by families in dealing with the heavy costs of the illness, in the form of organizing the status of service provision to various groups of patients (specific, terminally-ill patients, and vulnerable classes) through reforming the

financing system and accumulating scattered funds in order to provide the necessary drugs with the cooperation of charity organizations and NGOs."

PC's definition

Providing a comprehensive care is a great necessity and challenge that need to achieve a common definition by policy makers and providers to develop PC in the country. Document No.2 states that "PC is the improvement in the quality of life in patients with an advanced, progressive, and terminal illness, such as cancer, and in their family members. This care begins upon diagnosis and focuses on psychological problems, social issues, and spiritual health concerns in patients and their companions, through prevention and controlling physical symptoms."

PC's dimension

According to document No. 5, "PC must include all physical, psychological, spiritual, and social aspects of patients and their family, must relieve the pain and other distressing symptoms,

Table 2. Theme, main categories, and subcategories

Theme	Categories	Subcategories
The Requirements for the Integration of PC into PHC	Principles and basics	PC scope
		PC definition
		PC dimension
	The legislation and policy-making	Stewardship
		Planning
		The integration of relevant institutes
	The establishment of PC system	Providing structures
		Providing the process
		Providing the outcome
	The need for civil support	Social justice
		The activation of NGOs and charities
		interacting with insurance organizations

PC: Palliative care, PHC: Primary Health Care, NGOs: Non-Governmental Organizations

and consider death as a natural process, while preserving life; it should coordinate and integrate the psychological and spiritual aspects of patient care and provide a supportive system for helping patients to live as actively as possible before passing away. This could be obtained by creating a support system for them, (and finally) using a teamwork solution to meet the needs of the patient and family."

Legislation and policy-making

This category consists of the three subcategories including stewardship, planning, and the integration of the relevant institutes.

Stewardship

According to No. 2, "The stewardship in PC is defined as the identification and the empowerment of executive rules and the provision of directives and strategies for all the people involved in PC, and also accepting the large-scale responsibility and responsiveness at the highest level, which falls on the Ministry of Health and Medical Education, on the behalf of the government."

Planning

It is essential to formulate goals, plans, and strategies in order to provide palliative services in PC system. "Organizations and health care provision centers should make clear and effective policies in the field of futile care, and develop proper practical guidelines. Moreover, it is necessary for health policy-makers in the country to appropriately plan for the-integration of palliative medicine in the PHC." (Document No. 5).

The integration of relevant institutions

Various documents have emphasized the integration and effective cooperation between different institutions, such as the Ministry of Health, with various institutions in order to ensure health. For example, "the Ministry of Health and Medical Education must take measures to implement a comprehensive and public health service system by the prioritization of health and prevention over treatment, based on PHC and using a referral system and by focusing on family physician through using family and general practitioners, nursing groups in providing nursing care at the community level and in homes, and the classification of services." (Document No.7).

Establishing a PC system

According to the upstream documents, the establishment of a PC system in Iranian health system requires the identification of general situation of the country, and the models governing the health system, health network, and dominant structures of universities. This category includes providing the infrastructure, process, and outcome.

Providing infrastructure

The infrastructures required in this step include designing an information management system, providing equipment and facilities, financing, providing human resources, and developing inter-disciplinary groups. "The large-scale supporting processes in various systems, on which the quality and efficiency companies around the world focus, include governance, policy-making, and

supervision processes (the process of providing and managing financial resources, the process of providing and managing human resources, the information management process, the quality improvement management, the knowledge management process, and the equipment management process)." (Document No 2).

Providing the process

Concerning the process, it is necessary to understand the model of governing the health system, the general structure of Iranian health system, and its network of health and treatment. In this analysis, access to medicine, and service provision in the form of a comprehensive and public health service system, as well as the formulation of guidelines and applied researches were extracted. Document No.4 states: "it is necessary to the implement a national guidelines, preparing universities, and implementing and integrating plans for preventing and controlling non-communicable diseases at the PHC level".

Providing the outcome

This aspect of PC system establishment focuses on the patient's satisfaction, improving the quality of life, and determining the cost effectiveness of PC economical functions. An example of the outcome which was also mentioned in the documents is as follows: "the launch of a satisfaction management system for specialty centers (ASM), the creation of a database of the approved centers, as well as the launch of a management system and customer satisfaction measurement (CSM) system with the purpose of filing complaints (for service receivers), and conveying the problems, advantages and weaknesses of these centers, by Nursing Deputy." (Document No. 6).

The need for civil support

According to the documents, people's participation and support is one of the essential requirements for the successful implementation of any program. This category includes three subcategories of social justice, activating NGOs and Charities, and interaction with insurance organizations.

Social justice

"The health system's policy, with respect to patients' right to receive proper PC at final stages of life, emphasizes the observation of justice, and rational and logical principles in providing services." (Document No. 5).

Activating NGOs and charities

Note. 2 of the document mentioned "By the formation of the National Committee for Cancer Support and the Palliative Care Working Group, the support of the public, NGOs, etc. can be attracted." (Document No. 3).

Interaction with insurance companies

Document No. 5 states "In order to achieve social justice, legal support, and appropriate insurance, government resources should be available to patients and their families."

Discussion

Based on the findings of the present study, four categories are needed to integrate palliative care into the primary care. This study focused on the requirements for the integration of PC into the PHC by analyzing the national documents of health system in the Islamic Republic of Iran. Herein, the "requirements for the integration of PC into the PHC" was extracted according to four major categories: "principles and basics", "the legislation and policy-making", "the establishment of PC system" and "the need for civil support".

The principles and basics of PC

The initial step in the expansion of PC in Iran is to explain its principles and basics, which include the three subcategories of scope, definition, and aspects of the PC. The scope of PC in Iran consists of cancer patients who are provided with PC services, while in advanced countries, the scope of PC includes a wide range of patients with terminal illnesses, such as heart failure, COPD and dementia.[13] This is due to the importance of cancer as the third leading cause of death in Iran, as well as its high costs of treatments and the need of these patients and their families to physical care and the other non-physical types of care in the last stages of life. The definition and dimensions of PC require an

agreement between the PC decision-maker and presenting a comprehensive definition in this field. In the study conducted by Borimnezhad et al., two general dimensions of the final stage of life and general PC have been mentioned.[19] Meghani argued that PC is a dynamic concept that, over time, takes on new meanings such as terminal care, pre-terminal care, and end-of-life care.[20] However, in 2002, concerning the definition of PC, World Health Organization (WHO) referred to the quality of life in patients and their families encountering life-threatening illnesses, which includes physical, mental, psychological, social, and spiritual aspects.[21] This definition has been considered in different countries, which is consistent with the results of this study. Obviously, this similarity is due to utilizing documents and data from the leading countries in the formulation of related documents in Iran.

Legislation and policy-making

Legislation and policy-making, another fundamental element of providing services in the PHC, was extracted, which consists of stewardship, planning and the integration of relevant institutions. The stewardship of Iranian health system, based on its coherent and focused structure, reflects the need for attention to all the institutions providing PC. Planning is the next subcategory. For the effective provision of PC in the community, WHO referred to the four dimensions of the public health strategy, including appropriate policies, drug availability, educating, and implementing PC services.[22] Furthermore, in 2012, Iran developed a national comprehensive plan for the provision of supportive and palliative cancer care in order to provide PC. But so far (up to 2019), structures for PC provision have not yet been well-formed. Asadi Lari et al. suggested that PC requires the integration of various institutions (public, private, and charities).[16] In countries such as England and Romania, the capacity of charities and volunteers has been extensively employed to provide palliative services; 60% of the costs of hospice and PC services are provided by local volunteers and gcharities.[23] The first step towards PC in Iran

was taken by the establishment of Ala' Charity Foundation, in the city of Isfahan. Regarding this successful experience, it is necessary to make the most of the capacity of NGOs and charities

Establishing a PC system

The establishment of a PC system consists of providing the infrastructure, process, and outcome. Infrastructure design includes designing an information management system, designing service packages, providing equipment and facilities, providing financial resources, formulating guidelines, and human resources. The process also includes providing access to medicines, providing research, offering services in the form of a comprehensive services system, and creating an interdisciplinary group. Health, cost-effectiveness, and economic functions were the dimensions of outcome. In 2016, this organization stated that the integration of PC in the health care system includes six dimensions of policy-making, funding, service provision, human resources development, and having access to medicine, information and research.[5] Asadi Lari et al. mentioned that in Iran, like many developing countries, PHC does not provide any PC or end-of-life care to patients and their family. These services require service provision models, financial resources, budget levels, health insurance coverage, and various systems (public, private, and charity) in association with PHC.[16] In the study conducted by Lu et al., it has also been argued that in China, none of the PC provision structures are integrated into the health care provision system.[24] Our results are in accordance with WHO guideline texts on the integration of PC into the health care system. The dimensions considered in this category are in line with the dimensions of the guidelines.

The need for civil support

Ultimately, the need for civil support includes three subcategories of social justice, activating NGOs and charity organizations, and interaction with insurance companies. The policies of the government and the Ministry of Health need civil support and acceptance. Social justice is one of the fundamental principles of PC and PHC.[9] The pivotal point of people's participation in the

community health care is in line with Alma-Ata Declaration, because developing a public health policy on top of the empowerment of community engagement and actions are two of the strategies in this declaration which emphasizes people's actions and participation in their own health.[25] Kumar et al. reported that PHC and PC require community and social participation in making policies and response mechanisms to ensure that an acceptable, cost-effective and scientific health system has been developed.[26] Damari et al. also mentioned in their study the inadequate communication between NGOs and the government, and the government's weak confidence in NGOs' role of these organizations.[25] Accordingly, as long as there is no community participation, acceptance and support in the decisions and interventions made by the Ministry of Health, no fundamental actions will be taken.

In the current work, which was developed scientifically through using the national documents of the Iranian health system, the requirements for PC integration were extracted. The advantage of this study is utilizing the national documents which are consistent with the structure and texture of Iranian health system. Meanwhile, as the weakness of this work, we can mention the limitations of national documents in the field of PC, due to the novelty of PC science and its recent emergence in the developing countries, such as Iran. It could be argued that the results of this study can be used as a resource to develop a broader perspective for those involved in PC in the country.

One of the major limitations of the present study was the lack of an English translation and even an English abstract of the national documents. Another limitation was access to documents as there was no clear place to access to documents in the websites. Yet document analysis can demonstrate performed activities and future plans in the field of palliative care. Therefore, policy makers and managers can comprehend the general view of palliative situation in the country.

Conclusion

In regard to the growing elderly population in the country, a surge in NCDs and the increase in health care costs, the integration of PC into PHC is an undeniable necessity. The WHO Guideline has focused on the necessity of the integration of PC into PHC and has obliged different countries to integrate PC into PHC. Therefore, the concept of PC is required to be a point of consensus between the decision makers and providers of health care services. In addition, governmental organizations should create the necessary infra-structures for this integration, in co-operation with charity organizations, NGOs and volunteers through appropriate policy-making.

Acknowledgement

Conflict of Interest

None declared.

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