

# Perceived factors to providing palliative care for patients with cancer - a qualitative systematic review

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## Abstract

Palliative care (PC) is one of the necessary cares given throughout a patient's experience with cancer. The aim of this study was to identify the perceived factors to providing PC for patients with cancer. Our study was a systematic review of qualitative literature. To this end, electronic databases, including CINAHL, PubMed, PsycINFO, Ovid, and Web of Science as well as Persian databases were searched and qualitative studies on the role of PC in patients with cancer published between Jan 2008 and Dec 2017 were selected. Generally, 12 studies were reviewed. A thematic synthesis approach was used to analyze the data. Exploring the selected articles, the findings on the perceived factors to providing PC for patients with cancer were categorized into three themes, including organizational factors, ethical factors, and psychological factors. This qualitative systematic review expands our knowledge about factors influencing the provision of PC for patients with cancer. It is necessary for health system managers and caregivers to pay attention to all aforesaid factors in order to improve PC for cancer patients.

## Introduction

Cancer is considered as one of the most important reasons of death in the world and can happen in all people and in all ethnical, racial, sexual and age groups as well as in all social and economic

groups.<sup>1</sup> For more than a decade, cancer incidence rate has been stable in women and it has decreased by 2% annually in men. Moreover, cancer death rate in both sexes has decreased by 1.5% annually.<sup>2</sup> This disease is recognized as a growing problem in Middle East countries and it is predicted that the total number of deaths from cancer will increase 45% up to 2030.<sup>1</sup> Cancer diagnosis is a considerably unpleasant experience. This disease disturbs social, economic, family and personal status, and generally the life of the afflicted person. The afflicted person cannot continue his/her previous usual life due to physical disabilities caused by cancer that can result in quality of life reduction.<sup>3</sup> In fact, cancer causes considerable social and mental problems for patients disrupting their routine life habits.<sup>4</sup>

Palliative care (PC) is one of the necessary cares given throughout a patient's experience with cancer. It was developed in the late 1960s and its primary purpose was to consider care needs of patients suffering from serious diseases. This type of care was started officially in 1970 with the aim of supporting patients spiritually, socially, psychologically and physically at the end stage of life utilizing a multidisciplinary team.<sup>5</sup>

PC is an approach for promoting the patient's and his family quality of life and supporting them in dealing with problems limiting their life. To this end, PC primarily aims to prevent or treat, as early as possible, the symptoms and complications induced by the disease; and secondly to diagnose and treat the related psychological, social, physical, and spiritual problems. This type of care is beneficial throughout life and also in difficult situations such as famine and it should not be used just for end-stage patients.<sup>6</sup> PC is provided throughout a patient's experience with cancer initiating at diagnosis and continue through treatment, follow-up care, and the end of life. When the disease is far gone, the need for these kinds of care is felt more intensely. However in some countries such as Iran, offering PC services for patients with cancer is quite limited and there is only one referral public hospital in Iran.

It has been observed that despite the growing process of qualitative researches in the field of PC, unfortunately the use of their findings has not been extended. Each qualitative research alone revealed only one aspect of facts about health and illness, but generally it was unable to explain this phenomenon comprehensively. Therefore, there is a need for a method that can perform qualitative research using an organized review. Hence, it seems that the findings of the present study can be a response to the quiddity of PC concept for patients with cancer so that the concept will be better identified. The better identification of the concept will help authorities of health systems make better care and educational decisions.

Previous researches evaluated the experiences of different cancer patients regarding PC. However, to the best of our knowledge, no qualitative systematic review is available on this topic to clear the gap of knowledge and advance the theoretical develop-

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ment of other related studies. The aim of this qualitative systematic review was to identify the perceived factors to providing PC for patients with cancer.

## Methods of research

The present study was a qualitative systematic review. It is a qualitative methodology in nursing and health-care research that tries to develop perception of study participants' opinions to determine original themes among different outlooks.<sup>7</sup> Our study was a qualitative study in which the results of qualitative researches on PC were summed up and their similarities and differences were compared. These steps were as follows: drafting the questions of the study, reviewing systematically, searching and selecting proper articles, extracting information from the article, analyzing and combining qualitative findings, and controlling quality and reporting findings. In the present study, the question was: *What are the perceived factors to providing PC for patients with cancer?*

## Search method

Qualitative studies on the concept of PC among cancer patients published between Jan 2008 and Dec 2017 were searched from authentic databases in English and Persian Languages (CINAHL, PubMed, PsycINFO, Ovid, Web of Science and Persian databases). Defined words in MeSH system under the title of "palliative care", "qualitative research", "patient" and "cancer" were used as key words for searching. The following additional search terms were also used: "perception" or "experience."

## Search outcome

In the initial search, 658 articles were found; their titles were studied and repeated items were deleted. The number of selected articles reached to 103 in this stage. Those studies which were unqualified or had not clearly explained the concept of study were omitted. Thus, 82 were excluded based on the exclusion criteria. Six more articles were excluded because the studies were not relevant to our review's aim and inclusion criteria. Of the remaining, 15 articles were full-text assessed. Upon full-text assess, 3 articles were excluded for the following causes: Two articles explained the process of a larger project and one article was narrative report of PC. Finally 12 articles were selected (Figure 1).

Defined inclusion criteria included study with qualitative approach in healthcare disciplines, being published during 2008-2017, published articles in English and Persian in online scientific journals, and studies which had carried out PC for patients with cancer at home and in healthcare settings.

## Appraising the findings

The rigor of these articles were studied using the Critical Appraisal Skills Programme (2013) Qualitative Research Checklist.<sup>8</sup> Its 10 items evaluate a qualitative research's aim, methodology, sampling procedure, data collection and analysis technique, ethics, and results. The second author and a qualitative research expert performed the quality appraisal separately. Their comments concerning findings were observed and a consensus was achieved. All selected articles were identified to have good methodological trustworthiness.

## Classifying the findings

In this study, findings of previous studies were considered as data (Table 1). To this end, when intended studies were assessed by authors, all findings of those studies were considered as qualitative data and thematic synthesis was run for data analysis. In this

method, the codes were extracted from articles and then they were re-coded and finally another coding was done on the concept in order to obtain themes. In this study, first all codes were extracted from qualitative articles, then considering the concept of each code and based on their similarities and differences, these codes were classified in a similar concept and themes were obtained, respectively.<sup>9</sup> The second author and the qualitative research expert combined the results from the 12 articles and synthesized these results into themes. All findings were agreed by the second review author (Table 2).

## Results

Details about the reviewed researches regarding the concept of study are shown in Table 1. In the present study, selected studies were related to the countries of the Netherlands, England, Scotland, Belgium, Germany, Brazil, Canada, The United States, and Iran. Types of qualitative studies were as follows: content analysis (11 studies) and grounded theory (1 study).

The findings on the perceived factors to providing PC for patients with cancer were categorized into three themes, including organizational factors, ethical factors, and psychological factors. Codes which resulted in themes are depicted in Table 2.

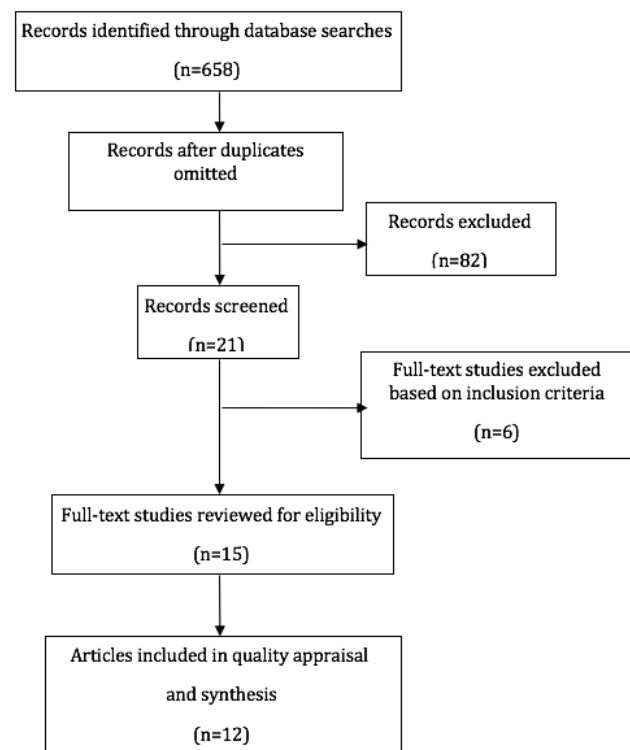


Figure 1. PRISMA flow diagram.

## Discussion

In this systematic review, the findings on the perceived factors to providing PC for patients with cancer were categorized into three themes, including organizational factors, ethical factors, and psychological factors.

### Theme 1: Organizational factors

Theme of organizational factors and its role in services related

to PC are factors which include equipment and human resources in their concepts on the one hand, and equipment suppliers and inhuman resources for these services on the other hand. Therefore, if any problem occurs with the sources supply, the aforesaid equipment and their performance, PC service for patients will face many challenges. In this regard, one study in the United States stated that planning by PC givers is one of the factors which leads to better services to patients.<sup>10</sup> However, results of a study in Belgium revealed that some of the organizational factors such as lack of access to PC givers for patients, lack of medical staffs' time, and

**Table 1. Characteristics of the studies selected for review.**

Author/ Year/ Country	Aim	Approach	Participants	Results
Audrey <i>et al.</i> 2008 England	Explaining usefulness of palliative chemotherapy for patients with cancer	Content Analysis (CA)	37 patients, 9 oncologists	Most patients with cancer were informed of the effectiveness of PC.
De Graaff <i>et al.</i> 2010 Netherland	Identifying participants' PC perception about	CA	83 patients with cancer, Turkish, living in the Netherlands and their families	PC is a good care which is offered at final stages of life and has an important role in making the patient hopeful.
Johnston <i>et al.</i> 2012 Scotland	Identifying perception of patients with cancer from end of life care	CA	20 patients	Preparing for death was one of the most important concepts regarding end of life care. Patients were willing to be supported concerning dependency and staying at home.
Sheard <i>et al.</i> 2012 England	Identifying physicians' viewpoints about obstacles they face in diagnosis and treatment of patients with cancer	CA	45 physicians	Difficulties in treatment and decision-making for doctors about patients with cancer at final stages of life make it necessary for them follow a moral framework. Based on this framework, decisions which are the most profitable and less harmful should be made.
Hamooleh <i>et al.</i> 2013 Iran	Explaining nurses' perceptions of PC based on ethics for patients with cancer	CA	14 nurses	Human dignity, vocational honesty, and altruism in PC have an important role. Respecting patients' values, having supportive behavior, and being responsible while caring for patients are important in PC.
Seyedfatemi <i>et al.</i> 2014 Iran	Identifying nurses' perceptions of PC for patients with cancer pain	CA	15 nurses	Alleviating psychological pain is done in the form of supportive behavior.
Back <i>et al.</i> 2014 United States	Explaining role of specialists in offering integrated PC for patients with cancer	CA	6 experts in PC and 2 nurses	The most important role of experts included facilitating coping skills, patient acceptance, and planning in care.
Pfeil <i>et al.</i> 2015 Germany	Explaining the role of nurses and physicians in the field of oncology about PC to patients in the final stages of life	CA	12 specialists in PC and 6 nurses	Patients' unreal expectations are a challenge in PC.
Paiva <i>et al.</i> 2015 Brazil	Explaining viewpoints of family members of patients with cancer receiving PC in the area of spirituality	CA	30 family members of patients with cancer	Families of patients with cancer use spirituality as a coping strategy.
Horlait <i>et al.</i> 2016 Belguim	Identifying obstacles that oncologists face regarding PC of patients with cancer	Grounded Theory	15 oncologists	Obstacles in psychological aspects such as patient's anger, anxiety about stigma resulting from disease, obstacles related to family and organizational obstacles are identified.
Khoshnazar <i>et al.</i> 2016 Iran	Highlight the views of stakeholders to know the challenges of providing PC for women with breast cancer	CA	10 health-care providers and 9 patients	PC services have not been correctly defined in the Iranian health system. Although the demand for these services is high, sufficient services are not offered by caregivers in this regard.
Melhem and Daneault/ 2017 Canada	Explore the needs of cancer patients in PC	CA	12 patients with cancer	Cancer patients needed assurance by means of clear information about their disease.

absence of official training for employees about PC can be considered as obstacles in offering favorable services for patients.<sup>11</sup> Results of a study in Iran stated that in the viewpoint of professional employees of health system concerning PC of patients, inter-professional cooperation is necessary.<sup>12</sup> In addition, the results of another study in Iran revealed that PC services have not yet been correctly defined in Iran's Health System and while the demand for these services is high, caregivers do not offer sufficient services in this regard. It was also determined that absence of referral system for patients, lack of guidelines and protocols, lack of insurances support by PC service, and weakness in teamwork are the biggest challenges for PC faces.<sup>13</sup> These findings stated that in order to offer PC to cancer patients, it is necessary to strengthen structures of these kinds of care through codifying related protocols and guidelines and supporting health systems by ensuring these kinds of services covered by insurance.

Findings of the present study confirmed the role of some of the organizational factors in offering PC to patients. Factors such as having a plan in offering PC, the necessity for inter-professional cooperation, teaching medical staff, and providing equal access to receiving PC services which can be supplied by health system managers and authorities are among the proposed organizational factors. In contrast, weakness in teamwork, lack of guidelines and protocols, absence of a referral system for patients in order to receive PC services, absence of support by insurance companies are among the organizational factors which threaten the integrity of offering these services.

## Theme 2: Ethical factors

The results of our study confirmed the role of ethical factors theme in offering PC services to patients with cancer. This theme included the concepts of ethical care, end of life considerations, and spirituality. Ethical factors generally include elements which have ethical concepts such as honesty in patient's care as well as human dignity. Furthermore, some of these factors, including considerations related to end of life care is part of both PC and spiritual dimensions. Based on findings, considering ethical factors can

lead to facilitation of PC services for patients.

The results of the present study revealed that PC of patients with cancer is a kind of ethical care. In this regard, a study in Iran revealed that PC of patients with cancer reinforces human relations via nurses' emphasis on maintaining human dignity.<sup>3</sup> In addition; the results of another study in Iran showed that PC in patients is related to factors such as maintaining human dignity, altruism, and professional honesty. Human dignity includes respect for patient and attempting to maintain values; altruism includes comprehensive admission of patient and nurses' accountability; and vocational honesty includes honest action and speech.<sup>14</sup> Findings of a Canadian study indicated that cancer patients needed assurance by means of clear information about their disease.<sup>15</sup> However, results of a study in England revealed that some patients were not aware of the benefits of chemotherapy.<sup>16</sup> This means that they were not provided with the required information in this regard. Concerning giving information to patients in the field of PC, the results of a study in Belgium revealed that in the opinion of oncologists; it is sometimes difficult to talk about PC with patient because the patient has responded well to anti-cancers drugs and has a good physical condition. On the other hand, there is little chance to talk about PC with patients whose cancer has advanced in them and they will refer to treatment centers sooner or later. Furthermore, there is sometimes no agreement between members of caring team on PC.<sup>11</sup> Another factor which is proposed in ethical care of patients in the field of PC is the unreal expectations of some patients. They expect a miracle in their treatment. In this regard, a study in Germany revealed that unreal expectations of patients are a challenge for medical staff when offering PC.<sup>17</sup> This highlights the necessity to focus on realities and facts in ethical care of these patients.

Considerations related to end of life care is one of the concepts related to ethical factors theme. According to a study carried out in the Netherlands, patients and their families consider PC as a good care which is offered at the final stages of life.<sup>18</sup> Result of a study in Scotland revealed that preparing for death is one of the most important concepts related to end of life cares for patients. In this

**Table 2. Summary of thematic analysis.**

Main themes	Code in the texts	Source article
Organizational factors	Lack of access to PC services for patients	(Horlait <i>et al.</i> , 2016); (Khoshnazar <i>et al.</i> , 2016)
	Inequality in offering PC services	(Hamooleh <i>et al.</i> , 2013); (Khoshnazar <i>et al.</i> , 2016)
	Lack of official training for employees	(Horlait <i>et al.</i> , 2016); (Khoshnazar <i>et al.</i> , 2016)
	Absence of guidelines, weakness in teamwork	(Horlait <i>et al.</i> , 2016)
Ethical factors	Honesty in patient's care	(Hamooleh <i>et al.</i> , 2013); (Melhem & Daneault, 2017)
	Honesty in giving information to patient	(Melhem & Daneault, 2017)
	Attention to human dignity	(Johnston <i>et al.</i> , 2012)
	Altruism	(Hamooleh <i>et al.</i> , 2013)
	Maintaining patient's dependence at the final stage of life	(Johnston <i>et al.</i> , 2012)
	Making the best decision at end of life	(De Graaff <i>et al.</i> , 2012); (Sheard <i>et al.</i> , 2012)
Psychological factors	Respecting patients' values	(Hamooleh <i>et al.</i> , 2013)
	Patient's concern about stigma of disease	(Horlait <i>et al.</i> , 2016)
	Patient and family's use of coping strategies	(Paiva <i>et al.</i> , 2015)
	Psychological support	(Johnston <i>et al.</i> , 2012); (Seyedfatemi <i>et al.</i> , 2014)
	Empathy with patient	(Hamooleh <i>et al.</i> , 2013); (Johnston <i>et al.</i> , 2012); (Seyedfatemi <i>et al.</i> , 2014)
	Decreasing patient tension	(Johnston <i>et al.</i> , 2012); (Seyedfatemi <i>et al.</i> , 2014)

respect, patients with cancer were willing to be protected with regard to being independent and staying at home at the time of death.<sup>19</sup> Therefore, considering the importance of ethical concept of dependence for decision making about patients and considering the fact that these patients are not prepared to make the best decision, a study in England emphasized on this matter. In the aforementioned study, researchers stated that difficulties in treatment and decision-making for physicians about patients at the final stages of life require that they follow an ethical framework. According to this framework, decisions with the most efficacies and less losses should be made for patients.<sup>20</sup> Considering the fact that end of life care is considered as a part of PC for patients, it is vital that medical staff pay attention to these items.

In the present study, spirituality was determined as one of the other elements related to ethical factors theme in PC of patients with cancer. The importance of spirituality and use of spiritual strategy in PC of these patients has been determined both for the patients and their families in qualitative studies. Furthermore, results of a study revealed that patients use spiritual strategies while receiving PC services.<sup>21</sup> Moreover, researchers in Brazil stated that family members of patients who received PC, regarded spirituality as an important strategy in accepting the disease.<sup>22</sup> These findings demonstrated that the factor of spirituality plays an important role in PC of patients in different parts of the world.

### Theme 3: Psychological factors

Theme of psychological factors includes concepts of stress and its coping strategies as well as psychological support in PC of patients with cancer. The results of the present study indicated that PC for patients confers a psychological burden for patients, their families, and medical staffs. The findings of a study in Belgium revealed some obstacles related to patient against offering PC services such as concern about disease stigma and patient's anger.<sup>11</sup>

Due to stress imposed by the disease itself as well as stressful nature of PC receiving, it is necessary to use a series of strategies to cope with these stresses. In this respect, researchers in the United States revealed that one of the roles of specialists regarding PC services for patients is facilitating coping with disease.<sup>10</sup> According to results of study carried out in Belgium, patients receiving PC use a series of coping strategies, including getting help from medical staffs, family, and friends.<sup>21</sup> The importance of using coping strategies is also taken into consideration for family caregivers of patients with cancer in qualitative studies. Researchers in Brazil stated that the most important coping strategy for patients receiving PC in the family is a strategy for coping with the death.<sup>23</sup>

Another coping strategy for patients with cancer and their families was hope. The study carried out in the Netherlands demonstrated that PC has a role in giving hope to patients and their families.<sup>18</sup> The results of the present study revealed that psychological support of patients with cancer has a key role in offering PC for them. In this regard, a research in Iran indicated that PC of patients is done in an atmosphere of psychological support.<sup>3</sup> In addition, according to the result of a study in England, receiving PC at home is simultaneous with a feeling goodness and this feeling helps patients and their families establish a satisfactory relation with nurses.<sup>24</sup> This matter indicates that offering PC for patients occurs collectively with psychological support. Another study in Iran showed that in addition to alleviating physical pain, PC in cancer alleviates psychological pain. Alleviating psychological pain is done in the form of supportive behavior.<sup>25</sup> One of the factors embedded in PC of patients in the concept of psychological support is empathy. Similarly, researchers in Iran declared that psychological PC of patients is done in the form of decreasing tension

and empathizing with them.<sup>26</sup> Findings this study revealed that for more effective PC services, it is better to have nurses' cooperation. The present study did not evaluate the concept of PC in one specific kind of cancer and it takes into consideration all kinds of cancers. Therefore, it is recommended in future qualitative systematic review studies to consider a specific kind of cancer to obtain more comprehensive information about PC and its related factors.

It is worth mentioning that one of the limitations of present study was failure to take advantage of some articles related to study which were published in languages other than English and Persian. Furthermore, in this study different approaches of qualitative research were taken into consideration and no single approach was considered.

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## Conclusions

Review of studies revealed that PC for patients with cancer has psychological, ethical as well as organizational themes. This review expands our knowledge about factors influencing the provision of PC for patients with cancer. Concerning organizational factors, the necessity of paying attention to equipment and human resources is taken into consideration. Ethical factors related to PC for patients are integrated with ethical care and end of life considerations with spirituality. Psychological factors involved in this area were based on stress and its coping strategies as well as psychological support. Based on the findings, it is necessary for caregivers and health system managers to pay attention to all aforesaid dimensions in order to improve PC for patients. Furthermore, considering what was determined in reviewing qualitative texts, one of the organizational factors in offering PC to patients is its limited services. Consequently, these services are not equally distributed in the society and there is doubt as to whether this care is being properly performed or not.

## Implications for practice

Findings of present study can help authorities of the health system to establish more centers for offering PC service, because the researchers believe that receiving PC is the right of all patients with cancer throughout the world. The findings of this study could be a guide for medical practitioners in the field of PC in order to include this important concept in medical programs for the cancer patients.

## Ethical considerations

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