

## Priorities in Supportive Care Needs for Non-metastatic Cancer Patients Undergoing Chemotherapy in Iran: The Oncologists' Perceptions

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### Abstract

**Background:** Cancer patients undergoing chemotherapy have unmet needs. Oncologists play a central role in their supportive treatment. This study aims to describe Iranian oncologists' perceptions in terms of priorities in supportive care needs for non-metastatic cancer patients undergoing chemotherapy.

**Methods:** We conducted this study using a descriptive, exploratory qualitative approach with a purposive sampling method. Interviews were conducted from July to October 2016 with medical oncologists (mean age: 47.5 years) who had a mean work experience of 15.8 years. Data saturation was achieved with 15 participants. Interviews were semi-structured. Graneheim and Lundman's qualitative content analysis approach and MAXQDA software were used to analyze the data.

**Results:** There were two main categories obtained from data analysis: 1. continued comprehensive support in the disease continuum from diagnosis to rehabilitation (education and consultation, social and treatment support for patients, consideration of family support, addressing cultural conditions, psychological support, and financial support) and 2. Prerequisites in the preparation of the care system (the need for creating multidisciplinary teams, development and improvement of health care settings to provide services, and empowering the healthcare team to provide quality care).

**Conclusion:** Comprehensive care for these patients and integration of these supports are essential in routine care. Major needs which must be addressed more seriously in the Iranian care system include the need for continued comprehensive support in the disease continuum from diagnosis to rehabilitation and prerequisites in the preparation of the care system.

**Keywords:** Chemotherapy, Cancer patients, Oncologists, Supportive care

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## Introduction

Cancer is a main public health problem worldwide<sup>1</sup> and the third leading cause of death in Iran.<sup>2</sup> Given the increasing number of cancer patients, this disease challenges the health care system.<sup>3</sup> Currently, there are more than 15 million cancer survivors in the United States, and the total is expected to reach 20 million by 2026.<sup>4</sup> The surviving population is increasing daily.<sup>5</sup> Thus, the burden of cancer care is increasing universally.<sup>6</sup>

These data show the health challenges in life after cancer diagnosis and the importance of considering and addressing health conditions of cancer survivors.<sup>7</sup> Therefore, the increased life expectancy of cancer patients has made paying attention to the patient quality of life an important aspect of cancer management.<sup>8</sup> Surgery and chemotherapy are the preferred treatment for patients with non-metastatic cancer<sup>9</sup> and chemotherapy increases survival rates; however, few studies have addressed completion of adjuvant chemotherapy in patients with cancer. Studies show decreases in quality of life and survival rates of patients who do not undergo chemotherapy or complete this process.<sup>10</sup> Given the importance of adjuvant chemotherapy, assessment of the care needs of cancer patients is a critical step to provide high-quality care and obtain the satisfaction of patients and their families.<sup>11</sup> Cancer patients have unfulfilled needs<sup>12</sup> which prompt them to communicate with health care providers to meet their information and support needs. If these needs are met, their quality of life will increase. The physician-patient interaction has a critical importance in the process of cancer care, and oncologists play a unique role in the identification of patients' needs and planning to meet these needs.<sup>11, 13</sup> Oncologists should properly examine the symptoms and take actions to satisfy patients.<sup>14</sup>

Ghoshal et al. have reported that newly diagnosed cancer patients report more distressing symptoms; hence, oncologists do not pay enough attention to them. Therefore, increasing oncologists' sensitivity at the initial stages in terms of patient management can improve their comprehensive care.<sup>15</sup> Several studies have focused on aspects of care for these patients separately, including; investigating the

needs of patients and their families,<sup>11</sup> social support,<sup>16</sup> educational support,<sup>17</sup> financial management,<sup>18</sup> consideration of the cancer patients' culture,<sup>19,20</sup> and emotional support.<sup>21</sup> We noted three studies conducted in supportive care of cancer patients in Iran that assessed these needs by quantitative approach, closed questionnaires, and based on patients' views.<sup>22-24</sup> However, thus far, no study has been conducted with a comprehensive perspective. There is no information in different literature and sources that pertain to oncologists' perceptions of the care needs of cancer patients undergoing chemotherapy. On the other hand, attention to participants' perceptions is one of the features of a qualitative research.<sup>25</sup> Descriptive, exploratory qualitative studies directly describe the phenomenon and address an issue or problem which requires a solution.<sup>26,27</sup> We have chosen the qualitative approach for this study given the importance of chemotherapy patients' needs, cultural diversities in supportive care needs, the unique role of oncologists in their management, and the requisites of cancer care in Iran. This study aims to describe Iranian oncologists' perceptions in terms of priorities in supportive care needs for non-metastatic cancer patients undergoing chemotherapy.

## Materials and Methods

### *Research design*

We conducted this study by using a descriptive, exploratory qualitative approach. The purposive sampling method was used to select medical oncologists (mean age: 47.5 years) with a mean work experience of 15.8 years (Table 1). Inclusion criteria consisted of the desire to participate in the study, oncology specialization, and at least one year of work experience in this area. Exclusion criteria comprised not wanting to take part in the study, lack of work experience, or oncology residents.

### *Data collection*

In qualitative studies, sampling is usually performed on the basis of information needs until the point of saturation.<sup>28</sup> Here, we have collected the data in a quiet, peaceful environment with in-depth semi-structured interviews. In this study, conducted

with 15 participants and 20 interviews, we achieved data saturation when no new codes were achieved. The duration of each interview was approximately 40 min. Interviews were conducted from July to October 2016. Some open and general questions guided the researcher to collect the data. In this study, the main question was “What perception do you have regarding the care needs of patients with non-metastatic cancer undergoing chemotherapy?” Other questions were subsequently raised to attain more in-depth information.

### Data analysis

The analysis was performed simultaneously with data collection. We used Graneheim and Lundman’s qualitative content analysis for data analysis.<sup>29</sup> In this regard, at the end of each interview, the recorded remarks of each participant were repeatedly listened to, and we wrote verbatim comments. Each transcript was studied several times to understand the experiences and perceptions of the participants (SS and FT). Then, meaningful information and relevant remarks were underlined to determine meaningful units (SS and FT). Later, we summarized each meaningful unit into a condensed meaningful unit, and the initial codes emerged. SS carefully studied the initial codes and categorized them into subcategories based on the similarity of their concepts. During this inductive process, similar sub-categories were categorized in the main categories. This coding process and emergence of main categories were revised by a third researcher (PA) and discussed by SS and FT. Finally, we determined themes as explanations of the hidden content of the text. MAXQDA software was used to analyze the data.

### Trustworthiness

In this study, we used the four criteria of trustworthiness - credibility, confirmability, transferability, and dependability as suggested by Lincoln and Guba.<sup>28</sup>

In content analysis, the credibility of findings increased through peer review of transcripts, a review of the agreement between coding methods used by two persons, and validation of findings

**Table 1.** Participants’ characteristics.

No.	Age (years)	Sex	Years of Work experience
1	43	Female	15
2	36	Male	3
3	50	Male	23
4	60	Male	25
5	50	Male	20
6	52	Female	24
7	38	Male	4
8	46	Male	15
9	40	Female	6
10	54	Male	20
11	43	Male	16
12	32	Female	3
13	56	Male	20
14	55	Male	22
15	57	Male	21

via participants.<sup>26</sup> To improve credibility, extracted codes were referred to the participants. After their verification, we considered the findings to be valid (member-check method). In addition, the researcher referred findings and extracted codes to an expert in qualitative research who verified the validity of the research findings (peer-check method). Confirmability was obtained through bracketing (putting aside prior preconceptions), by careful reporting, recording different steps, and decisions were taken to provide the possibility of an audit trail by other researchers.

Data analysis was conducted by more than one researcher to ensure dependability of the findings. Finally, to ensure transferability, samples were provided from different places with various demographic characteristics.

### Ethical considerations

We collected the data after confirmation by the Vice-Chancellor in Research Affairs and Ethics Committee (code: 395651), the related hospitals, participant completion of the informed consent form, and oral verification of the participant. The participants were informed about the aims and the study method, which included permission for voice recording, their right to confidentiality of the information, anonymity, and their right to withdraw from the study.

**Table 2.** The coding process.

Categories	Subcategories 1	Subcategories 2
<b>Continued comprehensive support in disease continuum from diagnosis to rehabilitation</b>	Education and consultation	Helping in making informed decisions Helping in self-management of chemotherapy side effects Educating family caregivers
	Social and treatment support for patients	Support from families and friends Support by the healthcare team Establishment of support groups
	Consideration of family support	Reducing emotional stress of families Considering the care needs of families
	Addressing cultural conditions	Cultural change and trying to reduce cultural cancer-related stigma in the society Pay attention to the cultural stigma of cancer in the community
	Psychological support	Emotional support in coping with changes Providing psychological services to patients and families throughout the treatment trajectory
	Financial support	Economic support via healthcare policies Supports by charitable organizations and donors Comprehensive insurance coverage
<b>Pre-requisites in the preparation of the care system</b>	The need to create multidisciplinary teams	The need for other specialties alongside oncologists
	Development and improvement of health care settings to provide services	Preparing a desirable environment for patients Using well-mannered staff
	Empowering the healthcare team to provide quality care	Need for community/home care nursing  Need for skillful nursing staff Empowering oncologists in communication skills with patients and their families

### *Limitations of this study*

None of the oncologists explained sexual care for these patients, which necessitated a multidisciplinary team in caring for these patients. The oncologists did not consider spiritual care for these patients to be a priority, most likely because the Iranian community is predominantly an Islamic, religious society and the patients have spiritual care available.

### **Results**

A total of 15 oncologists participated in this study.

After data analysis, we determined 2 main categories: continued comprehensive support in disease continuum from diagnosis to rehabilitation and prerequisites in the preparation of the system (Table 2). Each category had a number of sub-categories.

### *Continued comprehensive support in disease continuum from diagnosis to rehabilitation* *Education and consultation*

This subcategory included three other sub-categories: “Helping in making informed decisions,”



"Helping in self-management of chemotherapy side effects," and "Educating family caregivers." In this study, participants noted the importance of education and providing needed information to the patients before, during, and after chemotherapy; help patients and their families make informed decisions and participate in the treatment trajectory; the effect of giving information to patients in reducing their anxiety and increasing treatment acceptance; and self-management of chemotherapy side effects, which would thus improve patients' quality of life.

*"In addition to verbal education to the patients about managing side effects of chemotherapy, I also designed a website for patients undergoing chemotherapy and their problems...."* No. 4.

Other issues raised in this sub-category included: patient's need to learn about a lifestyle consistent with chemotherapy, educating patients about specific complications of medications, warning patients about serious complications which would require medical intervention, and providing necessary trainings to patients and their families in various formats, such as launching a personal website to communicate with patients.

*"With the change of patients' lifestyles due to cancer and chemotherapy, I provide advice to them to improve their functional status, advice on nutrition, exercise, and..."* No. 10

According to oncologists' perceptions, support and education of family caregivers contribute to improving the quality of life of these patients and dealing with their stresses.

*"... Advice to families may be more extensive. Educating family caregivers to better support the patient is essential during the process of the disease."* No. 15.

### *Social and treatment support for the patient*

This subcategory included three other sub-categories: "Support from families and friends," "Support by the health-care team," and "The establishment of support groups."

*"I observed that those patients who receive adequate support from family, friends, and relatives will better accept the treatment process and its related issues ..."* No. 2.

*"Support provided by staff and identification of*

*patient needs by these people are crucially important ..."* No. 7.

Oncologists noted that support groups can interact with each other via virtual social networks and give patients a sense of hope by sharing experiences and coping strategies used by similar patients.

*"Launching sympathy groups and self-introducing cancer patients who have successfully lived several years after their diagnosis increases social support, gives hope to these patients, and improves treatment outcomes ..."* No. 6.

### *The consideration of family support*

This subcategory included two other sub-categories: "Reducing the emotional stress of families," and "Considering the care needs of families."

From the perceptions of oncologists, reducing mental stress of families and paying attention to their care needs is essential. Family members will experience a crisis considering the role of patients in the family. This crisis must be addressed.

*"These families are disturbed, distressed, and anxious... We must somehow calm them to avoid family harm..."* No. 8.

Other issues raised by oncologists included paying attention to the care needs of families with regard to the role of the patient in the family, preventing family devastation, and the importance of supporting and empowering families.

*"Family needs must be addressed because it is not a personal disease; rather it is a family disease and the family is alone!"* No. 11.

### *Addressing cultural conditions*

This subcategory included two other sub-categories: "Cultural change and trying to reduce cultural cancer-related stigma in the society" and "Pay attention to the cultural stigma of cancer in the community."

Oncologists have stated that it is necessary to conduct cultural programs in the society to accept cancer as a curable disease which is in need of care. Training on how to treat and communicate with patients, prevention of infections associated with chemotherapy-induced neutropenia, and other issues

must be planned by television and other popular media.

*"The mass media must promote the culture of accepting these patients and providing care for them by families and society." No. 10.*

Oncologists' attention to patient's fear of compassionate looks and respect for the patient's wishes in hiding the diagnosis from others, and taking into consideration the insistence of families in hiding the diagnosis from others or the patient himself are other issues raised in this sub-category.

*"It is important to consider the demands of patients in hiding their diagnosis from others and even from non-clinical staff, especially in small cities." No. 9.*

### *Psychological support*

This sub category included "Emotional support in coping with changes" and "Providing psychological services to patients and families throughout the treatment trajectory."

Oncologists stated that after diagnosis, changes in mental, nutritional, and lifestyle affect the patient. After surgery and chemotherapy, issues that include coping with new conditions, experiencing a surgery, changes in body image and its related stress, and physical and psychological complications are major issues which must be addressed.

*"In addition to changes in patients' lifestyle after diagnosis, the term 'cancer' itself imposes a stress to patients and they must adapt to the new conditions, and should be accompanied and supported...." No. 1.*

They also noted the importance of providing psychological care services to patients and families throughout the treatment. This sub-category involves the importance of the role of psychological consultation to motivate patients to begin treatment and the importance of meeting the psychological and health needs of patients before and during chemotherapy.

*"Patients and families must be supported emotionally throughout the course of the treatment ..." No. 14.*

### *Financial support*

This subcategory included three sub-categories:

"Economic support via healthcare policies," "Support by charitable organizations and donors," and "Comprehensive insurance coverage." In this regard, oncologists have noticed the high cost of cancer treatment, which required social workers and financial support for cancer patients during the treatment process, and the importance of a national health care reform plan such as the plan currently being implemented in Iran. One of its objectives is to reduce the cost of health care for poor people and those with incurable diseases. According to oncologists, the healthcare system reform plan has been very helpful in reducing the costs of treating these patients and in increasing insurance coverage. However, these patients still face many financial problems.

*"The healthcare reform plan has been a positive step in reducing the cost of treating these patients; however, we still see their financial difficulties." No. 6.*

Oncologists have referred to support by charitable organizations; however, they stated that their financial supports are not sufficient.

*"Charities and NGOs supporting these patients must be reinforced ..." No. 2.*

*"There are charitable people who offer some donations informally, but these donations are not sufficient." No. 10.*

The insurance coverage of chemotherapy drugs must be enhanced and consultation with insurance agencies must agree to provide additional support for these patients.

*"Negotiations must be arranged with insurance agencies to further support these patients..." No. 9.*

### *Pre-requisites in the preparation of the care system*

This subcategory included three other sub-categories: "The need to create multidisciplinary teams," "Development and improvement of health care settings to provide services," and "Empowering the health care team to provide quality care."

#### *The need to create multidisciplinary teams*

The oncologists stated the need to have other specialties alongside. They emphasized the necessity of coordination between health care team members, shared decision-making, and the need for an inter-

professional team to guide the patient through the treatment trajectory as well as the importance of access to a team to meet the needs of the patient.

*"A multidisciplinary team should be created to provide these patients with their care needs and to obtain better treatment outcomes," No. 7.*

#### *Development and improvement of health care settings to provide services*

Issues raised in this sub-category included the need for maintaining personal and environmental hygiene by the patient and his family during the course of chemotherapy, preparation of a desirable environment for patients, both in structural terms and in terms of personnel and facilities, well-mannered staff, the need for maintaining a patient privacy, and respect patients undergoing chemotherapy.

*"The setting must be relaxing; in terms of the shape and structure of buildings, the use of comfortable beds, behavior of the nurses and staff who work in different wards and..." No. 1.*

#### *Empowering the health care team to provide quality care*

The oncologists stated the need for community/home care nursing and skillful nursing staff, empowering oncologists in communication skills with patients and their families.

Other issues included creating the possibility of communication by patients with community health personnel after discharge, follow-up periodic laboratory tests during treatment, necessity of providing home care services, advising patients to call or visit a health center in case of problems, examining patients in terms of chemotherapy side effects, advising them to improve their physical and functional conditions, communicating with the relevant physician via telephone and the Internet, and removing their concerns and misunderstandings.

Empowering nurses in the IV line insertion procedure and taking care of patients under chemotherapy, understanding the sensitivity of accuracy in taking care of these patients, and the need to empower oncologists to have better communication with patients and their families are other issues mentioned in this subcategory.

*"Certified employees should be hired who are*

*competent in all aspects and issues related to these patients." No. 8.*

## **Discussion**

This study aimed to describe Iranian oncologists' perceptions in terms of priorities of care needs of non-metastatic cancer patients undergoing chemotherapy.

This study showed that education and consultation for cancer patients undergoing chemotherapy were essential due to the necessity for increased self-management capabilities of patients in controlling chemotherapy side effects, increasing their compliance with the disease, and increasing their adherence to the treatment. In addition, education empowers families to care for their patients. Other studies also confirmed that issues which included the provision of information, patient support, and empowering patients and their families to take better care of their diseases and self-management supports are essential for improving care and outcomes.<sup>30</sup> Educating patients on managing side effects and behavioral strategies can reduce their health-related discomfort. It will also increase adaptability, reduce anxiety, and promote self-care.<sup>31</sup> López-Gómez et al. have indicated that physicians must make sure that their patients receive reliable information online and help the patients to resolve misunderstandings that result from searches on the Internet.<sup>32</sup>

In this study, oncologists noted the need to provide social and treatment supports for these patients in the form of support groups and the importance of support by families, friends, and staff in addition to the consideration of family support. Khoshnazar et al. have shown that patients and caregivers often find ways to talk to people with similar experiences to help them better understand and accept symptoms, which they encounter during the course of the disease.<sup>33</sup> Virtual social support networks also provide a unique opportunity to the patients to compare their own conditions with their counterparts and enable them to enhance their hope, perception, and understanding through comparing their conditions with others.<sup>34</sup> This study has emphasized the importance of support provided by

family caregivers, which is consistent with other studies. Family members, friends, and health care providers play important roles in supporting newly diagnosed cancer patients undergoing chemotherapy, and this encourages patients to cope with their disease and its treatment.<sup>35, 36</sup>

The need for support of families was expressed by participants, with regards to the susceptibility of families and prioritizing their needs. In addition, Steinwedel has indicated that caregiving is a long-term activity; patients and family caregivers are influenced by inherent challenges of cancer and its treatment.<sup>37</sup> Therefore, it is necessary to consider the needs of family caregivers in the treatment planning process.

The results of this study have shown that it is necessary to address cultural conditions for these patients in areas that include cultural change, attempts to reduce cultural cancer-related stigma in the society, and taking into consideration cancer-related stigma of cancer. Findings of other studies have also confirmed that cancer-related superstitions and stigmas are significant challenges in cancer control. Daher reported that cancer-related cultural stigma could be a tremendous challenge for adherence of patients to treatment, which should be addressed.<sup>19</sup>

The results of this study also emphasized the necessity of psychological support for patients. Results of other studies also indicated the importance of this issue; psychological factors have been reported as major determinants that specify supportive care needs of cancer patients.<sup>38</sup> Regardless of diagnosis and management of physical complications of cancer and its treatment, comprehensive care should address psychological and psychosocial needs of cancer patients.<sup>15</sup>

Financial support, another category in this study, included three sub-categories of “Economic support via healthcare policies,” “Support by charitable organizations and donors”, and “Comprehensive insurance coverage.” Participants noted the positive impact of the health care reform plan on reducing treatment costs. A study by Salarvand et al. showed that one of the objectives of the well-received healthcare reform plan in Iran was the reduction in

out of pocket payments by patients, which increased patient satisfaction<sup>39</sup> and has been considered a financial support by healthcare policy makers. Other studies have also addressed policies by the government for financial support of these patients.<sup>40</sup> In terms of comprehensive insurance coverage, Khoshnazar et al. reported that most patients believed that health insurance coverage was inadequate and did not meet their needs in Iran.<sup>41</sup>

Participants have noted financial support by charitable organizations and donors. The role of charitable organizations and public donations is undeniable in patient support and reducing the financial burden of treatment. Although we have found no study on financial support of charitable organizations and donors for cancer patients, other studies referred to donations by charities worldwide.<sup>42-45</sup>

Participants pointed to pre-requisites in the preparation of the care system, which included the subcategories: “The need to create multidisciplinary teams,” “Development and improvement of health care settings to provide services,” and “Empowering the health care team to provide quality care.”

Regarding the need for multidisciplinary care teams, other studies have shown that a multidisciplinary team is essential to provide patients with high-quality care.<sup>46</sup> Multidisciplinary care is the best practice in the area of health care planning. Evidence suggests that in terms of cancer care, a team approach can increase survival rates and patient quality of life.<sup>47</sup> However, there is no such approach in Iran’s health care structure.

Oncologists noted the need for development and improvement of the physical environment of health care settings to provide services to patients undergoing chemotherapy. Medical centers must pay special attention to the quality of care settings. We did not find any study that addressed this issue.

The need to empower the health care team to provide quality care was another finding of this study. Stewart et al. showed that by empowering nurses, they would realize the value of their work and the meaning of their tasks.<sup>48</sup> Community/home care nursing does not have a formal role in Iran. In addition, nurses employed in oncology wards



have not passed any academic oncology courses, which present some challenges for the care system.

Zheng indicated that telephone follow-ups meet the need of patients for information and facilitate their coping with the disease. In addition, after a hospital discharge, patients will still have unmet needs which must be addressed.<sup>49</sup>

The importance and necessity of empowering employees such as oncologists and nurses in skillful cancer care has been approved in several studies.<sup>50-52</sup>

## Conclusion

Identification of multidisciplinary supportive care needs of non-metastatic cancer patients undergoing chemotherapy contributes to better planning and determining the treatment trajectory. Holistic care of patients and integration of these supports is important in routine care. Major needs which must be addressed more seriously in the Iranian care system include continued comprehensive support in disease continuum from diagnosis to rehabilitation, prerequisites in the preparation of the care system, lack of a Comprehensive Cancer Center, and other approaches used to continue provision of care services in Iran.

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## Conflict of Interest

No conflict of interest is declared.

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