

Iranian Cancer Patients Perceptions of Barriers to Participation in Decision-Making: Potential Impact on Patient-Centered Care

Naism Aminaie¹, Jila Mirlashari^{2,3}, Rebecca H. Lehto⁴, Marzieh Lashkari⁵, Reza Negarandeh⁶

¹Department of Medical Surgical Nursing, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran; ²Department of Pediatric and Neonatal Intensive Care Nursing, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran; ³Obstetric and Gynecology Department, University of British Columbia, Canada; ⁴College of Nursing, Michigan State University, East Lansing, MI, USA; ⁵Radiation Oncology Research Center, Cancer Institute, Tehran University of Medical Science, Tehran, Iran; ⁶Nursing and Midwifery Care Research Center, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran



Corresponding author: Reza Negarandeh, PhD

School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

Tel: +98 (21) 66421685; Fax: +98 (21) 66421685

E-mail: rnegarandeh@tums.ac.ir

Received: January 07, 2019, Accepted: March 14, 2019

ABSTRACT

Objective: The purpose of this study was to explore perceptions about barriers to decision-making in Iranian patients with cancer about their care. **Methods:** Utilizing a qualitative approach, semi-structured interviews were conducted with 15 cancer patients. **Results:** Data analysis revealed four central categories reflecting patient perceptions about barriers that included medical dominance (uninformed decision-making, perceived inability to disagree secondary to despair, and patient objectification), healthcare system mistrust (physician, nurse, and medical center facility and equipment), healthcare system characteristics (services and facilities' limitations, poor communication, healthcare setting compulsion), and cultural barriers

(feeling unfamiliar, insecurity in an unfamiliar environment, language barriers, limited attention to religious beliefs). **Conclusions:** Barriers may impact the perceived ability of Iranian patients' with cancer ability to participate in decision-making regarding their care. Such barriers contain the potential to disrupt patient-centered care. Perceptions about barriers articulated by patients are modifiable. While some Iranian healthcare systems may have problematic challenges, targeted allocation of resources and education of healthcare providers convey strong possibilities to enhance patient-centered care.

Key words: Cancer, decision-making, healthcare providers, patient care, patient-centered care, qualitative methods

Access this article online

Quick Response Code:



Website: www.apjon.org

DOI:
10.4103/apjon.apjon_11_19

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: reprints@medknow.com

Cite this article as: Aminaie N, Mirlashari J, Lehto RH, Lashkari M, Negarandeh R. Iranian Cancer Patients Perceptions of Barriers to Participation in Decision-Making: Potential Impact on Patient-Centered Care. *Asia Pac J Oncol Nurs* 2019;6:372-80.

Introduction

In general, cancers are recognized as chronic conditions that have a sustained impact on the physical, mental, and social well-being of patients over the course of the survivorship trajectory.^[1] Internationally, improved cancer care delivery has been achieved through a revision in approach that moves the patient to the center of care, a practice that has been adopted in many healthcare systems globally.^[1] Patient-centered care has resulted in better service integration of health services responsive to consumer needs and preferences while providing adequate informational support to ensure that patients are able to understand and make informed decisions about care.^[2] A patient-centered focus impacts patient's general well-being by empowering and expanding their personal role in determining their health care^[3,4] while moving a traditional top-down culture to one where there is mutual collaboration among all health team members.^[5]

Ensuring patient involvement in personal care plan decision-making is one of the key elements in patient-centered cancer management.^[6-8] In this regard, when all members of the oncology team concentrate on individualizing care to each patient, it necessarily requires the involvement of the patient in decision-making. Further, increasing the patient's participation and responsibility for their health care can improve adherence to treatment and reduce errors and untoward economic expenditures.^[9] Personal involvement in the decision-making process can enhance patient satisfaction, while improving their understanding of the selected treatment direction amidst potential alternative directions and inspiring confidence in professional providers.^[10]

Patients with advanced cancer have shown preferences toward open and honest communication regarding their prognosis and treatment-related information including factors such as economic costs.^[11] Studies suggest that patients desire to participate in personal treatment decisions.^[11,12] Many factors such as uncertainty about the long-term effects of cancer treatment, number and types of potentially relevant therapeutic choices, life expectancy, and maintenance of quality of life have increased the challenges for patients with cancer to engage in informed decision-making.^[13,14] Such complexities heighten anxiety, increase perceptions of doubt, and reduce hope in patients with cancer. However, the coordinated impact of an interdisciplinary team of health professionals may serve to allay any potential negative psychological impact of increased involvement in personal care options.^[14]

Findings from a comprehensive literature review suggested that decisions by elderly patients, the highest user of cancer-related services, regarding medical treatment acceptance or rejection were mostly affected by physician's recommendations, trust in their provider, expectations

of treatment side effects, and their previous therapeutic experiences with anticancer regimens.^[15] On the other hand, the level of patients' and their family's participation in the process of decision-making will depend on personal styles of family decision-making, potentially complicating cultural factors and existence of emotional support.^[7,16]

The process of patient decision-making in care planning could be significantly impacted by contextual factors including cultural issues that affect this process.^[17] Importantly, cultural differences globally contribute to variations in patient involvement in treatment decision-making patterns particularly when comparing western countries with nonwestern countries.^[18] For example, findings from an ethnographic study conducted in the country of Iran show that patients mostly have passive reactions to the decision-making that is made in regard to their treatment process. Other researchers have identified that passivity may reflect a power differential between patients and their care providers with the result that the patient's culture and values may be neglected in treatment decision-making.^[19] While studies have been conducted regarding decision-making by cancer patients, limited research has descriptively evaluated factors for how the decision-making has been conducted in nonwestern countries. Most importantly, there are limited studies in Iran that have been conducted to determine perceptions about barriers to decision-making by cancer patients.

The understanding of perceived barriers which hinder Iranian patients' engagement in decision-making could assist nurses and other health team members to better support the autonomy of the patients and their families.^[20] Recognizing such barriers from the patients' perspective can potentially lead to improved treatment outcomes and promote patients' treatment adherence.^[21] Further, identifying common understanding of patients' perspectives may improve nurses' capacity to assist in supporting patients to contribute to treatment decisions regarding their health while also serving in patient advocacy roles.^[22] The finding from this study can provide guidance to cancer nurses to understand oncology patients' which affect their decisions.

Healthcare decision-making occurs in a natural setting but represents a complex process that involves a variety of factors stemming from both the context and the imbedded culture in which it occurs. Thus, a qualitative approach would be a useful method for gaining a better understanding of the patient perspective regarding decision-making in the context of cancer treatment directions.

Therefore, the study purpose was to explore Iranian patients with cancer perceptions regarding their perspectives of participation in treatment decision-making.

Methods

Setting and participants

A qualitative methodology incorporating content analysis was used to meet the study aims. The primary participants included cancer patients referred to the chemotherapy and radiotherapy outpatient clinic and/or hospital departments from one of the cancer institutes of Tehran.

Inclusion criteria for the participants were being at least 18 years of age, having a confirmed diagnosis of advanced cancer, being able to understand and speak Persian, and possessing the cognitive capacity to participate in the study with willingness to describe their personal experiences. Purposive sampling to ensure variation regarding age, sex, background factors, and duration of illness were used in the patient selection process. After explaining the goals of the study, potential volunteers were invited to participate. Consenting volunteers were then interviewed in a private clinic room away from distractions and other people.

Ethical approval

The study protocol was approved by the ethics committee of Tehran University of Medical Sciences (code IR.TUMS.VCR.REC.1395-485). The aims and the study methods were comprehensively explained to potential participants before elicitation of informed signed consent. Participants were assured that their health record information and recorded interviews would remain confidential and anonymous. Participating in the study was completely voluntary, and the participants recognized that they had the right to withdraw at any time.

Data collection

The interviews occurred between mid-2016 and end of 2017. A demographic and health characteristics' questionnaire was used to glean individualized background information. The primary method used for data collection incorporated individualized in-depth and semi-structured interviews with adherence to a standardized interview guide. The interview guide contained open-ended questions that related to perceived potential barriers of patient participation in their treatment decision-making [Table 1]. After the main open-ended questions, probes were used to elicit further responses as needed. An additional question at the end of each interview addressed whether or not any information was missed.

All interviews were completed in a private clinic room in the oncology clinic. Given the compromised health status of the participants, the researcher emphasized keeping the interviews as brief as possible to avoid participant fatigue. Interviews were discontinued at the participants' request for any perceived reason and additional interviews scheduled

Table 1: Interview guide

Patients	Initial questions
	What were your concerns when you were asked to make a treatment decision regarding your health problem?
	What factors have influenced your treatment decision-making?
	How would you become interested in participating in decision-making about your care planning?
	What barriers did you face that impacted your ability to make decisions regarding your healthcare planning?
	Questions based on primary extracted categories
	Did you have enough information to make your decision? If no, what additional information did you need? What suggestions do you have to improve provision of adequate information?
	Who did you share your thoughts about your decision with?
	Did you want to participate in decision-making about your healthcare treatment?
	What assistance did you seek (for example, nurse, physician, another patient, family member, or a friend) in making your decision?
	Did you ever consider that the physician should have made the decision for you? Why or why not?
	While you were making decisions about your treatment, what role or level of involvement did the nurse serve to assist you?
	What personal factors that influenced your decision?

if needed as per the participants' choice. Accordingly, only one follow-up interview was conducted (participant 14) through telephone. This interview followed the same protocol as the semi-structured face-to-face encounters. The duration of the interviews ranged from 15 to 77 min with an average of 36 min. Recorded interviews were reviewed and transcribed verbatim.

Statistical analysis

Inductive content analysis was used in this study to analyze the experiences of participants. Content analysis was incorporated as a systematic method that allows the researchers to explore theoretical applications to enhance understanding the data. Analysis process includes open coding, creating categories, and abstraction.^[23] For obtaining open coding, the recordings were transcribed verbatim and then were reviewed line by line and a coding scheme was developed to determine the relevant concepts. Next, the derived codes were compared for similarities and differences independently by two nursing researchers. Similar codes were then placed into the same categories and merged to group subcategories as appropriate.^[24] Interview data were analyzed before conducting the next interviews to ensure awareness of data saturation thresholds. Descriptive statistics was used to evaluate the demographic and medical characteristics of the sample.

Trustworthiness

Trustworthiness was verified through the credibility, transferability, dependability, and confirmability criteria,

based on Lincoln and Guba's documented approach.^[25] To ensure credibility, the researchers spent a prolonged period of time with the participants. In line with the prescribed approach, a member check was used. In addition, the study findings were discussed with two of the participants to determine whether the researchers' interpretations reflected their perceptions accurately. The representativeness of participants for this follow-up is a key factor in gaining a better sense of the transferability of data. Therefore, the maximum variation strategy was used for selecting the two participants. Further, to ensure comprehensive analysis of transferability, the researchers provided enhanced background information on the selected patients and the research context. Dependability was achieved by the following methods: (1) The interviews were conducted using a standardized interview guide; (2) all interviews were audiotaped and transcribed by the same consistently trained transcriptionist; and (3) the study processes were recorded through field notes by a research investigator to improve an audit trail for evaluating and replicating results. The audit strategy can also be used to evaluate confirmability. This strategy involved a designated researcher who followed the project and evaluated how and why decisions were made in terms of both conduct and analysis of study findings.

Results

Most participants were male with an average age of 54.6 years. Demographic and health characteristics associated with the cancer diagnosis (type, duration of

illness, and treatment) of the study participants are shown in Table 2. Data analysis revealed four content categories that were labeled: (1) medical dominance, (2) mistrust of the healthcare system, (3) characteristics of the healthcare system, and (4) cultural barriers, which were identified as perceived barriers to decision-making regarding the type and process of how their care was delivered [Table 3].

Medical dominance

This category referred to factors associated with physician dominance in regard to medical decision-making. Subcategories included "uninformed decision-making," "perceived inability to disagree," "despair," and "perceived objectification for secondary gain."

Uninformed decision-making

Informed decisions about medical care require sufficient information. A lack of comprehensive information about care was perceived to occur when limited perceived effort on the part of the provider was expended toward providing sufficient explanations. In this regard, some patients who complied with treatment appeared unaware of why or how treatment decisions were made. Medical decisions that were made with limited awareness of potential outcomes were reported by patients with less education despite the presence of signed consent forms required by the hospital before performing all treatment procedures. For example:

"The physician said you should have a surgery. We did not know that this would happen after surgery (points to the asymmetric facial muscles). The physician said nothing about this". (P, 5)

Table 2: Characteristics of patient informants

	Gender	Age (years)	Marital status	Education	Employment status	Type of cancer	Duration of illness	Treatment
1	Female	64	Married	None	Homemaker	Esophageal	5 years	Surgery, chemotherapy, radiation
2	Female	72	Widowed	None	Homemaker	Laryngeal	7 months	Surgery
3	Male	59	Married	High school diploma	Manual worker	Skin	8 years	Surgery, chemotherapy, radiation
4	Male	59	Married	University graduate	Retired	Esophageal	2 years	Surgery, chemotherapy, radiation
5	Male	53	Married	University graduate	Employed	Parotid	5 years	Surgery
6	Male	58	Married	Less than high school	Farmer	Skin	12 years	Surgery
7	Male	52	Married	University graduate	Manual worker	thyroid	4 months	Surgery
8	Male	58	Widowed	Less than high school	Farmer	Cardiothoracic	5 months	Surgery, chemotherapy, radiation
9	Male	57	Married	University graduate	Employed	Stomach	8 months	Surgery, chemotherapy
10	Female	56	Married	High school diploma	Homemaker	Breast	11 months	Surgery, chemotherapy, radiation
11	Female	50	Single	University graduate	Employed	Breast	2 years	Surgery
12	Male	53	Married	University graduate	Employed	Colon	1 year	Surgery, chemotherapy, radiation
13	Female	43	Divorced	Diploma	Employed	Breast	2 years	Surgery, chemotherapy, radiation
14	Female	46	Married	Diploma	Homemaker	Breast	10 months	Surgery, chemotherapy, radiation
15	Male	39	Married	University graduate	Employed	Salivary glands	1 year	Surgery

Table 3: Perceived barriers of patients with cancer participation in treatment decision-making

	Content category	Sub-category
Obstacle against patient-centered care	Medical dominance	Uninformed decision-making
		Inability to disagree with the physician's decision
		Making decisions because of despair
	Mistrust of the healthcare system	Perceived objectification of the patient for secondary gain
		Physician mistrust
		Nurse mistrust
	Characteristics of the healthcare system	Medical center facility and equipment mistrust
		Limitation in services and facilities
		Poor communication
		Healthcare setting compulsion
	Cultural factors	Feeling unfamiliar
		Insecurity in an unfamiliar environment
		Difficulty in communications due to language barriers
		Ignoring religious beliefs
		Inability in information seeking in an unfamiliar environment

"The physician said ... we can take the biopsy without anesthesia. It took about three and a half hours and it was very distressing. Such as I was sitting when they used a scalpel to cut my head. I was really scared." (P, 6)

Perceived inability to disagree with the physician's decisions

Patients described an inability to disagree with their physician's decision-making that could likely be interpreted from a cultural perspective. For example, due to the physician's prestigious reputation in Iranian society from the patients' perspective, they may be hesitant to interfere and/or try to participate in decision-making about their care. Such views are based on medical hegemony in Iranian society. For example:

"The physician had told me that there were only two tumors at the three o'clock and twelve o'clock positions and we would only remove them. But on the day of surgery, when the doctor saw the new ultrasound results, 'x' said that the tumors have grown bigger ... so it is better to remove entire breast. I did not like this decision but I was shy to ask anything. I felt ashamed and asked no questions. I thought that I would waste 'x's' time. Well 'x' is a doctor after all and I could not disagree with 'x'. I even thought that if I say no, 'x' would not even visit me the next time. I was scared." (P, 13)

Another patient described a situation where they underwent a medical procedure deemed necessary from the physician's point of view. The patient felt reluctant but signed the informed consent anyway.

"I said I do not want another surgery. If it is going to grow again why should I do it? But they said that the physician has decided on the surgery. They even got my consent." (P, 15)

Making decisions because of despair

Study participants described situations where they felt pressured and/or were not offered alternatives due to personal despair and fears about disease progression and limited time. Patients would thus accept the treatment that was offered by the physician and the healthcare team. Many participants perceived that once they acquired a physician and had started their anticancer treatments, they did not have control over the decision unless they decided to withdraw from treatment.

"Even I do not know how I agreed to treatment... When the doctor says that you should have surgery, who am I to say no? Well they would send me back home. This (tumor) would grow bigger and bigger then; it would get worse." (P, 12)

Perceived objectification for secondary gain

Some participants described a perceived existence of a culture whereby patients were viewed for material gain depending on the type of hospital system. For example, participants identified that in teaching hospitals, patients are utilized in the education of medical students and for testing new treatment methods. On the other hand, in private hospitals, patients when they utilize healthcare resources generate revenue for the system. Instead of facilitating a patient-centered focus, patients perceived that they were implicitly marginalized based on predetermined criteria that serve the needs of the medical centers that perform specific services. For example, one patient described a teaching hospital experience as follows:

"...I told the physician that I want you to perform the surgery because you are the professor, but I was told that the resident is a fresh surgeon and knows modern methods. So the resident performed the surgery and as I thought, because the entire site was not evacuated, the masses grew again.... Later I was told that this is an educational hospital and residents should learn something too." (P, 15)

Another patient stated:

"I went to visit a highly educated specialist. I paid a lot of money for the office visit and then I was told that they needed to perform an endoscopy and that a biopsy should be taken. I was hospitalized in a private hospital for the biopsy where I had to pay many providers for no apparent reason...." (P, 9)

Mistrust of the healthcare system

Participants expressed that mistrust of the health system impacted their participation in decision-making. Such mistrust emanated from mismatches in scheduling, lack of clarity and transparency in provision of services, unclear communication of the implication of procedure results, lack of information about their medical and nursing providers, and overall

mismangement such as nonfunctioning equipment. Mistrust of the healthcare system is divided into the subcategories of physician, nurse, and facility/equipment mistrust.

Physician mistrust

Some participants described instances of physician behavior that resulted in mistrust. These included perceived inattentiveness or dismissiveness regarding the patients and their family's problems, misguided interpretation of a medical condition, and dissatisfaction with treatment for specific medical conditions. For example:

"I was hurt by an ... physician. I took my last mammography but he/she paid no attention to it. A few months later, I visited an ultrasound specialist and he/she told me that you had the same mass in your breast before. Why haven't you done anything about it yet? I said that nobody has told me anything. I trusted in the health system but after that, I have been changed." (P, 11)

Nurse mistrust

Participants reported distrust of the nurses as a result of shortcomings in provision of professional care, lack of scientific knowledge relative to health conditions, and lack of support. In these cases, the patient was doubtful about the accuracy and relevance of information that was provided which could affect their decision-making. Examples of these comments include:

"The nurses would not explain things thoroughly; they would not even answer when you asked a question." (P, 5)

"The nurses answered my questions but I didn't know whether they were aware of the problems or not. Not everybody recognizes my symptoms. Even when I asked the nurses, I was not sure whether their answers were accurate." (p, 11)

Facility and equipment mistrust

Participants also described having distrust relative to the equipment and facilities at the medical center where they received primary care. They identified that the administrative systems were unclear with lack of follow through with scheduling and even errors that resulted in wasted time. For example:

"I called last month to make an appointment for surgery. They said that they would call with my appointment time before surgery. How would I know when my surgery is? I think that this is a public hospital, so they do not care about the time of the procedures." (P, 8)

A few participants expressed distrust relative to the use of outdated and worn equipment and facilities in public healthcare facilities. For example:

"My physician told me to go there [public hospital] for radiotherapy. I told 'x' that the devices are out of order, they do not function properly. Even if they work, they cannot be trusted. That's why I went to a private hospital; their devices are newer and cleaner." (P, 10)

Characteristics of the healthcare system

Characteristics of the health system were identified as contributing factors in the disruption of patient-centered care. These characteristics included the subcategories of limitation in services and facilities, poor communication, and healthcare setting compulsion.

Limitations in services and facilities

Health system factors that disrupted the patients' autonomy in decision-making participation included imposed limitations on the availability of service and facilities as well as access to alternative choices. Given the lack of choices because of service availability, patients could be put in a situation where their treatment would be inevitably delayed. Participants complained about the large numbers of patients needing treatment resulting in long wait times, the closing of medical centers during holidays, lack of access, and unbalanced allocation of equipment and facilities.

"They said that they would call me about the time of the surgery but we didn't hear from them. I called again and again but they did not give an appointment. Then I came to Tehran and stayed there until I was hospitalized." (P, 5)

"As long as the mass is small, there is no time for surgery. A couple of months later when it is time for your appointment, they say that you have come too late." (P, 3)

Poor communication

Participants also described not receiving clear information to inform a basis for their decision-making process and a perceived lack of professional accountability.

"No one has clearly explained what the problem is. I have been hospitalized for a few days and ... I have no idea at what stage I am at this time and what should be done." (P, 5)

Healthcare setting compulsion

Some patients perceived that there was compulsion from the healthcare setting. Such perceptions complicated their ability to decipher what was going on and fostered emotional distress and ambivalence about care decisions. For example, one participant stated:

"I was really upset; sometimes I would not be treated respectfully. We are honorable people; they cannot treat us like that. We do not want pity. We need attention. I was a person with no family or financial problems, but I really suffered." (P, 11)

Cultural barriers

Participants elaborated on cultural barriers that negatively impacted care stemming from ethnic and religious differences. Many participants had concerns about receiving care in environments that felt unfamiliar, difficulties in communication due to language barriers, health providers who ignored personal religious beliefs,

and lack of ability to seek out information in an unfamiliar healthcare environment; issues that would restrict access to information necessary for making an informed decision. Patient-centered care was perceived as compromised due to lack of knowledge and/or consideration of individualized differences secondary to ethnic and religious background of patients from nondominant cultural orientations.

"The doctors are really good here but I would have preferred ... my own town. At least there, everybody would understand you and pays attention to you. But here, if anything happens, we do not know the physicians and nobody knows us either." (P, 3)

"We are unfamiliar in Tehran. Here is not like our own town where everyone knows each other and explains everything to answer your questions. If in our hometown, about 80% of the nurses would answer patients' questions, but here only about 5% of them would answer your questions." (P, 5)

"The physician had not told me that we should not have intercourse during chemotherapy. After I fell into trouble he blamed me, I was embarrassed. I always go to the hospital with my daughter and I feel shy to ask the doctor these questions when she is with me; the physician should explain these things but he doesn't." (P, 14)

"I do not know Farsi very well. Before the surgery they told me something, but I did not understand. I thought that they would take a piece (part of breast)... But when I came out of the operating room I was really sad. I still do not know what is going to happen." (F, 7)

Discussion

The study evaluated perceived barriers of Iranian patients with cancer that could potentially reduce participation in decision-making about their care. Such perceptions about barriers to decision-making include factors such as medical dominance, mistrust of the health system, health system characteristics, and cultural barriers that also carry potential to disrupt patient-centered care.

When the medical establishment is viewed as the primary decision-making entity in healthcare systems, important interpersonal dialogue relative to the patient's psychological concerns about the treatment impact, necessary self-management, and essential communication about alternative options may be missed.^[25] In this study, despite the derivation of signed informed consent, a number of patients did not appear to know what to expect following treatment, a finding that is consistent with other studies.^[26,27] Empowering the health team to develop skills in establishing therapeutic communications with both the patient and their family members could potentially improve such dynamics with communicating treatment needs.^[28] Patients also may lack a sense that they can disagree with the physician's decisions about their care.^[29] Other research has identified paternalistic perspectives that underlie medical care models contribute to the perception that "Doctor's know best."^[30]

While physicians may indeed possess the best knowledge relative to moving forward with treatment strategies, such a stance may also serve as a barrier to patient's participation in decision-making.^[28-30]

Some participants in this study expressed health system mistrust that included the factors associated with the healthcare system, the physicians, and the nurses. Such mistrust in the health system can erode patients' perceptions of security in the care that they are receiving. Given a diagnosis of cancer, a disease that evokes fears of death, it is essential that patients feel safe and secure in the hands of a capable healthcare team that has the patients' best interests in mind. Characteristics of the health system such as lack of availability of services and facilities and poor communication including untimely responsiveness impacted patients' perceptions negatively. Such problems have been observed as the healthcare systems' struggle to respond to the needs of growing populations in developing countries.^[31-33] Economic and political factors may contribute to insufficient public health system resources, gaps in allocation of needed resources to various health programs, poor quality of the services, and a lack of access to appropriate and timely care.^[31] Challenges secondary to a limited supply and inequalities in geographic distribution of specialists to vulnerable regions and reduced availability of higher level services and facilities also limit physicians' ability to discuss potential options with patients. If a service or treatment option is simply not feasibly available, it is not likely that such options would be discussed with patients. Importantly, there are time management issues for both physicians and nurses who juggle large patient care loads. Such barriers reduce the possibility for providing patient-centered care, increase the potential for patient depersonalization, and reduce effective communication of essential information that could guide patient choices in clinical decision-making.^[34] Adequate communication of relative treatment options requires patience and time, especially in the context of very ill patients who may be experiencing emotional distress.

There were also perceived barriers described that emanate from the cultural paradigm. Cultural barriers secondary to ethnic, religious, and linguistic differences were reported by participants. Research in other countries has also revealed that cultural factors can deter informed decision-making and quality of care. For example, in the United States, women with breast cancer with limited understanding of the English language identified facing problems in establishing therapeutic communication with the physicians and less access to services.^[35] Muslim women who are referred to the health centers in North America have also reported that healthcare providers may lack understanding of religious

and cultural needs.^[36] Such barriers along with problems caused by language deficits may affect patient-centered care.^[36] Study findings from one participant suggested that language deficits potentially by impacting their access to useful information contributed to barriers to shared clinical decision-making and hence perceptions of regret, results that are consistent with findings from international studies.^[37,38] By accepting and considering individualized cultural differences, healthcare providers can improve patients' participation in informed decision-making. Translators may also help resolve communication problems and assist with recognition of special cultural needs to improve delivery of patient-centered care.^[39]

Limitations

The results of this study are limited given the exploratory qualitative nature of the study design. The aim of the research is to generate increased awareness patients' perceptions and of experiences in Iran relative to their treatment engagement. A limitation is that the focus was on perceived barriers; so, there is no information about positive perceptions that could potentially balance the viewpoints expressed in the study. Further, the study is also limited by a small convenience sample of patients who had different types of cancer and heterogeneous background. Research is needed that evaluates antecedents associated with the patient populations, as well as evaluation of strategies to increase patient involvement in decision-making among patients with cancer in the country of Iran. Research that captures patient's perspectives across the survivorship trajectory is needed.

Conclusion

Perceived barriers were identified relative to ensuring the participation of Iranian patients with cancer in the decision-making process regarding their cancer care. Such findings including problems relating to medical dominance, mistrust, healthcare system impedances, and cultural barriers are modifiable factors. Many problems that impact patient-centered care are rooted in the economic and political situation faced by countries whereby the care is delivered. Understanding perceptions about barriers to be able to participate in decision-making from the patients' perspectives is essential as nurses support and advocate to empower patients to optimize their ability to participate fully in their proposed care. Clear information and tailored education, respect for multicultural values and patient needs, and the provision of emotional support are strategies to improve patient-centered care delivery.^[40] Further research is needed to evaluate factors associated with improving delivery of patient-centered care and enhancing patients' capacity to participate in decision-making in Iran.

Financial support and sponsorship

This work was supported by a grant from Tehran University of Medical Science and Health Services (Grant No. IR.TUMS.VCR.REC.1395-485).

Conflicts of interest

There are no conflicts of interest.

References

- Ouwens M, Hermens R, Hulscher M, Vonk-Okhuijsen S, Tjan-Heijnen V, Termeer R, *et al.* Development of indicators for patient-centred cancer care. *Support Care Cancer* 2010;18:121-30.
- Zucca A, Sanson-Fisher R, Waller A, Carey M. Patient-centred care: Making cancer treatment centres accountable. *Support Care Cancer* 2014;22:1989-97.
- Pelzang R. Time to learn: Understanding patient-centred care. *Br J Nurs* 2010;19:912-7.
- Allgar VL, Neal RD. Delays in the diagnosis of six cancers: Analysis of data from the national survey of NHS patients: *Cancer*. *Br J Cancer* 2005;92:1959-70.
- Hubbard G, Kidd L, Donaghy E. Preferences for involvement in treatment decision making of patients with cancer: A review of the literature. *Eur J Oncol Nurs* 2008;12:299-318.
- Kane HL, Halpern MT, Squiers LB, Treiman KA, McCormack LA. Implementing and evaluating shared decision making in oncology practice. *CA Cancer J Clin* 2014;64:377-88.
- Leon-Carlyle M, Spiegle G, Schmocker S, Gagliardi A, Urbach D, Kennedy E. Using patient and physician perspectives to develop a shared decision-making framework for colorectal cancer. *Implement Sci* 2009;4:81.
- Goggins KM, Wallston KA, Nwosu S, Schildcrout JS, Castel L, Kripalani S. Health literacy, numeracy, and other characteristics associated with hospitalized patients' preferences for involvement in decision making. *J Health Commun* 2014;19 Suppl 2:29-43.
- Garchinski CM, DiBiase AM, Wong RK, Sagar SM. Patient-centered care in cancer treatment programs: The future of integrative oncology through psychoeducation. *Future Oncol* 2014;10:2603-14.
- Stacey D, Samant R, Bennett C. Decision making in oncology: A review of patient decision aids to support patient participation. *CA Cancer J Clin* 2008;58:293-304.
- Hoerger M, Epstein RM, Winters PC, Fiscella K, Duberstein PR, Gramling R. Values and options in cancer care (VOICE): Study design and rationale for a patient-centered communication and decision-making intervention for physicians, patients with advanced cancer, and their caregivers. *BMC Cancer* 2013;13:188.
- Davison BJ, Breckon EN. Impact of health information-seeking behavior and personal factors on preferred role in treatment decision making in men with newly diagnosed prostate cancer. *Cancer Nurs* 2012;35:411-8.
- Tariman JD, Berry DL, Cochrane B, Doorenbos A, Schepp K. Preferred and actual participation roles during health care decision making in persons with cancer: A systematic review. *Ann Oncol* 2010;21:1145-51.
- Martin MY, Fouad MN, Oster RA, Schrag D, Urmie J, Sanders S. What do cancer patients worry about when making decisions about treatment? Variation across racial/ethnic groups. *Support Care Cancer* 2014;22:233-44.

15. Puts MT, Tapscott B, Fitch M, Howell D, Monette J, Wan-Chow-Wah D. A systematic review of factors influencing older adults' decision to accept or decline cancer treatment. *Cancer Treat Rev* 2015;41:197-215.
16. Michael N, O'Callaghan C, Baird A, Hiscock N, Clayton J. Cancer caregivers advocate a patient- and family-centered approach to advance care planning. *J Pain Symptom Manage* 2014;47:1064-77.
17. Fly LM. *Intervention Strategies Oncology Nurse Navigators Use to Negotiate Cancer Care Barriers* [3571071 M3 – Ph.D.]: The University of Oklahoma Health Sciences Center; 2013.
18. Obeidat R, Khrais HI. Jordanian physicians' attitudes toward disclosure of cancer information and patient participation in treatment decision-making. *Asia Pac J Oncol Nurs* 2016;3:281-8.
19. Bozorgzad P, Peyrovi H, Vedadhir A, Negarandeh R, Esmaeili M. A critical lens on patient decision-making: A cultural safety perspective. *Nurs Midwifery Stud* 2017;6:189-95.
20. Edwards SB, Olson K, Koop PM, Northcott HC. Patient and family caregiver decision making in the context of advanced cancer. *Cancer Nurs* 2012;35:178-86.
21. Teh YC, Shaari NE, Taib NA, Ng CH, See MH, Tan GH. Determinants of choice of surgery in Asian patients with early breast cancer in a middle income country. *Asian Pac J Cancer Prev* 2014;15:3163-7.
22. Obeidat RF. Promoting emancipated decision-making for surgical treatment of early stage breast cancer among Jordanian women. *Asia Pac J Oncol Nurs* 2015;2:257-63.
23. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008;62:107-15.
24. Hickey G, Kipping C. A multi-stage approach to the coding of data from open-ended questions. *Nurse Res* 1996;4:81-91.
25. Epstein R, Street R. *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. Bethesda, MD: National Cancer Institute, NIH Publication; 2007.
26. Fu MR, Xu B, Liu Y, Haber J. 'Making the best of it': Chinese women's experiences of adjusting to breast cancer diagnosis and treatment. *J Adv Nurs* 2008;63:155-65.
27. Xiong M, Stone TE, Turale S, Petrini MA. Women's experiences of making healthcare decisions about their breast cancer: A phenomenological study. *Nurs Health Sci* 2016;18:314-20.
28. Tallon MM, Kendall GE, Priddis L, Newall F, Young J. Barriers to addressing social determinants of health in pediatric nursing practice: An integrative review. *J Pediatr Nurs* 2017;37:51-6.
29. Lewin SA, Skea ZC, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev* 2001; CD003267.
30. Sandman L, Munthe C. Shared decision making, paternalism and patient choice. *Health Care Anal* 2010;18:60-84.
31. O'Donnell O. Access to health care in developing countries: Breaking down demand side barriers. *Cad Saude Publica* 2007;23:2820-34.
32. Huang R, Gionfriddo MR, Zhang L, Leppin AL, Ting HH, Montori VM, *et al.* Shared decision-making in the people's republic of China: Current status and future directions. *Patient Prefer Adherence* 2015;9:1129-41.
33. Saurman E. Improving access: Modifying Penchansky and Thomas's theory of access. *J Health Serv Res Policy* 2016;21:36-9.
34. Sainio C, Eriksson E, Lauri S. Patient participation in decision making about care – The cancer patient's point of view. *Cancer Nurs* 2001;24:172-9.
35. Karliner LS, Hwang ES, Nickleach D, Kaplan CP. Language barriers and patient-centered breast cancer care. *Patient Educ Couns* 2011;84:223-8.
36. Hasnain M, Connell KJ, Menon U, Tranmer PA. Patient-centered care for muslim women: Provider and patient perspectives. *J Womens Health (Larchmt)* 2011;20:73-83.
37. López ME, Kaplan CP, Nápoles AM, Hwang ES, Livaudais JC, Karliner LS. Satisfaction with treatment decision-making and treatment regret among Latinas and non-Latina whites with DCIS. *Patient Educ Couns* 2014;94:83-9.
38. Kwok C, Koo FK. Participation in treatment decision-making among Chinese-Australian women with breast cancer. *Support Care Cancer* 2017;25:957-63.
39. Ngo-Metzger Q, Massagli MP, Clarridge BR, Manocchia M, Davis RB, Iezzoni LI. Linguistic and cultural barriers to care. *J Gen Intern Med* 2003;18:44-52.
40. Barry MJ, Edgman-Levitan S. Shared decision making – Pinnacle of patient-centered care. *N Engl J Med* 2012;366:780-1.