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The shadow of paternalism on patient-centeredness in oncology nursing care: A barrier of health-care promotion

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Abstract:

BACKGROUND: Patient-centered care (PCC) is a key component of high-quality care. Given the different effects of cancer on patients, patient-centeredness is very important in oncology nursing care. The aim of this study was to explore nurses' perceptions of the patient-centered in oncology nursing care.

MATERIALS AND METHODS: This descriptive qualitative study was conducted in 2018–2020, Iran. Data collection methods included observation and semi-structured interviews. Patient, family, and nurse behaviors were observed (total: 318 h). In addition, interviews were conducted with nurses and nursing managers (12 interviews). Data analysis was performed using Graneheim and Lundman's approach.

RESULTS: Data analysis resulted in the emergence of four themes: "Organizational structure as a barrier to the PCC," "Lack of institutionalization of PCC in nurses," "Understanding and paying attention to the patient as PCC," and "Situational PCC." The final theme of this study is "PCC in the shadow of paternalism."

CONCLUSIONS: The paternalism approach in the context of oncology nursing care has made the realization of PCC difficult. The first step to promote PCC is increasing nurses' awareness of the impact of paternalism on patient-centeredness. Providing patient-centered oncology nursing care requires changing attitudes, values, and behaviors at individual, professional, and organizational levels.

Keywords:

Cancer, nursing, patient-centered care, qualitative research

Introduction

Cancer is one of the major health problems and the second cause of death in the world.^[1] According to the World Health Organization (WHO) cancer is the third cause of noncommunicable diseases mortality in Iran.^[2] Cancer as a life-threatening disease is a crisis in the life of both patients and families. A person with cancer faces physical, emotional, social, and spiritual challenges that these can be intensified by complex therapies, treatment complications, and uncertain

outcome.^[3] The impact and consequences of cancer are different in persons, because the values, priorities, and needs of each person are unique.^[4] Cancer care is effective when it is provided based on the needs, preferences, and limitations of the patient. Hence, patient-centered care (PCC) has been considered as a central aspect of cancer care.^[3]

The WHO has identified PCC as a key component of high-quality care.^[5] The PCC can reduce medical errors and improve patient safety.^[6,7] The PCC is a shift from paternalistic, caregiver-driven, disease-oriented approaches.^[8,9] Common

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characteristics in patient-centered definitions include considering the patient as a person with unique preferences, needs, and experiences.^[8] “The person is considered free to act and take responsibility for making choices, family members are to be involved in care decisions, and decision making is to be conducted in partnership with the patient and, if possible, family members.”^[10] The PCC benefits in oncology care included improved well-being, adherence to treatment, patient satisfaction, and confidence in health professional team.^[11,12]

The literature review shows that previous studies have addressed only some aspects of PCC. Nevin *et al.*^[13] examined the patient and provider perspectives about factors contributing to positive cancer care experiences in Peru. They found that individual care for patients was a positive experience of cancer care and health-care providers have also considered individual care necessary and depended on their norms. On the other hand, several barriers to PCC delivery have been reported.^[14,15] The context and culture of the care environment have been revealed as the most important factor for restricting or supporting PCC in practice.^[16] Nurses, as a member of the health team, play an important role in shaping the culture of care. Hence, their perceptions of the PCC have an important effect on the implementation of PCC. The research evidence does not provide a comprehensive and transparent picture of the values, norms and behaviors of nurses in providing PCC in cancer care context. Indeed, how nurses translate PCC into practice remains a challenge. Therefore, there is a need to develop knowledge for PCC in practice.^[10,17] The first step to promote PCC is to investigate the daily practice of patient-centered nursing care. The aim of this study was to explore nurses’ perceptions of the patient-centered in oncology nursing care.

Materials and Methods

Design and study population

This paper presents the findings from part of a dissertation entitled the culture of nursing care in cancer. This is a qualitative descriptive study. To achieve the maximum variation, nurses from different work experience and job position were selected.

Data collection and analysis

Data collection was performed from June 2018 to January 2020 using semi-structured interviews and observations. The first author was observer and interviewer. Behaviors of the nurses, head nurses, supervisors, patients, and family caregivers were observed. In the observations (morning, evening, and night shifts), the interactions of the nurses with the patients and family members, patient involvement

in the care plan, nurses’ care priorities, and barriers and facilitators of patient-centered nursing care were considered. Overall, 318 h of participant observation were completed.

After the initial observations, a semi-structured interview was done to obtain further information and answer to some questions posed to the researchers, including barriers to PCC by nurses. The researcher purposefully interviewed seven nurses, three head nurses, and two supervisors [Table 1]. The average time of each interview was 65 min. Sample questions of the interviews were “Describe your 1-day work, please,” “How is the PCC in the nursing care of this center?” and “What are the barriers and facilitators of the PCC in the center”? Observations were immediately documented by the field notes written during the observations and interviews were tape-recorded and transcribed verbatim. Data collection was stopped after data saturation. Data collection and analysis were concurrent. Data analysis was performed using Graneheim and Lundman’s approach. Interviews were transcribed, and field notes were read several times to gain a general understanding of the participants’ statements. Afterward, the meaning units were determined, and the related codes were assigned to them. By constantly comparing the similarities and differences between the codes, subcategories and categories were created. MAXQDA software version 10 was used to manage the data during analysis.

Study setting

This study was conducted in a university hospital in Isfahan Province, Iran. This is the main oncology center in central and southern Iran. The center includes inpatient units (emergency, internal medicine, surgery, hematology, transplantation, and intensive care) and outpatient units (day clinic, chemotherapy, and radiotherapy). Its offers diagnostic, therapeutic, and care

Table 1: Demographic characteristic of the participants

Participant number	Job status	Age (years)	Work experience (years)	Degree of education
N1	Nurse	36	12	Master degree
N2	Nurse	29	7	Bachelor degree
N3	Nurse	37	14	Master degree
N4	Nurse	26	4	Bachelor degree
N5	Head nurse	39	16	Bachelor degree
N6	Supervisor	45	23	Bachelor degree
N7	Nurse	28	6	Bachelor degree
N8	Nurse	42	18	Bachelor degree
N9	Nurse	33	11	Bachelor degree
N10	Supervisor	43	21	Bachelor degree
N11	Head nurse	49	24	Bachelor degree
N12	Head nurse	37	15	Master degree

services, including bone marrow biopsy, diagnostic and therapeutic surgery, chemotherapy, radiotherapy, and bone marrow transplantation to patients with cancer.

Rigor

Four criteria of Guba and Lincoln were considered to ensure the trustworthiness of the study. To strengthen the credibility, long-term presence in the study setting for 7 months, using observation and interviews for data collection, selecting nurses with different work experience and job position as participant, using peer and member check was done. Dependability was also improved by engaging researcher team in data analysis. Confirmability was enhanced by keeping a clear audit trail of all research activities, and thick description of the behavioral patterns was used for transferability.

Ethical considerations

This study obtained ethical approval from the Ethics Committee of Isfahan University of Medical Sciences (Ethics code: IR.MUI.RESEARCH.REC.1398.161). The researcher explained the study goals to the participants. Written informed consent was obtained from all participants. The principle of anonymity was preserved in recording observations, interviews and presenting the results of the study.

Results

The findings showed that PCC is in the shadow of paternalism. Four themes and subthemes emerged in the data analysis are presented in Table 2.

Organizational structure as a barrier to the patient-centered care

It was revealed that the organizational structure, especially its rules and regulations, is one of the main barriers for PCC. It was also a strong barrier to individual and professional efforts for PCC. This theme includes three subthemes: "Ignoring patient preferences caused by structural problems," "The priority of nonnursing tasks," and "Reverse protection replaces informed consent."

Ignoring patients' preferences caused by structural problems

Structural problems lead to the ignoring of patient preferences and needs. These problems include limitation in the number and composition of nursing staff, workload, and managers' inattention to the orientation of novice nurses, unprincipled patient allocation and performance appraisal, and lack of a specific care model. One of the nurses in the informal interaction said: "On paper, we work with case management and levels of care, because it's necessary for the accreditation program; however, in practice, patients are divided among the nurses based on the number." N4.

The priority of nonnursing tasks

In addition to direct and indirect patient care, the nurses were in charge of managing the unit's nonnursing affairs. In other words, nonnursing affairs were a priority over nursing care for nurses and managers. The nurse's ability to manage nonnursing affairs was considered as a criterion for her/his competency. In the oncology unit, "The shift manager went to the patient's bedside throughout the shift only if the nurse asked for help to perform a procedure. Most of the shift.

Reverse protection replaces informed consent

In this culture, reverse protection replaces informed consent, which means providing documentation of the patient's consent to perform a procedure without following the principles of informed consent. The patients or their attendants signed the consent form. The purpose was documenting for accreditation (a program to assess the quality of hospitals, which was, conducted by the Ministry of Health and Medical Education and the protection of health-care providers against legal issues and patient complaint that could be accrued. The nurses never asked the patient for permission to nursing care and procedures:

"The patient was a 47-year-old man with colon cancer. The nurse called the patient's wife and said: This form Sign and leave a fingerprint on it. The patient said: What is this? The nurse said: It's for blood transfusion...The nurse didn't answer other questions raised by the patient and his wife." Obs7.

Table 2: Themes and subthemes

Final theme	Themes	Sub-themes
Patient-centered care in the shadow of paternalism	Organizational structure as a barrier to the patient-centered care	Ignoring patient preferences caused by structural problems The priority of nonnursing tasks Reverse protection replaces informed consent
	Lack of institutionalization of the patient-centered care in nurses	Nurses are task-centered, not patient-centeredness Lack of concern about the patient's preferences and desires Nurse dissatisfaction with patient and family involvement
	Understanding and paying attention to the patient as patient-centered care	Understanding the patient; A feature of the cancer nurse Behavioral manifestations of the nurses' understanding of the patient
	Situational patient-centered care	Nursing care is patient-centeredness if conditions are favorable Ignoring the patient-centered care in critical situations

Organizational structure, including the number and composition of nurse, rules and regulations, processes and routines is a barrier to PCC.

Lack of institutionalization of the patient-centered care in nurses

Patient-centeredness as a value was not institutionalized in most of the cancer nurses. In the care plan of most nurses, the preferences of patients and their family had no place. The nurses were upset of the patient and family involvement in the nursing care planning. This theme includes three subthemes: "Nurses are task-centered, not patient-centeredness," "Lack of concern about the patient's preferences and desires," and "Nurse dissatisfaction with patient and family involvement."

Nurses are tasked-centered, not patient-centeredness

From the nurses' point of view, they had to perform their tasks. They considered time constraints, high number of patients, evaluation of nurses by nursing managers based on job descriptions, lack of motivation for change, and routine-oriented as the causes of their task-centered. One of the nurses said: "*There is workload, Time limitation and shortage of nurses. As soon as we do our tasks, it's great! In the handover time, no one asks if you fulfilled the patient's desires?!!! Did you empathy?!!! Everyone checks the IV line catheter, medication and the presence of bed sores.*" N3.

Lack of concern about the patient's preferences and desires

Most of the nurses did not consider the patient and family as a unique unit that has specific characteristics, needs, preferences, and desires. The patient was a case for the nurses. They performed routine care, including medication, checking vital signs, changing dressing, and preparing samples for testing. Furthermore, physical care was provided equally to all patients, regardless of individual differences. The nurses did not concern about the spiritual, psychological, and social needs of the patient and family. One of the nurses said: "*Nurses are not responsible for the religious, family, psychological and social needs of the patient. As we give the patient medication, check their vital signs, and a like, the center clergy, Psychologists and physicians must do their own tasks (including spiritual and psychological needs).*" N2.

Nurse dissatisfaction with patient and family involvement

Most of the nurses believed that the patients are not aware of the nurses' workload, so they should not be involved in the nursing care planning. The nurses believed that the decision-making was up to the nurses. They became angry when they were forced to comply with the requests of the patient and the family. This was internal anger and did not manifest itself in the nurses' behavior. One of the nurses said: "I think the patient and family do not know many things; we know better what

to do; the supervisors force us to do their request. We are really dissatisfied about it; they (the patient and family) do not have the competency to tell us what to do."N4.

In most nurses, patient-centeredness was not institutionalized and was not considered a professional value. In fact, they consider themselves superior than the patients due to having knowledge about cancer and its management and consider the decision-making to be the sole right of the nurses and physicians, not the patient and family.

Understanding and paying attention to the patient as the patient-centered care

A group of cancer nurses at this center were patient-centeredness. One of the observed behavioral patterns of these nurses to provide PCC was "understanding and paying attention to the patient." They considered the understanding of the patient as a necessary attribute of the cancer nurse. The nurses were consciously performing behaviors reflecting their understanding of patient. This theme includes two subthemes: "Understanding the patient; a feature of the cancer nurse" and "Behavioral manifestations of the nurses' understanding of the patient."

Understanding the patient; a feature of the cancer nurse

Patient-centered nurses believed that they were dealing with a human being with a disease, not a case. They knew that the patients were experiencing difficult conditions due to the life-threatening illness, complex and costly treatments with unclear outputs. Therefore, a care plan should be implemented according to the patient's condition. In informal interactions with one of the nurses stated: "*When you work as a cancer nurse, your first skill is to understand the patient that his condition is difficult, so behaving according to the patient's requests is the least the task of a nurse.*"N1.

Behavioral manifestations of the nurses' understanding of the patient

The nurses' understanding of the patient was demonstrated in practice by their concern for meeting the patient's needs. Nurses showed their support by following the patient's wishes. To improve nursing care, they sought to be in-depth understanding of the patient. They sought to respect the patient's right to choose, especially in matters relating to nursing:

"The nurse entered the room to insert the IV line catheter. The patient was a young man and said: If you can come back in another hour, I'm bored. The nurse agreed and left the room." Obs17.

In fact, patient-centered nurses moved toward patient-centeredness by accepting the patient's condition

and sought to be in-depth understanding of the patient's needs and wants and so tried to meet them.

Situational the patient-centered care

Situational PCC means that the realization of patient-centeredness was conditional. Patient-centered nurses provided PCC in favorable conditions. In critical situations, patient-centeredness was not a priority for these nurses either. This theme includes two subthemes "Nursing care is patient-centeredness if conditions are favorable" and "Ignoring the PCC in critical situations."

Nursing care is patient-centeredness if conditions are favorable

From the nurse's point of view, the conditions of the ward and the nurse should be considered in the care planning, not just the patient's requests, because when the workload is high or the patient is in critical condition, not all his/her preferences and needs can be met. The nurse's belief in patient-centeredness also played a key role in its realization. In this case, one of the nurses said: "If the conditions are OK, I meet the requests of patient, it isn't problem for me. But, sometimes, it isn't possible, maybe due to time limitation or emergency patient." N2.

Ignoring the patient-centered care in critical situations

From the perspective of nurses, the situation is critical when the patient's life is threatened. The nurses believed that in critical situations, the patient has no competency to decision making and should act according to the physician's prescription. In this way, the nurses save the patient's life and protect themselves from future complaints and legal issues:

"The patient had shortness of breath following a blood transfusion. The nurse came to the patient after calling the physician to inject hydrocortisone. The patient and his wife refused to inject. The nurse said the delay in injection was dangerous and injected the drug." Obs12.

When the patient's life was threatened, the nurses ignore patient-centeredness and follow a paternalistic approach.

Discussion

The aim of this study was to explore nurses' perceptions of the patient-centered in oncology nursing care in one of the main cancer care centers in Iran.

The finding of this study revealed that patient-centeredness in oncology nursing care is in the shadow of paternalism culture that was prevailed in the hospital and nursing care culture. The findings of a study showed that most of health-care providers had a paternalistic approach to care delivery and emphasized of on taking action to the benefit of the patient. They wanted to promote health, even if it was forced.^[18] "Paternalism is the intentional

overriding of one person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose preferences or actions are overridden."^[19] In paternalistic approach, the position of the health-care providers is superior to the care recipient.^[20] The predominance of biomedical approach has highlighted the physical dimension of cancer care and treatment. On the other hand, health-care providers believe that they have special and professional knowledge about the physical health of the patient. Therefore, they consider themselves in a superior position to make decisions in the care and treatment plan. That is, the power between the nurses and the patients is not balanced^[21] and the patient is not involved in nursing care planning. This has led to the dominance of paternalism culture in oncology nursing care; it considers the benefit of the patient, which is determined by healthcare providers and depends on conditions of the nurses, other patient and the system.

In the present study, the organizational structure, including laws and regulations acted as a barrier of PCC. Bokhour et al.^[8] found that regulations hinder the innovations of health-care providers and cause them to prioritize the expectations of the organization in the face of patient demands that are contrary to the rules of the organization. As in the present study, due to the law of nondisclosure of information by nurses to the patient, the nurses did not provide information or did not tell the truth. Fix et al.^[22] in a study aimed at conceptualizing PCC by hospital employees concluded that there should be a patient-centered approach at the organizational level. Lack of a share organizational culture in relation to PCC causes that each of the health-care providers ignores patient-centeredness in some times. The share definition of PCC is the first step in creating a PCC culture. This is done by changing the attitudes of managers, especially nursing managers and nurses through rethinking their practice and considering professional values. Therefore, it is necessary for the hospital to promote patient-centeredness with its structure, processes, and culture in a way that the patient is central to the social and technical system of the hospital and all health-care providers are patient-centered and considered it as a routine.^[22]

In this study, the noninstitutionalization of patient-centeredness was evident in most of the nurses. Nurses' caring perspective is very important for providing PCC. Fix et al.^[22] found that for some health-care providers, patient-centeredness is not a priority. One of the main reasons is the individual characteristics and beliefs of nurses in relation to human existence. Nurses who do not have a holistic approach to the patient cannot provide PCC. Considering that

the presence of these nurses in the hospital prevents the PCC.^[8] Therefore, one of the main measures to promote PCC is to hire patient-centered nurses.

In this study, patient-centeredness behaviors by nurses were displayed as understanding and paying attention to the patient. Rohani *et al.*^[23] found perception as one of the characteristics of empathy in care from the perspective of nurses. Empathy is one of the components of PCC.^[24] As a result, promoting empathy in oncology nursing improves PCC.

PCC is provided if the conditions are favorable. This pattern of behavior is the same as soft paternalism seen in health care.^[25] "Soft paternalism involves interfering with the liberty of someone who has compromised decision-making abilities, due to lack of information, immaturity, mental disability, or other factors."^[26] Soft paternalism in the Iran health system can be rooted in the guardianship of physicians and the health team for the patient.^[27] In addition, in Iranian culture, families play a key role in the process of patient treatment and care.^[28] Therefore, decisions are made by the family with the priority of saving the patient's life. This threatens patient autonomy, which is essential to PCC. Therefore, a context is created for the health team, including nurses, who ignore other wishes, needs, and rights of the patient with benevolence.

Given that the caring culture is influenced by the culture of the patient, family, health-care providers and society, it is necessary that nurses consider the patient and family as a unique unit, as well as their preferences and values. Nurses also need to rethink nursing as a profession, not a job, as well as the values of the nursing profession. Clinical guideline development is based on Iranian culture for patient and family involvement in care planning. Managers should be a role model in patient-centeredness in all matters.

Conclusions

The findings of the present study revealed the shadow of soft paternalism on patient-centered oncology nursing care. Given the importance of the physical dimension of cancer care, it seems that it is not possible to completely reject soft paternalism. Promoting a culture of PCC requires attention in student education, the orientation of novice nurses, role models, organizational structures, and patient-centered managers.

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Conflicts of interest

There are no conflicts of interest.

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