

# Lived experiences of pediatric oncology nurses in Iran

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## ABSTRACT

**Background:** Caring is a valuable task. The staff in any profession that involves patients' fear, anxiety, pain, and suffering may experience similar feelings. As a professional group, oncology nurses deal with patients and their relatives and caregivers under very stressful conditions. They encounter pain, suffering, and death as a part of their daily life. A number of studies have evaluated the experiences of pediatric oncology nurses in other countries. Therefore, conducting a survey about the experiences of Iranian nurses of caring for children with cancer can reveal their demands, stress, and limitations.

**Materials and Methods:** In a qualitative research, in-depth, unstructured individual interviews with open-ended questions were conducted to evaluate the experiences of pediatric oncology nurses in a hospital in a metropolitan city of Iran. The subjects all consented to participate and had at least one year of working experience in the ward. Content analysis was performed to analyze the data.

**Results:** The lived experiences of pediatric oncology nurses were categorized in five main themes. These themes included attachment, supportive care, trying to repress feelings, feeling of helplessness, and the need to be supported.

**Conclusions:** According to these results, nurses who provide care for children with cancer require support. This research also highlighted the roles, limitations, and needs of nurses in pediatric oncology wards.

**Key words:** Iran, lived experiences, pediatric oncology nursing qualitative research,

## INTRODUCTION

Patient care is a valuable task. In every profession involved with patients' fear, anxiety, pain, and suffering, the staff may experience similar feelings.<sup>[1]</sup> As a professional group, oncology nurses deal with patients and their relatives and caregivers under very stressful conditions.<sup>[2]</sup> They routinely confront pain, suffering, and death<sup>[2]</sup> and experience various challenges due to continuous changes of the therapeutic environment. Furthermore, advancements in therapeutic methods and rapid professional changes make their working conditions different.<sup>[3]</sup> Nurses of pediatric oncology wards should be familiar with not only palliative care but also special pediatric care.<sup>[4]</sup> Moreover, working in different groups consisting of several fields of specialty

requires specific characteristics and abilities. On the other hand, patients usually prefer to refer to nurses in case of any problem.<sup>[3]</sup> Although being a nurse has some advantages, it may affect various aspects of a person's life including all physical, psychological, familial, and environmental dimensions of quality of life.<sup>[1]</sup> Occupational stress of pediatric oncology nurses impacts on their quality of life in both the workplace and their personal lives.<sup>[2]</sup>

Pediatric oncology nurses can improve their provided care by having a deep understanding of their duties and patients.<sup>[5]</sup> Such understanding can even be helpful in their daily life. In a review by Loftus and McDowell, oncology clinical nurse specialists in adult oncology wards of Britain were found to deserve support.<sup>[5]</sup> Another study on the experiences of nurses supporting a cancer patient suggested the nurses to be in need of support themselves.<sup>[6]</sup> A study in Sweden showed that oncology nurses suffered from stress in individual, group, organizational, and cultural levels.<sup>[2]</sup> Swedish and Iranian studies have reported nurses' experiences of fear management<sup>[7]</sup> and pain control in caring for children with cancer,<sup>[8]</sup> respectively. A previous study asked cancer patients and their nurses and physicians to prioritize the complications of cancer and its treatment. The patients' ideas were different from the nurses' and the physicians in five and 10 items, respectively. The researchers thus emphasized that caregivers should more carefully assess the concerns of patients in oncology wards.<sup>[9]</sup> Another study asked pediatric nurses to record their experiences

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and memories of managing the ward during one month. However, their caring experiences were not studied.<sup>[10]</sup> An Iranian study investigated the experiences of fathers of children with cancer at the time of diagnosis.<sup>[11]</sup> Research on experiences of nurses who cared for children with cancer has indicated that their most frequent experiences were associated with death, survival, returning to normal life, and intimate relationship between nurses and children.<sup>[12]</sup>

The majority of the mentioned studies about nurses' experiences of care were performed in adult oncology wards. Psychological and physical differences between adults and children cause differences in their care. Furthermore, caring has strong relationships with cultural and social characteristics.<sup>[13]</sup> Since nurses are the most important part of the caring process, evaluating their experiences in different communities can provide a more comprehensive understanding on the concept of care. However, few Iranian studies have assessed care experiences of nurses in pediatric oncology wards. Therefore, this research tried to explain Iranian nurses' experiences of caring for children in oncology wards in order to identify their demands, concerns and limitations.

## MATERIALS AND METHODS

This qualitative study explored the experiences of oncology nurses of a pediatric specialty hospital in a city of Iran. Nurses were included if they were willing to participate and had at least one year of experience in the ward. All nurses of this ward were female. In-depth, unstructured individual interviews were conducted out of working hours to extract the subjects' experiences of caring for children with cancer in the oncology ward. Since the questions were open-ended, the participants could freely express their feelings, thoughts, and ideas. Data collection continued until data saturation.

In order to perform content analysis, every interview was immediately transcribed and the contents were studied several times to understand the general points.<sup>[14]</sup> Then, the initial codes (meaning units) were extracted and classified

based on their similarities. All analyses were conducted using One Note 2007. Finally, the main themes were extracted to illustrate the nurses' experiences.

## RESULTS

The characteristics of the participants are summarized in Table 1. A total of seven interviews were performed and transcribed. After analyses, five main themes of experiences of pediatric oncology nurses were extracted.

### Attachment (attachment of nurses to patients and patients to nurses)

According to the participants, long hospitalization and numerous referrals of the patients, the chronic nature of the disease, and the recurrent chemotherapy periods caused an emotional relationship between nurses and the patients and their relatives. They mentioned stronger bonds with patients with younger age or longer stay. As our subjects believed, parents thought the nurses shared in their grief as they sympathized with sick children. Therefore, deeper, mutual attachments were formed. "... After making an emotional bond with patients, they will be like your own friends. You would like to be with them all the time. They sometimes call you just to say hello. Their mothers also call you to inform you that the treatment has been stopped or..." stated a nurse.

Such attachments may permanently occupy nurses' mind and cause professional problems. Sometimes, the patients would only let their first nurse take care of them. On the other hand, sometimes nurses go beyond what is reasonable or expected in caring for a patient. "... It is really hard when you have known a patient for four or five years and have established a deep relationship with him/her. For instance, a few years ago, during cardiopulmonary resuscitation (CPR) of a patient, the physician and more than five nurses and auxiliary nurses were crying. We should have filmed that scene. The patient was undergoing CPR while everyone was crying. That was because we had known the patient for more than four years and had a relationship with him;

Table 1: Demographic information of pediatric oncology ward nurses

Participant code	Age (years)	Work experience (years)	Work experience in the oncology ward (years)	Number of interviews	Duration of interview (minutes)
1	55	30	13	1	20
2	37	12	4	1	20
3	40	14	4	2	39
4	25	2	2	2	41
5	36	13	13	2	20
6	26	3	2	2	44
7	24	2	2	1	26

well, it should not have happened to him, but it happened anyhow and we lost the patient...” explained a nurse.

### Supportive care (emotional support, physical care)

The needs of children are of highest importance. Due to their different experiences, children with cancer require more support. Fears and physical and emotional needs of children and their parents, the frightening experience of approaching death without even knowing its meaning, changes in appearance and face of the child during the treatment period, the complex and sometimes frustrating process of the disease, and finally, complicated treatment measures necessitate substantial supportive care for a child in an oncology ward. Due to constant contact with sick children, sometimes nurses consider a certain pattern for the disease and its treatment and complications. They will then unconsciously follow the pattern in their provided care. As a participant mentioned: “... they are like other children with no difference. I have the same feelings toward them as I would have about any other child. But, because they're sick and under a lot of stress from their families and the disease, they are more sensitive than other children and we should take care of them much more precisely. They are more likely to experience depression. They consume corticosteroid and are more likely to be angry and upset...”. Supporting children with feelings of depression, anger, and despair is one of the important duties of these nurses. “... We are working with these kids. With the same horrible moods and spirits they have. They have depressed spirits. They do not have hair, eyebrows, or eyelashes. Just take a look at this ward and see what is going on. You will see patients who have no hope to survive. We are really involved with children's spirits here” stated a nurse.

### Trying to repress feelings

Nurses who take care of children with cancer should constantly repress their feelings. As our subjects mentioned, successful care of patients requires the nurses to control their emotions. Therefore, they mostly suppressed their emotions. The nurses' minds are generally occupied with tragic issues of the patients as they are permanently involved with risky situations and move sadness to their unconscious. Our participants also considered lack of possibility to express their feelings and emotions in grievous situations, valuing people who repress their feelings in Iranian culture, and general expectations from individuals to conceal their feelings as effective factors in suppressing their emotions. When parents are unaware of their child's diagnosis, nurses are forced to hide their feelings. An obvious sign of their suppressed emotions during the interviews was their constant attempts to escape from memories of lost patients. They talked about their caring experiences with red, teary eyes but smiling lips.

“... He had two big front teeth and he was tall... I took some days off, when I came back, they said he passed away; I couldn't be convinced at all. He was the first patient I really liked. Then suddenly, he was absent at the time of my arrival to the work. Oh my God, I was really sad. I said I wouldn't even cry for this, it might impact my emotion but I wouldn't cry. But I really got sad then. I do not cry in front of others, but I got really sad for him. No! I did not cry, I rarely cry...” said a participant.

### Feeling of helplessness (weakness, purposelessness)

A feeling of helplessness against the disease and its process was also common among almost all participants. They of course resented that feeling. At the time of a child's admission, they mostly thought about his/her possessions which could be wasted sooner or later. “... At the beginning, you'd see someone so hairy, pretty, cute and handsome; and finally what! It's the rule; first in a regular room, then in an isolated room, thereafter, their mouth will be full of plague, then some weird rashes will manifest on their skin. They are being treated but they also get worse. The next day they will be transferred to the ICU (intensive care unit) where we can't even see their death. Otherwise, they'll die in front of our eyes...” stated a nurse.

The majority of the participants considered their efforts to be ineffective. When the opinions of nurses about the treatment were asked, one participant said: “... No, we don't believe in treatment! We, ourselves, are watching children's death all the time. Ultimately all of them would die anyway”. This feeling was persistent throughout the treatment time and the nurses believed that “children's happiness was not real in the ward”. They mentioned patients' recovery as an incredible miracle and as a rare experience for the nurses. In fact, in some stages of the treatment, they felt so desperate that they tried every single way to ease and comfort the patient. “It was like he wanted to take oxygen by force. He was breathing but it seemed oxygen was useless. It was as if he was being suffocated. Imagine you see someone suffocated! That was pretty hard. I constantly prayed to God to help Ali die and rest in peace and comfort. There, I really prayed for his death. You couldn't look at him at all,” explained a nurse.

Watching children's incomplete life, inability to understand the meaning of life, and confusion concerned were unique experiences of pediatric oncology nurses. “You may ask why this happened to the child? I feel like I should not have a beautiful child because bad things happen to nice children. I really have no idea but I am afraid to give birth to a baby,” expressed a nurse.

### Need for emotional support

Most patients in the studied oncology ward were non-native. Being unfamiliar with the city, the horrifying diagnosis of cancer, and painful conditions and prolonged hospitalization of the patient imposed a great deal of stress on patients and their families. They were thus deeply in need of support. The families are often supported by nurses and sometimes by other families. "Once a boy desired for some French fries. He was originally from a village. I said I would get some. His mother prayed a lot for me...", said a participant.

On the other hand, patients and their relatives are not the only people who need to be supported. Our participants believed that for providing appropriate and comprehensive care, they required some sort of support and a minimum time to be with the child and refresh in order to sympathize with patients and their parents. Common problems of nurses include compressed work shifts, lack of support from managers and other members of the treatment team, and cumbersome rules like limited time to perform procedures. These problems and the complex and severe circumstances of patients in pediatric oncology wards necessitate support for nurses. Due to the mysterious nature and indefinite prognosis of the disease, nurses are constantly worried about its diagnosis either in themselves or in their beloved persons. "Everybody thinks we get used to it. We should sometimes clear our minds by say going to a shrine and cry for a while. It will certainly influence our lives. You can't say that after 9 years of working here, I got used to it. However, it subsides... Most children who are admitted here cry a lot in the first month. We have had people who could not tolerate it and left," explained a nurse.

Patients' problems affect not only the nurses but also their families. A participant stated that "We were in my sister's house for the New Year. My kid and my niece were playing with two hairless dolls. My kid hugged her doll and said: "Doctor! This is my child, she has cancer. She underwent chemotherapy; you see she has no hair and eyebrows! She got cancer, she won't be healthy anymore. You know if someone has cancer, she won't recover." She told her cousin to cry too because she also had a baby with cancer...!"

### DISCUSSION

Emotional attachment is a strong relationship between the patient and the caregiver due to the chronic nature of cancer and the prolonged hospitalization of the patient. It was the first subject that concerned most of our participants. Olson *et al.* pointed out to similar attachments between pediatric oncology nurses and patients.<sup>[12]</sup> According to Dowling, depending on patient

characteristics, nurse-patient attachments in oncology wards may be created during the first greeting and increase during care provision. Nurses in the study of Dowling stated their experience of intimate as reciprocity in reaction to the self-disclosure of patients. In fact, nurses considered patients as their professional friends and the caring environment as a place to experience intimacy. Dowling suggested nurse and patient satisfaction as the major outcomes of such attachments which in turn help patients feel they are better understood. However, as stated by the participants of the mentioned study, intimacy could impose emotional impacts and stresses on nurses.<sup>[15]</sup> Since experiences of attachment can either promote the quality of the provided care or cause problems in care implementation, appropriate understanding of attachment is necessary to minimize its negative effects on the client and the care provider and hence improve the care giving process. McLeod introduced attachment as an important facilitator in care provision.<sup>[16]</sup>

A large number of parents in the study of Lam *et al.* announced that pediatric oncology nurses worked too hard. They mentioned that they did not expect nurses to perform the entire care and some caring tasks should be assigned to the parents. They preferred nurses to supervise the care they implemented. Furthermore, mothers were really willing to be involved in caring for their children.<sup>[17]</sup> Nurse-patient attachments will lead to a mutual understanding which in turn promotes efforts to provide supportive care for the patients and their families. Moreover, supportive care will be effective in creating better attachments. Yoo *et al.* found attachments to be positive factors in family care provided for patients with cancer.<sup>[18]</sup> Loftus and McDowell considered supportive care as a reflexive response to changing conditions.<sup>[5]</sup> Hollis reported the multiple roles of pediatric oncology nurses and announced that nurses are often the first choice of patients in need of support.<sup>[3]</sup> In another study, parents of sick children expected nurses to put diagnoses and test results in simple words and explain changes in conditions of their children. Knowing about the events during their absence made them feel that even when they are not there, their children will enjoy sufficient support.<sup>[17]</sup> Bjork *et al.* mentioned that parents of children with cancer required nurses' support in cognitive, emotional, and behavioral domains.<sup>[19]</sup>

The caregivers of children with cancer had to suppress their emotions and feelings. More often, nurses were preoccupied with death of children. While the society expects nurses to conceal their feelings, they need to talk about them in order to cope with death or survival of children. Yoo *et al.* reported that nurses felt isolated.<sup>[18]</sup> As Olson *et al.*<sup>[10]</sup> and Loftus and McDowell<sup>[5]</sup> stated, nurses realized the limitations of patient



care and decided not to judge about treatment outcomes and to provide emotional care. People who try harder to suppress their feelings and do not have the opportunity to cope with their unpleasant feelings will experience increased levels of helplessness. Ekedahl and Wengström suggested emotional needs of nursing care as a source of stress in this profession.<sup>[2]</sup>

Helplessness against a disease whose treatment is riskier than the disease itself will result in feelings of guilt, fear, and inability. Yoo *et al.* mentioned feelings of anger, pressure, stress, inability, depression, and heavy responsibility as a negative concepts of providing care for patients with cancer.<sup>[18]</sup> According to Bjork *et al.*, parents caring for children with cancer experienced a combination of fatigue, sadness, despair, and anxiety.<sup>[19]</sup> Mental and emotional stability of patients require support and training. Zargham-Boroujeni *et al.* reported positive effects of education on viewpoints of nurses in end-of-life care in pediatric wards.<sup>[20]</sup> Formal and informal support of colleagues is also necessary for better, more sustainable nurse-patient attachments.<sup>[15]</sup>

Pediatric oncology nurses with long-term experiences of caring for children with different physical and emotional needs face various problems. The society expects them to ignore and hide their feelings. They are unconsciously attached with patients and feel more helpless as a new patient is admitted. They live with the constant fear that every new patient could be their own child. The death of a patient is also a tragic image that nurses usually face in pediatric oncology wards. Cheerful moments in this ward are miracles that remain in nurses' minds for many years. Such experiences make caring for patients unbearable. Therefore, many pediatric oncology nurses wish to leave work. In fact, the number of nurses who want to quit these wards is always greater than those who volunteer to work there. Similar to previous research,<sup>[5,6,12,21]</sup> the present study supports the idea of necessity of help for these nurses.

## CONCLUSION

Cancer is a chronic disease which influences all aspects of a person's life. The results of this study indicated that caregivers of children with cancer are under complicated circumstances. The experiences of pediatric oncology nurses deeply affect their professional, individual, and even family life. The findings of this study can be useful in planning interventional programs to support these nurses. Moreover, our findings will indirectly lay ground for future qualitative and quantitative research to evaluate different aspects of this topic which need supportive, educational, managerial,

and counseling interventions. Such studies can highlight the roles, limitations, and requirements of pediatric oncology nurses in providing care for children with cancer.

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