The perspectives of Afghan refugee mothers on the experience of caring for a child with cancer: a qualitative analysis

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Abstract

Background: Cancer in children causes many challenges for the family. When a refugee family experiences it, its impacts may be different and more specified considerations for care may be needed.

Aims: This study aimed to explore this experience of Afghan mothers living in the Islamic Republic of Iran who have a child with cancer.

Methods: For this descriptive qualitative study, which was conducted in 2017, refugee Afghan women with children affected by cancer, and referred to one of the cancer referral centers in Tehran, were selected through purposive sampling. Face-to-face, semi-structured and in-depth interviews were conducted for data collection until data saturation was attained. The resulting data was analyzed based on Graneheim and Lundman’s approach. MAXQDA 10 was used for organizing the data.

Results: We interviewed nine Afghan mothers in the age group of 24–44 years who had children with cancer. Data analysis demonstrated one theme and five sub-themes. The primary theme was entitled “Passive acceptor” with five sub-themes: “Chronic suffering”, “Health issues”, “Lack of skills”, “Maladaptive coping” and “Enthusiasm”.

Conclusion: The findings demonstrated that in spite of many issues in common with similar groups in other countries, some cultural implications should be considered in the care plan for an Afghan child with cancer and the family if residing in the Islamic Republic of Iran.

Keywords: Refugee, cancer, children, qualitative research, Iran

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Introduction

Although the population of children with cancer is growing, the outcomes of the disease have improved as a result of new treatment modalities (1). However, financial issues, uncertainty, the inability to define the illness and its outcomes, and other evidenced psychological problems in the family of the children with cancer have been frequently reported as major challenges (2–5). Mothers use different ways to adapt themselves to the above-mentioned challenges, which are affected by several internal and external factors (6).

The increasing numbers of immigrant refugees is a global problem that affects many countries, including the Islamic Republic of Iran, where the majority of Afghan refugees immigrate, and approximately 2 million legal Afghan immigrants live in the country (7). Political and economic problems have been mentioned as the most common causes of the immigration of Afghans to the Islamic Republic of Iran over the last 37 years. Along with immigration-related challenges, such as illiteracy and poverty (especially for illegal immigrants) (8), chronic diseases in children put Afghan refugees at a much greater level of stress (7). The quality of life in such a family, especially for the mother, is reported to be below average (9). So far, there has been no research conducted in the Islamic Republic of Iran regarding the care challenges for Afghan immigrant families with a child affected by cancer.

Given the large number of immigrants in the country and the moral obligations of the receiving countries to provide them with health services, it is necessary to study the effects of cancer in children on Afghan refugee mothers living in the Islamic Republic of Iran. Such a study makes it possible to plan for a more comprehensive family-centered care based on the obtained data. In addition, it provides the opportunity to help improve these mothers’ quality of life and, consequently, that of the child with cancer. The purpose of this study is to explore the experience of Afghan mothers while caring for a child with cancer.

Methods

This qualitative descriptive study was conducted from April to July 2017 to explore the perspectives of Afghan mothers who had to care for children with cancer regarding their experience using conventional content analysis (10). The study setting was a referral paediatrics educational hospital in Tehran. The participants were purposively selected if they met the following criteria: having a child with a definite diagnosis of cancer (not in the end stage), living with the spouse, speaking Persian, and no history of mental illness. Participants were met by the research team during their visit to the outpatient department.
or during their child’s hospitalization. Since two of the researchers for this study regularly attended the hospitals as nursing instructors and knew most of the patients and their families, a good rapport had already been formed between them and the participants, who were informed about the aims of the study. No Afghan children with final stage cancer or requiring intensive care were included. Participants had the right to leave the study at any stage. The ethics committee of Shahid Beheshti University of Medical Sciences approved the study. Consent forms were used to inform the mothers about the study’s purpose.

The data were collected through semi-structured in depth interviews. Recorded interviews were transcribed, and then listened to again to ensure the accuracy of the transcriptions. MAXQDA software10.0 was used to manage the textual data. To analyze the data, constant comparative method (11) was used including the following step based on the Grenneheim and Lundman descriptive content analysis. Each interview text was read several times; meaning units (a unit of analysis) were identified from which important points in the texts were extracted in order to consider the implicit and explicit contents of the meaning units (open coding). These codes were then classified under broader titles based on their similarities and differences (grouping and categorizing). This process continued until the secondary and the main themes were extracted (abstraction).

In order to evaluate the qualitative research, the four criteria of Lincoln and Guba (1985) were used after performing the analysis. Credibility could be reached through the researcher’s familiarity with the participants for a long period of time. Through member checking and peer debriefing, credibility was boosted. By choosing the interviewees’ quotes describing the results and integrating them, leading to the neutrality of the study findings, confirmability was ensured. An audit trail, themes, subthemes, and descriptions were used in order to record the participants’ experiences, which helped boost dependability. To secure transferability, the study documents were kept safe and efforts were made to explain the study methodology as extensively as possible in order to ensure the application of this research measure to other settings (12).

Results

Interviews were conducted with nine mothers aged 24–44 years. Their children were aged 2–9 years. Only one of the mothers had immigrated to the Islamic Republic of Iran the previous year for treatment; the rest had been living in the country for more than 12 years where their children had also been born. Except for one case, their spouses were labourers or traders, who were either illiterate or had elementary education. The types of cancer identified were Rhabdomyosarcoma, Leukaemia and Wilms’ tumour.

Results were categorized under one main theme of “Passive acceptor”, and five subthemes of “Chronic suffering”, “Maladaptive coping”, “Health issues”, “Lack of skills” and “Enthusiasm” (Table 1).
The participants who appeared as passive acceptors were those who had tried to combat their predicament caused by their child's cancer, which had added many problematic issues to the refugees’ lives. They did not have adequate or appropriate coping mechanisms, or social and financial resources to help them during this journey. They find themselves trying to manage the situation and were happy to be in a better environment compared to the former where they faced war and social injustice. However, their knowledge and actions are inadequate to lead to positive health outcomes for themselves and their children.

**Chronic suffering**

The memories of the war in Afghanistan have caused a pattern of chronic suffering in the lives of Afghan women. A 37-year-old mother of a child with a Wilms’ tumour stated, "I remember the war and the planes that dropped bombs. I was playing with my friend, but we had to run away. I did not have slippers on my feet. We got to our mothers’ tent. We saw that some people were killed. Fear is still in our hearts.”

It would appear that even though these women have been brought to the Islamic Republic of Iran at an early age, they remained traumatized by their experiences. All the participants had bitter memories of war, death, fear, danger and displacement, as well as poverty, unemployment and loneliness in their new adoptive country. The participants were struggling with multiple social and financial issues long before the diagnosis of their children’s cancer. Their child’s illness raised numerous problems not dissimilar to those experienced by mothers of children with cancer in other countries. However, issues such as uncertainty, chronic sorrow and feelings of guilt concerning the sick child, as well as the financial burden, had exhausted these mothers. One mother stated, “Although I know it is not heaven here either, you are still afraid you may lose something again.”

**Health issues**

Most of the participants, similar to their peers in the Islamic Republic of Iran, suffered from poor health even before the diagnosis of the disease of their children. Such a situation is the result of being refugees and the changes in their lifestyle due to immigration. However, the new challenge had worsened their health state in all dimensions. According to one mother, “I cannot sleep. I am stressed out. I say to myself, 'God, what is going to happen? Are they admitting my child to hospital again?'” When I go to the hospital, I do not care about myself. I do not eat anything”. Headaches, depression and anxiety were some of the most frequent complaints of the participants. Poverty, their spouses’ unemployment, and the lack of accessibility to health care and insurance problems were some of the obstacles mentioned that prevented them from seeking professional help. One mother said, "when I am here I hear from other mothers that we ourselves also need medication to keep our strength up.”
Lack of skills

Most of the participants had found themselves in a situation where they feared making mistakes and unable to take care of their child. Illiteracy, inaccessibility to social network support, the lack of general knowledge and skills in various fields put them in such a desperate state. The mother of a child with Leukaemia stated, "If I take him home and I find he has a fever, can he stay at home? Or must he go to the hospital? Most of the mothers were facing problems common to all families that had children with cancer, but they did not actively try to seek external help, and their own resources were insufficient to help them cope. Statements such as “Everyone knows that cancer is a disaster” were frequently heard from the participants who did not have any hope of recovery or faith in a happy future.

Maladaptive coping

Mothers were reluctant to actively engage in childhood disease treatment due to their lack of skills and knowledge as well as the multiple challenges they were facing. Therefore, they had just passively surrendered to the reality of the disease. They would rather turn to spiritual support as an emotional coping mechanism while avoiding problem-oriented coping strategies such as seeking out information or social support. The mothers considered religion as their only refuge and tried to improve the health of their child through prayer, since they also believed that sins in their own lives had resulted in divine punishment in the form of their child’s illness: “I thought that it is because of my sins. I thought it might have been the result of my own fault. Because of sinning God did this to me.” According to the mothers they did not attempt to obtain information about the child’s illness, although searching for information is considered as one of the strategies to deal with stress. The mothers reported only a few adaptive coping methods used throughout their lives after the diagnosis of their children’s disease. Most of them demonstrated signs of chronic depression and maladaptive coping methods such as constant crying or the feelings of isolation.

Enthusiasm

Mothers expressed their satisfaction and confidence in the Iranian health system in their various statements. A 28-year-old mother said, “Iran is very good. 80% of the costs are paid by benefactors. In Afghanistan, patients have to cover all the expenses themselves. There is no such a thing as charity there.” Another point the mothers referred to while expressing their satisfaction with the service was the lack of discrimination between them and Iranian patients. One of them pointed out that, “Wherever you go in Iran, they call my child by his name. I like this. It seems for them we are the same as others.”

Discussion

The research was conducted to analyse the perception of Afghan immigrant mothers of their child cancer experience. Although the results were similar to the findings of other
The analysis of the data led to the emergence of the main category: “Passive acceptor”. Although submission to “God’s will” is considered as one of the categories in many studies on mothers with cancer children 

(4,13,14), the acceptance of the child’s disease without even attempting to actively deal with it is considered a new finding. Afghan women, according to their cultural–educational background, believe that illnesses and other tragic events come from a superior divinity and that people have no choice but to accept it. By contrast, Lebanese parents described their experience of having a child with cancer as a battle (15), while in another study on Iranian mothers, the challenge of their children’s cancer had forced them develop and demonstrate higher potential and take an active role in the management of the disease (4). This may support the hypothesis that dealing with cancer of a child is affected by many cultural factors.

For the subtheme “chronic suffering”, the memories of war and migration were permanently fixed in the minds of those who have experienced it. This mentality has adverse effects that have been mentioned in various studies and manifest as psychological disorders (16–19). Here, a far higher prevalence of psychological disorders such as post-traumatic stress disorder (PTSD) has been reported in Afghan refugees in the Islamic Republic of Iran compared to the Iranian population as a whole (20). These consequences, which are a constant reminder of the insecurity of life during wartime according to the participants in the research, have created a permanent sense of suffering for them. The studies conducted on refugee parents have found that they face numerous difficulties providing shelter and care for their children, a situation which may be worsened by the child’s illness (21–23).

In addition, the unfavourable living conditions were all challenge these mothers had to face (16), as well as failure to address health issues – a common problem among Afghan refugees, especially among immigrant mothers. Studies show that the number of psychological problems is higher in mothers of immigrant families (24), yet immigrant mothers often refuse to admit their health problems due to a sense of shame (15), which is supported by the results of the current study. The participants also raised livelihood challenges as one of their primary issues, a fact often reported in ordinary citizens regardless of asylum and immigration status, and were also noted to be the problems of Syrian immigrant women with a child with cancer (25).

Although in a number of other studies the mothers emphasized primary shock, disbelief and crisis in their lives after receiving the diagnosis of their child’s cancer, they all demonstrated different adaptive measures in order to deal with the change in their lives (4). What is striking in this study was the lack of any maternal desire for problem-solving and the recourse to religion as an emotional solution. Mothers showed no inclination to develop new skills, which is a common approach to manage a crisis in the family by mothers. New
skills would help them to adapt and manage the consequences of the disease for the child and family more effectively. Getting help from peer groups and seeking social support by communicating with family members, relatives, and friends are considered to be a coping strategy that is highly recommended (26,27). Afghan mothers in the present study, in spite of the presence of other mothers with similar conditions, actively tried to isolate themselves and instead turned to prayer as a coping mechanism, and this has been found to be widespread according to other studies (4,28–30).

The family is considered to be the care-taker and the care-provider (31). Mothers suffer due to their caring burden and this has a negative impact on their health as well as the well-being of their children (3,32). Meanwhile, they have an important role in improving their children’s quality of life (33). In fact, supporting and helping mothers means extending care to the child and offers better chances of recovery. In the present study, it was shown that mothers caring for children with cancer had completely neglected their own health in their devotion to taking care of their children. In addition, mothers were found to be trying to shield their spouse from the realities of the situation in order to avoid tensions, which is similar to findings in other studies (3,4). For each mother, protecting the husband meant avoiding the emergence of another crisis, which is rooted in the popular cultural beliefs of the community, stating that, “Men turn to addiction to get away from household problems, otherwise they might have a stroke”. Thus, the strain on mothers is relentless, not only keeping the spouse away from issues of child cancer but also bearing the burden of care giving.

The lack of skills was another sub-theme of the study indicating the inactive role of Afghan mothers in managing child cancer at home, looking after their own health or that of others. This could have a cultural basis due to the fact that Afghan women in the Islamic Republic of Iran do not engage in activities that empower their role in the family and society. Most Afghan men do not allow their wives to have a job or participate in social activities (34).

One of the findings of the present study, which did not conform to findings elsewhere, was the lack of discrimination in health services by medical personnel in the Islamic Republic of Iran. Afghan women have a low level of education and have always been the victims of religious extremism, isolation and discrimination. In a number of studies conducted in the Islamic Republic of Iran, results indicated a sense of discrimination felt by Afghan women at health centres when receiving childbirth services (7). The reason for this possibly is the difference in communication style between the staff and the mother when it is a question of child disease rather than birth delivery. Centres such as Mahak hospital offer their services to all cancer children without discrimination. However, lack of complaint by Afghan refugee mothers about medical services is not congruent with other studies on the Iranian population (3,35,36), although there are indications of the fact that living as a refugee in
another country has a positive bias on their perceptions of the health care system in their new land of residence (37).

**Conclusion**

Cultural discrimination causes inequalities, misconceptions and promotion of stereotypes in the provision of care and the treatment of patients. Avoidance of discrimination is essential for equitable treatment Afghan mothers, who appear to need to greater assistance due to cultural barriers to self-empowerment when it comes to seeking help and understanding of the care for children with cancer. Therefore, tailored care plans are required for refugee Afghan mothers in the Islamic Republic of Iran.

Given that the challenges associated with the health of immigrants and refugees are considered to be everyday issues in the Middle East and North Africa, it would appear that a collaborative effort to train care providers in care provision and the status of refugees’ health and disease coping strategies, and their cultural-based perceptions of their physical and mental health, can help to promote the health of mothers who have a child with cancer.

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**References**

10. Schreier M. Qualitative content analysis in practice: The SAGE handbook of qualitative data analysis; 2012.
<table>
<thead>
<tr>
<th>Main theme</th>
<th>Themes</th>
<th>Sub-themes</th>
<th>Meaning (analytical) of units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic suffering</td>
<td>Ominous shadow of previous experiences</td>
<td>Being upset to remember the memories, not willing to go back to Afghanistan</td>
<td></td>
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<td></td>
<td>The plurality of problems ahead</td>
<td>Poor economical state, being unemployed of the father, being addicted of the father</td>
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<td>Passive acceptor</td>
<td>Livelihood difficulties</td>
<td>To live in a non-comfortable house, being far from the basic health care facilities, low financial income</td>
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<tr>
<td>Health issues</td>
<td>Lack of self-care</td>
<td>Not having visits for health care, not being familiar with adaptive coping methods</td>
<td></td>
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<tr>
<td></td>
<td>Neglecting self-health</td>
<td>Not following up the process of treatment for health problems of mother, to forget to get supplements prescribed by physicians</td>
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<td></td>
<td>Family shield</td>
<td>To have many children living in a small place, the close intervals of pregnancy</td>
<td></td>
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<tr>
<td>Lack of skills</td>
<td>Inability to management the care</td>
<td>To be dependent to others to follow the care of the child, not having enough information about the care of the child</td>
<td></td>
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<tr>
<td></td>
<td>The constant fear of mistake</td>
<td>To increase the feelings of anxiety when the child needs to be visited, not having the ability to read</td>
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<tr>
<td>Maladaptive coping</td>
<td>Maintaining the only shelter</td>
<td>Trying not keep the state unchanged as it seems safe now, to avoid new experiences in the life</td>
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<td></td>
<td>Isolation</td>
<td>Not having contacts with other mothers of children with cancer, not trying to join to social support systems in hospital</td>
<td></td>
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<tr>
<td>Ethusiasm</td>
<td>Believe in the effectiveness of the treatment system</td>
<td>To have trust to health care providers, not having any complains</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Satisfaction with the service</td>
<td>Praying for nurses and doctors, to feel happy in compare with the situation of care in Afghanistan, to feel lucky to be in Iran</td>
<td></td>
</tr>
</tbody>
</table>

**Table 1. Themes, sub-themes, and analytical units**