

Nurses' experiences of psychosocial care needs of children with thalassaemia and their families in Jordan: A phenomenological study

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Abstract

Aim: To explore the experiences of Jordanian nurses regarding the psychosocial care needs of children with thalassaemia and their families.

Design: A descriptive phenomenological approach was employed.

Methods: A purposive sampling strategy was used to select 10 nurses who had experience in caring for children with thalassaemia. Unstructured, face-to-face interviews were conducted. Coliazzi's data analysis process was applied.

Results: The analysis revealed three major themes: (1) valuing psychosocial support; (2) caring for paediatric patients needs certain competencies in nurses and (3) barriers to providing psychosocial care. Nurses expressed the importance of providing psychosocial care. A lack of specialists in psychosocial care as well as a lack of screening tools, and entertainment facilities for children was identified to be impeding effective psychosocial care. Implementing training programmes for nurses concerning providing psychosocial care and making the appropriate changes in nursing curricula at the educational level are recommended.

KEYWORDS

children, Jordan, paediatric nurses, psychosocial care needs, psychotherapists, thalassaemia

1 | INTRODUCTION

Thalassaemias are among the most severe diseases that are usually inherited through autosomal recessive patterns. Thalassaemia is a global health problem caused by mutations in the alpha and beta globin chains, and can lead to impairment in erythropoiesis which in turn causes anaemia (Angastiniotis & Lobitz, 2019). Thalassaemias affect as many as 15 million people worldwide (Yaish, 2015). In Jordan, the number of patients with beta thalassaemia major is around 1,500 which is relatively high (Gharaibeh et al., 2018). Jordanian people who are carriers of hereditary diseases are increasing at a rate of around

4%–6% of the total population (Gharaibeh & Gharaibeh, 2012). Beta thalassaemia major remains the most serious form of thalassaemias. For patients with this disease to survive vigorous treatment involving regular blood transfusions and iron chelation therapies is needed from early childhood (Angastiniotis & Lobitz, 2019). Children with beta thalassaemia major suffer from anaemia which makes them appear pale, listless, lethargic and intolerant of physical activities. Delayed sexual maturation, bone pain, bone changes such as an enlarged head, prominent facial bones, flat bridge of the nose, distended maxilla, protrusion of the upper central incisors and a small stature are common (Hockenberry et al., 2019).

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According to Pouraboli et al. (2017), differences in the physical appearance between children with thalassaemia and healthy children were major sources of suffering for parents of the affected children. Behdani et al. (2015) found that children with thalassaemia had more psychological problems such as depression and anxiety, and consequently, a poorer quality of life than healthy children. Likewise, nurturing a child with thalassaemia is associated with many challenges and burdens. Parents of children with thalassaemia felt angry, shocked and guilty when informed of their child's diagnosis (Pouraboli et al., 2017). They disbelieved in the diagnosis and did not accept it which led them to change the hospital. Parents believed that they passed the disease genetically to their children (Pouraboli et al., 2017).

A study in Jordan by Abu Shosha and Al Kalaldehy (2018) indicated that mothers having a child with thalassaemia reported their life as being difficult as they suffered from psychological distress, sadness, worries about child's future, social isolation and depression. Mothers also experienced financial burden associated with regular hospitalization and unpaid leave for employee mothers. Previous authors have argued that mothers of children with thalassaemia have numerous worries and concerns regarding their children such as frequent absenteeism from school, uncertainty about their future education, delay in puberty, and the children's ability to get married and find a job in the future (Abu Shosha, 2014; Pouraboli et al., 2017). However, with the availability of better treatment regimens, the life span of patients with thalassaemia is increasing; thus, the need to enhance the coping abilities of such children with stressors in their life has also increased (Hockenberry et al., 2019).

Previous studies conducted in Jordan have examined various dimensions of thalassaemia from the perspectives of patients and their families (Abu Shosha, 2016, 2019; Abu Shosha & Al Kalaldehy, 2018; Al-Awamreh & Suliman, 2019; Gharaibeh et al., 2018). Yet, little is known about the psychosocial care needs of children with thalassaemia and their families from nurses' perspectives. Therefore, this qualitative study explored the psychosocial care needs of children and their families from the perspectives of nurses. This would provide insight into nurses' perceptions and experiences and consequently, establishing the foundation for increasing and improving the psychosocial services provided for children with thalassaemia and their and families.

2 | METHODS

2.1 | Research design

This qualitative study applied a descriptive phenomenological approach. In general, a phenomenological study aims to explore the essence of the lived experience of a specific phenomenon. It is used when little is known about a specific phenomenon (Lopez & Willis, 2004; Speziale & Carpenter, 2007). It is also used to comprehend the fundamental meaning of participants' interactions with the environment (Lopez & Willis, 2004). Descriptive phenomenology was chosen for this study because little is known about Jordanian

nurses' experiences of psychosocial care needs of children and their families and the researchers sought to explore this phenomenon from nurses' perspectives (Lopez & Willis, 2004).

2.2 | Sample and setting

The researchers selected informative participants using purposive sampling strategy which is an intentional selection of participants who are able to illuminate specific phenomenon (Polit & Beck, 2017). The researchers selected participants who have rich experience with at least three years in caring for children with thalassaemia. This limit guaranteed that participants had rich experience and therefore, they were able to elaborate on the psychosocial care needs of children and their families. Participants were approached face-to-face by the primary researcher from three major government thalassaemia clinics in Jordan. The sample size was determined based on data saturation when no new ideas or concepts aroused by participants (Creswell & Poth, 2018). The sample size was 10 participants.

2.3 | Data collection

Unstructured, face-to-face interviews were conducted in a private place in the workplace as requested by participants. Each interview was conducted in the presence of only the primary researcher and the participant. The interview was guided by the interview questions developed from related literature (Farberman et al., 2017; Pouraboli et al., 2017; Appendix S1). The interview questions were confirmed by two experts in child health nursing and another qualitative researcher who investigated the interview questions and suggested some modifications on the questions. Demographic characteristics were collected by the primary researcher to obtain basic information from the participants. Participants were encouraged to dialog freely and to express their stories and experiences regarding the psychosocial care needs of children with thalassaemia and their families. Probes were also used throughout the interview to get in-depth data from the participants. Each participant was interviewed once in addition to another phone discussion conducted after data analysis to confirm the findings of the study. All interviews were digitally recorded and lasted around 45–60 min. Data collection was carried out from the mid of May to the end of June 2020.

2.4 | Piloting

A piloting was carried out by the primary researcher who had experience working in paediatric, haematology and oncology departments. Two participants who met the inclusion criteria were interviewed. The piloting revealed that the two participants were interested in talking about their experience, the questions were clear and understandable, and each interview lasted ~45 min to 1 hr. The two participants of the piloting were not part of the final sample size.

2.5 | Ethical considerations

Ethical approval was obtained from Zarqa University (approval number: 4/3/2019-2020) for conducting this study. Informed consent was obtained prior to data collection. Selected participants were identified with the assistance of unit head nurses who provided a list of all eligible nurses based on the inclusion criteria. All participants were assured of the right to reject, withdraw or terminate their participation at any time. Participants were informed about the electronic recording of the interviews. To ensure confidentiality, each participant was given a code in place of their identity. Participants were informed that quotes from the interviews will be included in the study report. All participants were asked to provide the researcher with their phone numbers so that they could be contacted again by phone calls for confirming the validity of the findings.

2.6 | Data analysis

All interviews were transcribed verbatim by the primary researcher. Double checks for the transcripts were conducted by other researchers (MK and NS). Demographic data of key participants were analysed using descriptive statistics, while qualitative data were analysed by Colaizzi's process of data analysis (Morrow et al., 2015). Colaizzi (1978) developed his approach of data analysis based on the descriptive phenomenology school (Fochtman, 2008). Therefore, this method of data analysis is suitable for analysing the data of this study. The transcript of each interview was read several times to understand the whole picture of the content. All emerging thoughts and feelings experienced by the researchers during this step were added to the bracketing diary. In bracketing, the researchers put aside their pre-conceived views, beliefs and ideas, and did not make any judgments about the phenomenon under study in order to understand the pure phenomenon from participants' perspectives (Lopez & Willis, 2004). Each significant statement related to the psychosocial care of children and their families in each transcript was extracted, and coded according to the transcript, page and line numbers. The researchers discussed upon these statements and agreed on each significant statement and its code. After that, meanings were formulated from these significant statements. That is, the researchers articulated the meaning of each significant statement (i.e. what does each statement mean). Then, the formulated meanings were grouped into categories, clusters of themes and themes. This means that each cluster of theme included all formulated meanings related to that cluster of theme. Afterward, all clusters of themes that reflected the same issue were merged together to form a distinguishing theme. All these themes were internally convergent and externally divergent. Then, all emergent themes of the study were integrated into an exhaustive description of the phenomenon. That is, the researcher combined all the study themes, clusters of themes and formulated meanings into an exhaustive description (i.e. rich description of nurses' perspectives of psychosocial care needs). The fundamental

structure of the phenomenon was described through the removal of any repetition or unnecessary descriptions from the text. Finally, member checks were performed as the findings were validated by the participants.

2.7 | Trustworthiness

The researchers of this study employed several techniques to enhance the rigor of the findings. First, the researchers engaged deeply with the participants to gain comprehensive and rich information about their experiences. Second, the researchers examined with a peer who is expert in qualitative research the development of codes, subthemes, themes and the final exhaustive description. This process is defined as "peer debriefing." Third, a thorough documentation of the audit trail was performed, in addition to providing rich and thick descriptions to communicate the study findings. Fourth, member checking, through telephone interviews was also performed to confirm the accuracy of the findings. Fifth, bracketing is an important element in phenomenological studies; therefore, the researchers deliberately put aside their own beliefs and ideas about the phenomenon under investigation. This added to the trustworthiness of the data and contributed to a precise depiction of the participants' perspectives by allowing the researchers to explore the pure phenomenon under study from participants' views (Creswell & Creswell, 2018).

3 | FINDINGS

3.1 | Participants demographics

A total of 10 nurses working in thalassaemia units participated in the study. All participants were female with a mean age of 37 years. All participants were Jordanian with 70% having a bachelor's of science in nursing and 30% having a diploma in nursing. The mean years of experience was 8 years. Table 1 displays the demographic characteristics of the participants.

Three major themes emerged from this study: (1) Valuing psychosocial support; (2) caring for paediatric patients needs certain competencies in nurses and (3) barriers in providing psychosocial care.

3.2 | Theme 1: Valuing psychosocial support

In this theme, participants discussed their perceptions of psychosocial care needs of children with thalassaemia and their families. Participants believed in the importance of providing holistic care. They asserted that children with thalassaemia need psychosocial care along with medical treatment. Participants argued that children with thalassaemia face various challenges associated with frequent admissions, invasive procedures, blood transfusion, absence from

TABLE 1 Demographic characteristics of participants (N = 10)

Participant age (years), mean (SD)	37 (6.18)
Education level, N (%)	
Bachelor's degree	7 (70%)
Diploma degree	3 (30%)
Religion, N (%)	
Islam	10 (100%)
Others	0
Work experience (years), mean (SD)	8 (3.48)
Gender, N (%)	
Female	10 (100%)
Male	0
Education/training in psychosocial care, N (%)	0

school and limitations of their activities. This condition created physical, psychosocial and financial burdens on children and their families. Therefore, participants declared that psychosocial care includes the provision of psychological, social, spiritual, financial, counselling and informational support.

One nurse, for example, reported:

Children with thalassaemia and their families are in need of comprehensive care...they face many challenges because of having a chronic disease as thalassaemia...I think that providing medical treatment is not enough to deal with these patients...they need more than blood and medications...healthcare providers should provide all support and education for children and their families.

(Participant 3)

Participants emphasized that the negative consequences of thalassaemia and its medical treatment on children and their families are evidenced by the sadness and depression experienced by such families most of the time. One nurse said:

Children with thalassaemia and their families live a miserable life. They encounter many difficulties due to the nature of thalassaemia and the required treatment. They really need comprehensive care in order to adapt to their condition.

(Participant 4)

Participant furthermore revealed that the parents of children with thalassaemia need psychological support because they feel guilty for passing on the disease genetically to their children. Therefore, parents appear sad, worried and uncomfortable most of the time especially when invasive and painful medical procedures such as cannulation are being performed on their children. Participants extensively described the distress and difficult situations encountered by such families. One nurse reported:

It is really a disaster to have such a situation; it is a very difficult situation. Most mothers come every month to thalassaemia clinic with their children and stay for a minimum of five hours waiting for the blood transfusion to finish...they look very tired and sad to see their children suffering from the disease...I believe that families with such situation need continuous psychological support all the time.

(Participant 5)

Social support was recommended by participants in this study. Participants recognized that families of children with thalassaemia experienced social burdens and therefore they need social support from the community. Participants also acknowledged the importance of spiritual support in helping Jordanian families to adapt with a demanding disease as thalassaemia. Religion and belief in God's decree were viewed as very important factors in accepting such disease. Participants asserted on the importance of providing financial support for families of children with thalassaemia even if thalassaemia treatment is free in Jordan. Participants reported that thalassaemia is a costly disease because of the regular visits to the thalassaemia clinic in addition to the cost of transportation.

Counselling and informational support were considered by participants in this study as vital factors that help in coping with the disease. One participant reported:

I think that children with thalassaemia and their families need all types of support...psychological, social, spiritual, financial, health education... in order to be able to cope with such demanding disease.

(Participant 8)

Participants emphasized that psychosocial support must be ongoing through the treatment journey and must begin immediately after the diagnosis of thalassaemia. They realized that providing psychosocial care will help families and children in accepting and adapting to the disease.

We [nurses] should provide families and children with psychosocial support. It helps them to continue their journey with thalassaemia, and face all difficulties and challenges in front of them. Children will be more adherent to treatment and more motivated to receive lifelong treatment for thalassaemia.

(Participant 1)

3.3 | Theme 2: Caring for paediatric patients needs certain competencies in nurses

This theme describes the competencies needed to enable nurses to deliver effective care for children with thalassaemia and their

families. These competencies are crucial for providing the best quality of care. It has two subthemes: (1) knowledge and skills, and (2) providing compassionate care.

3.3.1 | Subtheme 1: Knowledge and skills

Caring for children with thalassaemia requires nurses to have special knowledge and skills focusing exclusively on thalassaemia and its treatment. Participants in this study asserted that children with thalassaemia differ from children with other diseases in terms of regular hospitalization and blood transfusion, lifestyle changes, physical appearance and frequent complications of thalassaemia. Therefore, children with thalassaemia require special care and attention from healthcare providers. A nurse said:

Thalassaemia is different from other disorders; if it is not treated well, then many complications emerge such as heart disease and spleen enlargement. Therefore, children with this disease require nurses to be aware of the disease, its treatment, and complications.

(Participant 3)

Participants elaborated that they should be familiar with all the medical information about thalassaemia including the causes of the disease, types of thalassaemia, signs and symptoms, medical treatment, and the impact of the disease on children. This will help them in providing holistic care and educating families as needed. One nurse reported:

It is a must for nurses to know everything about thalassaemia such as pathophysiology, types, signs and symptoms, treatment.... etc. This is a very important issue because the nurse will not be able to provide comprehensive care unless she is familiar with all the medical information about thalassaemia...Parents always need health education and counselling.

(Participant 9)

The participants also emphasized that sometimes complications occur during blood transfusions for children which require the nurse to intervene quickly and deal with the complications in the fastest and best way possible. One nurse reported:

Sometimes children develop complications during blood transfusion; nurses should be competent in dealing with these complications, which may cause harmful effects to children. In addition, performing nursing skills for children is difficult, for example, inserting cannulas for children with thalassaemia is difficult.

(Participant 2)

Participants expressed the importance of communication skills as an effective way to interact with children and their families and build a therapeutic relationship with them. Participants asserted that all healthcare providers must master communication skills especially those who deal with patients with chronic diseases. Nurses have to convince children of adherence to treatment plan and to bear the pain which is not an easy task because of the developmental stage and cognitive abilities of children. One nurse explained:

One of the most important skills that nurses must master is the way of communicating with patients, especially children, so that the nurse can build therapeutic relationships with patients and thus enhance their desire to receive treatment and blood transfusions. This is very important as the treatment journey for thalassaemia is very long and needs full adherence.

(Participant 10)

Participants declared that their knowledge and skills increased with experience. According to them, work experience has a strong impact on the quality of the nursing services provided to patients and their families. Experience strengthens the capabilities of the nurses, and improves their ability to assess the needs and investigate the problems of patients and their families. This enables the nurses to provide nursing services that are commensurate with these needs. A nurse discussed the effect of experience as follows:

There is no doubt that work experience has a great role in refining the capabilities of the nurse to provide psychosocial care. Experience helps nurses identify the needs of patients and their families and develop communication skills for use with patients and their families. It also teaches a nurse how to control her feelings and how to behave in all circumstances.

(Participant 7)

3.3.2 | Subtheme 2: Providing compassionate care

Thalassaemia in childhood is an emotionally painful and distressing situation. Participants frequently described the difficult experience of children with thalassaemia and their families. Participants expressed their sadness and tenderness for seeing children and their families suffering from thalassaemia therefore, nurses treated them with kindness and empathy. According to participants, working with children for a long period strengthens the relationship between children, their families and nurses. One nurse described her feelings as follows:

Dealing with children with thalassaemia is a very sad thing... It is difficult to see children suffering with the disease, for example, some children come to the

hospital every 30 days for blood transfusion. It is sad to look at them with a cannula in their hands waiting for the blood transfusion to finish for at least 3 hours. It is a long journey, so all healthcare providers should treat them with kindness and love all the time.

(Participant 1)

Participants described their psychological reactions to the patients' conditions as reflected in their feeling depressed and sad even when returning home. A nurse said,

Often when I go home and remember the condition of children, I start to cry ... I cannot stop thinking about them because they have become a part of my life, I spend most of my time in the hospital and meet the same children repeatedly, they deserve to be treated with tenderness and kindness.

(Participant 4)

Participants declared that compassionate care is necessary to enhance patient's acceptance, adaptation and satisfaction with the provided care. According to participants, to provide compassionate care, nurses should understand their patients' suffering and acknowledge their feelings. On the other hand, participants were aware that they should control their emotions in order to be able to support the children and their families. One nurse pointed out:

We (nurses) must control our feelings when dealing with children and their families, so that we can provide them psychological support... nurses should be strong enough to control their feelings and treat patients kindly.

(Participant 6)

3.4 | Theme 3: Barriers in providing psychosocial care

This theme describes barriers that nurses encounter while providing psychosocial care. Participants asserted that these barriers hinder the provision of holistic care to children and their families. Participants reported a lack of specialists to provide psychosocial care and therefore, the major source of support for children and their families were nurses, despite the latter's lack of specialized training in this field. One participant stated:

Although we believe in the importance of providing psychosocial support, we do not have any specialized individuals in the hospital to provide psychosocial care for children and their families...they are really in need for such care, we try to do our best in providing support.

(Participant 7)

Accordingly, participants recommended having a dedicated psychotherapist who is specialized in providing psychosocial care. A nurse reported:

Paediatric patients and their families need specialized and dedicated psychotherapists and social workers to provide them with psychosocial support more effectively.

(Participant 8)

Participants in this study reported a lack of screening tools to assess patients and family members for psychosocial problems. One nurse said:

We do not have a screening tool or a checklist to assess the psychosocial problems of patients with thalassaemia and their families.

(Participant 10)

Therefore, participants stressed on the need for specific assessment tools to screen for psychosocial problems and needs of children with thalassaemia and their families. Participants elaborated that the availability of these tools will standardize the assessment process among nurses and remind them with all items they should ask about. The following excerpt describes the recommendations of the participants:

We (nurses) really need a standardized screening tool that specifically screens for psychosocial problems in children with thalassaemia and another one that specifically screens for these problems in families. This is an important factor in helping us identify the psychosocial care needs and provide appropriate care accordingly.

(Participant 3)

Another barrier reported by nurses was a lack of specialized educational courses and workshops concerning the provision of psychosocial care as reflected in the following excerpt:

I have not attended any formal seminar or educational program regarding psychosocial care here in the hospital. All seminars conducted here were directly related to medical and nursing care and did not discuss any comprehensive issue about psychosocial care.

(Participant 1)

Participants suggested conducting training programmes and seminars to improve nurses' abilities to assess psychosocial problems and needs. One participant said:

Unfortunately, we did not study a specific course in nursing about psychosocial care, but it is very

important now to improve our abilities by conducting educational courses and workshops regarding this issue

(Participant 4)

In addition, a lack of entertainment facilities for children was considered by nurses as a barrier to providing optimal psychosocial care. Participants asserted that children need entertainment to reduce the likelihood of experiencing psychosocial stressors and to spend their time during blood transfusion. A nurse commented:

Children spend about five hours in our thalassaemia unit; they need entertainment facilities to have fun because their treatment journey is long ... in this unit, there are no entertainment facilities such as a playroom, video games, or internet... children need these things instead of looking at each other during blood transfusion.

(Participant 3)

Participants also suggested the presence of playrooms for children in thalassaemia units as well as the need for entertainment tools such as age-appropriate games and Wi-Fi. One participant said:

We, in fact, need a lot of entertainment activities and services like laptops and games for children to play with instead of their looking at each other.

(Participant 10)

4 | DISCUSSION

It is unclear exactly how psychosocial care is demonstrated in practice (Hill et al., 2015). This study sought to explore the experiences of Jordanian nurses concerning the psychosocial care needs of children with thalassaemia and their families. Jordanian nurses in this study believed in the importance of providing psychosocial care for children with thalassaemia and their families which was viewed by them as a parallel strategy along with medical care. Psychosocial care was described by the participants as providing psychological, social, spiritual, counselling and informational support. Chen et al. (2017) defined psychosocial care as the culturally sensitive provision of psychological, social and spiritual care. It is a part of holistic patient care that includes informational and emotional support and through this psychosocial care nurses can develop therapeutic and trust relationships with patients (Legg, 2011). Similarly, it has been seen that nurses in Singapore also perceived psychosocial care to involve the provisions of holistic care, spiritual care, support for patients and their families, and display of empathy. In addition, psychosocial care includes communication among nurses and the patient and family members as well as collaboration between healthcare providers to ensure multidisciplinary care (Chen et al., 2017).

Participants in this study verbalized their concerns regarding the chronic nature of thalassaemia and how its treatment negatively impacts the lives of children and their families. Zaheer et al. (2015) emphasized that not only is thalassaemia a major concern for families, but the disorders associated with thalassaemia such as heart diseases also add to the psychological burden of families. Therefore, supporting the psychosocial status of parents is an important issue that needs attention and must be addressed to reduce the emotional burden felt by parents (Suryani, 2020).

An interesting finding to comment on in this study is the parents' feeling of guilt, as they passed the disease genetically to their kids. This finding is congruent with a previous study in Jordan showing that mothers of children with thalassaemia felt guilty because of the genetic nature of disorder (Abu Shosha & Al Kalaldehy, 2018). Shahraki-vahed et al. (2017) claimed that parents of children with thalassaemia considered themselves responsible for their children's disease as it is the parents who originally had the thalassaemia trait and therefore, they feel guilty and hopeless. Participants in the current study also emphasized that psychosocial support must be ongoing through the treatment journey and begin immediately after the diagnosis of thalassaemia. Similarly, nurses and physicians in Fan, Lin, Hseih, and Chang's study (2017) perceived psychosocial care as a complex dynamic process of assessment, intervention and follow-up care.

In this study, participants postulated that providing psychosocial care will help families and children in accepting and adapting to the disease. Current evidence suggests that effective psychosocial care improves patients' health outcomes and quality of life (Chen et al., 2017). Previous authors have asserted that a holistic approach of caring for children with thalassaemia can improve the quality of life among these children (Kavitha & Padmaja, 2017).

The competencies of nurses, essential to provide effective psychosocial care for children with thalassaemia and their families, were emphasized in this study. These two competencies were knowledge and skills, and the ability to provide compassionate care. Azize et al. (2015) found that the nurses in the Kurdistan region of Iraq lacked detailed knowledge about the genetics and management of thalassaemia and considered themselves as being uninvolved in patient education and providing psychological support. Fan et al. (2017) stressed that physicians and nurses should have the requisite skills and distinct characteristics including caring, passion, ability to form trusting relationships, and a genuine interest in patients and their families.

Communication skills were also identified as a vital skill to build a therapeutic relationship with patients and families. Legg (2011) asserted that effective verbal and non-verbal communication skills along with good assessment skills are necessary for nurses to establish a rapport with patients and develop therapeutic relationships with patients and their families. Participants in this study described how they are psychologically affected by the situation of the patients they interact with. This finding has also been observed in a previous study by Fan et al. (2017).

The findings of this study identified barriers in providing psychosocial support. These barriers included a lack of specialists for providing psychosocial care, as well as a lack of screening tools, training for nurses and entertainment facilities for children. Similarly, Fan et al. (2017) found that healthcare providers lacked standardized methods to provide psychosocial care such as asking questions and responding to patients. These challenges were in addition to their excessive workload and lack of collaboration and support from psychosocial care professionals. Chen et al. (2017) revealed barriers perceived by nurses in Singapore; these barriers included lack of time, language barriers, being task-oriented, excessive documentation, lack of family involvement and fear of complaints. Hence, to improve the psychosocial care in thalassaemia units, nurses in this study stressed on the need for specific assessment tools to screen for psychosocial problems and needs of children with thalassaemia and their families. Participants also suggested conducting training programmes and seminars to improve nurses' abilities to assess psychosocial problems and needs, and provide appropriate psychosocial care. Chen et al. (2017) recommended designing interventions to develop the skills and abilities of nurses to integrate psychosocial care in their practice, which will enhance patient outcomes. Participants further recommended having a dedicated psychotherapist or social worker who is specialized in providing psychosocial care and support for children with thalassaemia and their families. In this regard, Behdani et al. (2015) recommended establishing psychiatric clinics that deal specifically with children in addition to thalassaemia clinics such that the psychological problems associated with thalassaemia can be addressed and resolved. Authors of previous studies have also recommended training for healthcare providers to develop their communication and psychosocial care skills (Botti et al., 2006; Moore et al., 2018; Wallerstedt & Andershed, 2007). Communication skills training courses have been effective in enhancing healthcare professionals' communication skills, empathy and supportive skills while caring for patients with cancer (Moore et al., 2018). Multidisciplinary teams and support from psychosocial care specialists have also been suggested (Fan et al., 2017).

Participants in this study also suggested the presence of playrooms for children in thalassaemia units as well as the need for age-appropriate entertainment tools. A previous study conducted in Jordan revealed that children with cancer positively regarded the presence of entertainment facilities such as playrooms and age-appropriate games in a cancer treatment centre (Abu Shosha et al., 2013). According to Legg (2011), nurses should generate a supportive environment whereby the patient feels comfortable, calm, and safe to interact and communicate with others.

5 | CONCLUSION

Nurses demonstrated a range of experiences related to the present psychosocial care provided for thalassaemia patients and their families. Nurses should be further trained to provide psychosocial care for patients and their families. Having specialists to provide

psychosocial care and establishing entertainment activities for children are vital interventions to lessen the impact of thalassaemia on children. Teaching at least one course regarding the provision of psychosocial care in nursing faculties, conducting training courses and using specific assessment tools to assess psychosocial care needs are very important strategies to help in providing such care. Working within a multidisciplinary team that includes paediatric psychotherapists, and improving the infrastructure of thalassaemia treatment centres to be tailored to children age are also suggested. Future research is recommended to assess the psychosocial care provided for thalassaemia from the perspectives of children and their families.

6 | LIMITATIONS OF THE STUDY

The limitations of this study are the small sample size of 10 participants who were recruited purposefully to achieve data saturation. The findings of this phenomenological study cannot be generalized to a wider population. However, the findings can be generalized to other children and families with similar situations.

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CONFLICT OF INTEREST

The authors report no actual or potential conflicts of interests.


AUTHOR CONTRIBUTION

All authors have contributed to this work as follows: Ghada Abu Shosha and Noordeen Shoqirat: Writing the introduction and methods sections. Ghada Abu Shosha and Mahmoud Al-kalaldeh: Data collection. All the three authors: Data analysis, writing the results and discussion. All the three authors: Preparing the manuscript for publication.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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