RESEARCH ARTICLE

Parents’ Experience and Healthcare Needs of having a Hospitalized Child with Burn Injury in Jordanian Hospitals: A Phenomenological Study Protocol

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Abstract:

Background: A burn injury is a traumatic experience for the affected children and their parents. During the children’s burn injury treatment and hospitalization journey, parents experience many unmet needs. However, parents’ experiences and healthcare requirements during their children’s hospitalization have not been adequately addressed in the literature, especially in Jordan.

Objective: A study is designed to gain in-depth knowledge of the parents’ experiences of children who require hospitalization for treatment of unintentional burn injuries.

Methods: A descriptive phenomenological approach will be applied. Purposive sampling will be used to select parents from one teaching hospital and one public hospital. The researcher intends to collect data from the parents throughout their hospital experience from their child’s admission until after the child is discharged. The investigation and data gathering will continue until data saturation is reached. Data will be collected in three ways: multiple face-to-face semi-structured interviews with parents, the researcher’s field notes, and the parents’ diaries. The description of the phenomena will be performed following Colaizzi’s analysis method.

Result/Discussion: The findings of this study will be an original contribution to the current literature in enhancing the understanding of pediatric burn victims’ parents’ experiences and healthcare needs during their child’s hospitalization. It is believed that the findings will help improve the quality of healthcare services provided to the parents of pediatric burn victims.

Conclusion: This study protocol is shared to promote research quality and transparency and to inspire interested researchers.

Keywords: Burn injuries, Children, Descriptive phenomenological study, Healthcare needs, Hospitalization, Parents.

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1. INTRODUCTION

A burn is a skin injury that may involve an individual’s organs and other tissues. Burns are commonly caused by heat but may also result from exposure to radiation, radioactivity, electricity, friction, or chemicals. Globally, burns are the fifth most common cause of non-fatal childhood injuries, and children are more at risk of a burn injury than adults [1], creating a significant challenge to pediatric healthcare and children and family wellness worldwide.

Epidemiologic studies demonstrated a worldwide trend of non-fatal burn incidence and hospital admissions increasing among children and adolescents than adults [2, 3] and younger than older-age pediatric burn victims [4-6]. Non-fatal burn injuries in children are a leading cause of morbidity that requires prolonged hospital care [1]. Depending on the severity of the injury sustained, a pediatric burn victim’s hospital stay...
may range between 1 and 204 days [5, 7, 8]. Compared to children who maintain non-burn injuries, pediatric burn victims are usually required to be hospitalized for double the number of days [9]. This extended hospital stay may profoundly affect the family’s overall quality of life and disrupt their daily routine.

Generally, a stay in a children’s hospital is a stressful experience for both the child [10, 11] and their parents [12]; the parents of a pediatric burn victim are no exception [13]. The parents’ routine and schedule will need to be adapted, and the family dynamics may be altered accordingly. Parents of pediatric burn victims frequently experience social isolation and overwhelming changes in their parenting roles, family relationships, and their ability to care for siblings [13 - 15]. It is in addition to potential financial problems [16] and unmet physical needs that arise from sleep deprivation and irregular eating patterns [13, 17]. Parents of pediatric burn victims also experience significant negative psychological consequences [13, 18]. Many experience depression, significant emotional distress, profound guilt, self-blame, and posttraumatic stress disorder [19 - 21].

Ideally, healthcare professionals and nurses, in particular, should be trained to recognize these conditions and provide emotional support to these parents. It is imperative within a family-centered care model. Where family members act as caregivers and provide assistance with everyday activities, it is of great significance that patient care plans are developed and implemented within the family context [22]. However, a literature review reveals that the hospital experiences of parents of children with burn injuries are less than ideal and that their healthcare needs, including support and guidance, often go unnoticed and are unfulfilled [23].

The first step towards supporting the parents of pediatric burn victims is to identify their specific needs. To do this in culturally competent terms, there is a need to understand their experience of having a child in the hospital to treat a burn injury. Specifically, the healthcare workers would need to be sympathetically and knowledgeably aware of the parents’ experiences and evaluate these from their perspective and within their cultural context. Currently, there are few studies from which programs that enable nurses to understand the parents’ experience and needs during their child’s hospitalization can be generated. It is valid for East Mediterranean countries as well, including Jordan.

In Jordan, a few recent studies have been conducted on this topic, but they primarily focused on burn prevalence [3, 24, 25]. According to these studies, the highest incidence of burn injuries was recorded in children aged 10 or younger (44%) [24, 25]. However, the impact of these hospital admissions on the lives of families, parents, and children has not been investigated to date. No study has focused on the parent’s experience of having their child admitted to a hospital with burn injuries. To optimize the family-centered care of pediatric burn victims in Jordan, it is necessary to understand the parents’ experience and healthcare needs.

1.1. Purpose

This descriptive phenomenology study aims to fill a significant gap in academic and healthcare research and provide insight into parents’ experiences of pediatric burn victims during their child’s hospitalization in Jordan. It is intended to determine the healthcare needs of these parents during this difficult time. This qualitative exploration of the phenomena will be conducted with the long-term goal of enhancing nurses’ ability to develop and implement culturally competent family-centered care plans that respond to the parents’ needs and optimize their well-being during their child’s hospital stay.

2. MATERIALS AND METHODS

2.1. Research Approach

This study’s methodological approach and philosophical principles are congruent with descriptive phenomenology. Phenomenology is a philosophy that evolved into a research methodology [26] of the lived experience [27]. Through phenomenology, researchers can engage in a deeper investigation of the lifeworld and acquire a more comprehensive understanding of the everyday life experiences of people [27]. Applying descriptive phenomenology will give the participants a chance to have their voices heard, describe their own experiences, particularly how their child’s hospitalization has impacted their lives, and elaborate on their own identified healthcare needs. This study’s method will generate findings that will contribute to global nursing practice and help improve patient-family-centered care.

2.2. Sampling and Recruitment

The study sample selection is driven by the aim of reaching parents who have lived that particular experience of having a hospitalized child with a burn injury. Therefore, the parent’s enrollment will occur in the medium-level burn units where children and their families from various sociodemographic and geographic areas will be treated.

Participants will be enrolled from two selected hospitals (one university-affiliated hospital and one public hospital), in which specialized healthcare services are provided. The selected hospitals are large referral hospitals with high turnover rates of patients and within the reach and access of the researcher. Specialized healthcare services are provided in these hospitals for a wide range of Jordanian and non-Jordanian patients from rural and urban areas of Jordan, which enhanced the opportunity to recruit parents with diverse cultures, backgrounds, socioeconomic characteristics, and perspectives.

The researcher will enroll the parents by utilizing the purposive sampling method. The inclusion criteria will be as follows: individuals who are adults (aged 19 or older) and who are the parents of at least one child hospitalized for a non-intentional burn injury at the time of data collection will be considered. The children’s parents who will be eligible for participation should be between the ages of one and ten, and the children should have spent at least 24 hours at a medium care ward or burn unit to treat burn injuries.

The researcher will identify potential participants through the hospital’s medical records and will contact them to explain the purpose of the study and the data collection process. If the
parent agrees to participate, the researcher will ask the participant to choose a convenient place to sign the consent form and to hold a face-to-face, semi-structured interview. To raise awareness about the study being conducted at the hospitals, a flyer will be posted on bulletin boards in the nursing meeting rooms and hospital waiting rooms. It will include a description of the study purpose, the procedure to be followed for data collection, and the researcher’s qualifications.

There is no predetermined sample size for this study. Determining the sample size in a qualitative inquiry is a continuous process to reach a certain fullness of knowledge, where themes are confirmed, and patterns of experience are repeated, that is, data saturation. It is often identified by the point of reaching redundancy, where no new data emerges [28]. Therefore, the data collection and analysis will continue until the researcher achieves data saturation.

2.3. Data Collection Procedure

To grasp the essence of the parents’ experience and to reach self-immersion in the parents’ experience, the researcher will investigate the participants’ experiences from the time they agreed to participate, throughout the child’s hospitalization until discharge, and if needed, after the child is discharged and sent home. Additionally, the researcher will utilize a triangulation of three data collection methods: multiple face-to-face semi-structured interviews with the participants, entries from the participants’ structured diaries, and the researcher’s field notes and reflexive journaling.

Interviews are considered the “gold standard” method of generating qualitative data [29]. It permits the researcher to enter the participant’s world, assist them in expressing their individual perspectives concerning their lived experiences, and expand upon the meaning behind their experiences [29]. Additionally, the flexibility of semi-structured interviews allows for an open dialogue and conversation between the researcher and the participants while still enabling them to focus on the primary questions related to the study’s purpose [30]. The participants will be offered diaries to reflect on their experience while attending to the children in the hospital. The diary entries will provide an in-depth and detailed description of each participant’s everyday life and potentially be more focused on the phenomena of interest [31]. Using field notes, the researcher will record all the participants’ nonverbal cues, their interactions, environmental factors of relevance, and salient information related to the participant’s experiences. Additionally, utilizing the field notes, the researcher will reflexively verify their assumptions, feelings, thoughts, observation, and experiences during the interview.

The principal researcher (first author) will conduct all the interviews in person. The interviews will be performed a few days after the children’s admission and when the parents demonstrate being ready to talk to the researcher. That is because the parents may be shocked by the burn accident, and the prognosis is uncertain immediately after the children’s admission; the parents’ focus is expected to be on their children’s health, and the interview may be difficult. This time allows parents to have experiences that would enable them to reflect on what they have experienced and their needs. The researcher will conduct the interviews in the participants’ home language, which will most probably be Arabic, and will avoid any sophisticated or complex vocabulary and concepts. The researcher will initiate a simple conversation to introduce herself to the participant and to break the ice. Then, the researcher will provide the participant with a copy of the Informed Consent Form and discuss the consenting procedure. The researcher will answer the participant’s questions if any. After signing the consent form, the researcher will gather the participant’s and the child’s sociodemographic information and clinical information using a specially designed datasheet.

Then the interviews will take place. The researcher will begin with open-ended, non-leading interview questions, moving from general to specific questions to build rapport. The researcher attempt to gain in-depth information from the participants and will focus on each participant’s experiences. The interview questions will relate to the parents’ perspectives and needs in respect of three specific experiences: 1) Their memories of and emotions related to the accident; 2) The hospital admission process and inpatient experience, 3) The recovery stage and the discharge process. Some guide interview questions are:

1. How did the accident happen?
2. How did the accident affect you physically, emotionally, etc.?
3. Tell me about your experience of being at the hospital?
4. How does it feel to see your child in the hospital?

Before the end of each interview session, the researcher will engage in a debriefing session with each participant to discuss the data gathered in the interview and the accuracy of their account as understood by the researcher. At the end of the interview, the researcher will provide participants additional time to clarify and discuss the information related to their shared experience. The participant will then be given a diary and be encouraged to record their everyday experiences and to document their feelings while staying at the hospital with their children and even after their child is discharged. The researcher will retrieve the diaries from the participants at the end of the data collection period. Finally, the researcher will thank the participants for their assistance. Immediately after each interview, the researcher will prepare field notes. The researcher will document all nonverbal cues the participants displayed, environmental factors of importance, and salient information related to the participant’s experience. Additionally, the researcher will use field notes to record their assumptions, feelings, thoughts, observations, and experiences during the interviews.

Each interview is expected to last between 30 to 60 minutes. The researcher will interview either one of the parents in person separately, in a private and convenient place at the respective hospitals, away from the child. The reason is that some parents may not feel comfortable sharing their experiences in front of their children. Multiple interviews will be arranged with each parent who accepts the invitation to participate until the researcher reaches a sense of saturation about the parents’ experiences.
2.4. Data Management and Analysis

The interviews will be audio-recorded using a digital recorder and transcribed verbatim. The researcher will transcribe each interview on the same day as the interview takes place or so soon after that as circumstances permit. The primary researcher will verify the accuracy of the transcribed data by double-checking the transcribed data while listening to the recorded interviews. Data analysis will be conducted simultaneously with data collection.

Qualitative data analysis is a nonlinear, continuous, and cyclic process. As the researcher initiates the data collection, analyzing these data will begin [29]. To generate an accurate and credible analysis of the parent’s experiences, the researcher will utilize Colaizzi’s analysis method [32]. The researcher will begin by reading the transcribed interviews, field notes, and parents’ diary entries. The researcher will then follow the procedural steps of Colaizzi’s analysis method:

1. Familiarizing themselves with the content of the transcripts to develop a sense of each transcript.
2. Extracting significant statements from each transcript.
3. Formulating what is meant by each powerful statement.
4. Grouping the formalized meanings into a set of themes.
5. Developing an exhaustive description.
6. Generating the fundamental structure of the phenomena, and,
7. Seeking verification of the fundamental structure and findings from the participants.

2.5. Ethical Considerations

Ethical approval has been obtained from the scientific committee of the School of Nursing (Pds. 21.6), and the relevant institutional review boards (IRB) of the Minister of Health (MOH/REC/2021/179) and the university-affiliated hospital (2021/307). Helsinki Declaration has been followed for involving human subjects in the study and written informed consent has been taken from the parents. Each participant has received a written information sheet containing the particulars of the study and has been asked to sign a written consent form before the interviews commence. The researcher verbally discussed the contents of the written information sheet with the participants to ensure that they understood the study’s objective, their role, and what will be expected of them. The researcher has advised the participants that their participation is entirely voluntary and that they may withdraw from the study at any time. The researcher has assured the participants that their participation will not affect the quality of their children’s healthcare at the hospital and that their answers will be kept strictly confidential.

The researcher will provide each participant with a reasonable period to review the written information sheet and informed consent form; the participants will be given adequate time to ask the researcher any questions they may have. Once these formalities have been dealt with, the researcher will be able to commence the interviews and will begin each interview session with a general conversation with each participant to establish rapport and eliminate any awkwardness before proceeding to ask the substantive interview questions.

It is unlikely that physical or economic risks will arise due to parents’ participation in this study. However, parents discussing their experiences and remembering the accident may be emotionally harmful to parents of affected children. Therefore, the parents who may feel distressed or uncomfortable recalling the children’s burn experience will be offered to end the interview immediately, complete it later or withdraw from the study. In case of psychological harm, a referral will be provided to additional psychological professional help if requested or needed.

To maintain confidentiality, each participant’s name will be replaced with an identification number; these numbers will be used in the transcription records and throughout the data analysis and presentations, including any reports or publications. Electronic copies of the interview recordings will be saved on the researcher’s personal computer, which is password-protected. Any hard reproductions of data (diaries and transcribed interview recordings) and consent forms will be kept in a locked cabinet, and no individual other than the researcher will access the locked cabinet. The researcher will be the only individual to transcribe the audio-recorded interviews. The audio recordings of the interviews will be erased upon the completion of the study.

2.6. Rigor and Trustworthiness

The trustworthiness and credibility of this study will be maintained by using the criteria and techniques identified by Lincoln and Guba [33]. According to Lincoln and Guba [33], trustworthiness is “How can an inquirer persuade his or her audience (including self) that the findings of an inquiry are worth paying attention to and worth taking account of.” To build the trustworthiness of a qualitative study, Lincoln and Guba [33] suggested four main criteria: credibility, dependability, confirmability, and transferability.

The researcher will utilize the prolonged engagement technique to establish credibility and build rapport and trust in the relationship between the researcher and the participants. It means that the researcher will engage and immerse themselves thoroughly in a prolonged process of data collection and will interview the participants on the day that the child is admitted to the hospital, at various points throughout the child’s hospitalization (even if the child is transferred to another hospital), and after the child is discharged from hospital. In addition to multiple interviews, the researcher will use methodological triangulation to incorporate data from examining their own conceptual lens, explicit and implicit assumptions, preconceptions, and values and ascertain how they affect research decisions in all phases of qualitative studies (reflexivity) and field notes and the parents’ diaries. The researcher will focus on situations, observe the parents’ attitudes towards the healthcare and providers, explore every healthcare issue and need in detail, and analyze the data that would be salient to the phenomenon to be studied.

The researcher will conduct ongoing member checking whenever data are collected using probing questions to ensure that the participants’ views are correctly understood. In
addition, the researcher will establish member checking after data is transcribed and after data analysis is completed. To this end, the researcher will meet face-to-face with each participant and have them review the transcript of the recorded interview to confirm the accuracy of the transcription. Moreover, upon completion of data analysis, the researcher will again discuss the findings and themes generated with the participants to ensure that they accurately represent the parents’ experiences.

To address the confirmability and dependability of the findings, the researcher will utilize the face-to-face semi-structured interviews, field notes, and participants’ diary entries as triangulation methods to collect credible data accounts. In addition, all collected data (e.g., audiotapes, notes, observations, transcripts, etc.) will be archived and organized for auditing the data collection process and validation of the data analysis.

Finally, to address the transferability of the findings, the researcher will provide comprehensive descriptions of the study participants, the setting, the data collection methods, the data analysis procedure, the thematic synthesis, and direct quotations of participants’ words. Additionally, the researcher will utilize field notes and reflexive journaling as tools to provide more detailed information and a description of the study environment and the researcher’s thoughts and ideas throughout the study. Furthermore, the researcher will encourage the participants to record their daily experiences in a dedicated diary.

3. RESULTS AND DISCUSSION

A detailed account of an in-progress study protocol has been shared in this study. A descriptive phenomenological qualitative approach will be used to explore parents’ experiences of having their child hospitalized for burn injury treatment and understand their healthcare needs during this period. To understand parents’ experiences comprehensively, the researcher will combine several data collection methods: face-to-face, semi-structured interviews, field notes, and parents’ diary entries. Furthermore, the researcher will use Colaizzi’s analysis method to guarantee an accurate and credible investigation of the parents’ experiences.

There are many benefits to be gained from sharing a detailed description of a study protocol with other researchers. Publishing a study protocol assists researchers with similar research interests to be introduced to alternative research methods, to encourage a focus on various other issues, or motivate them to continue with their current research [34]. It also assists in preventing duplication of the same research topic and theoretical perspective [35 - 37]. In addition, sharing a research protocol may enhance research quality and transparency [36] as it allows for comparability between the final findings reported and the proposed study aim and methodology [35, 37]. It also assures that the researcher who conducts the proposed study and analyzes the collected data will do so according to the planned protocol [36], thereby eliminating biases [35, 37] and avoiding the repetition of the same flaws or limitations of a study protocol [34, 38].

This study is designed to fill a known research gap in healthcare knowledge not only in Jordan but also in the literature worldwide. Investigating and describing the experience and the healthcare needs of parents who find themselves in this particular situation will provide reference information to nurses, pediatricians, healthcare providers, educators, and policymakers who should be interested in optimizing the well-being of patients and their families and in improving family-centered care. In addition, healthcare policies could be developed or modified to provide parents and pediatric burn victims with the best care possible. For instance, if healthcare providers had a better understanding of parents’ experience, they could support parents and facilitate improved coping strategies to avoid the negative consequences of the hospitalization experience.

In pediatrics, the family-centered care approach is based on recognizing parents’ vital role in their children’s recovery, as they are their children’s primary source of support [39]. To provide comprehensive family-centered care for pediatric burn victims in Jordan, nurses need to better understand parents’ experiences and unmet healthcare needs during their child’s hospital stay. In Jordan, there is insufficient awareness of the needs of the parents of sick children. Consequently, these needs are frequently overlooked, and parents are not involved in the healthcare plans made for their children in Jordan [40]. Generally, nurses in Jordan have little focus on the involvement of parents in their child’s healthcare planning and do not consider parents’ experience in clinical practice. This situation is particularly true for inexperienced nurses who have not specialized in pediatric care [41]. Thus, if healthcare providers, nurses, in particular, have a better understanding of parents’ healthcare needs, it will promote the development of plans to address them. Moreover, this awareness should facilitate the inclusion of parents in the decision-making process, thereby strengthening the partnership between the family and healthcare providers and should improve the quality of family-centered care. Parental participation in the healthcare of their hospitalized children has been associated with parents’ sense of fulfillment of their parenting duties and has predicted lower parental depression scores [42].

This study will make an original contribution to the national and international body of knowledge in the field of parent and child nursing care. This study is the first qualitative study to explore the experiences and healthcare needs of parents of pediatric burn victims in Jordan. The findings will provide baseline information about Jordanian parents’ healthcare needs, upon which further quantitative and qualitative research and recommendations could be initiated.

4. IMPLICATIONS FOR NURSING

One of the potential limitations of this study would be the generalizability of findings. Generalizability concerns the applicability of the research findings to other individuals and portions of the population beyond the study participants [31]. Qualitative inquiries are usually more concerned with transferability than generalizability [43], as the qualitative researcher aims to understand the individuals’ experiences and generate context-based knowledge. Therefore, the results of a qualitative study are not expected to be generalized widely but rather to be able to be transferred to other settings within the
same context of the particular study [31].

CONCLUSION

In this study, a descriptive phenomenological qualitative approach will be utilized to explore the parents’ experience of having their child hospitalized for burn injury treatment and to understand their healthcare needs throughout this hospitalization period. It is submitted that the study results can be transferred to other settings and contexts where a child is hospitalized.

AUTHORS’ CONTRIBUTION

All authors made substantial contributions to writing the study’s full manuscript and approved its final submitted version.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval has been obtained from the scientific committee of the School of Nursing (PDs. 21.6), and the relevant institutional review boards (IRB) of the Minister of Health (MOH/REC/2021/179) and the university-affiliated hospital (2021/307).

HUMAN AND ANIMAL RIGHTS

No animals were used in this research. All procedures performed in studies involving human participants were in accordance with the ethical standards of institutional and research committees and with the 1975 Declaration of Helsinki, as revised in 2013.

CONSENT FOR PUBLICATION

Informed consent was obtained from all participants.

AVAILABILITY OF DATA AND MATERIALS

The data and supportive information are available within the article.

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest financial or otherwise.

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REFERENCES

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