

ORIGINAL RESEARCH

PERIOPERATIVE MEDICINE

Lived experiences of mothers caring for children with burn-induced disabilities

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ABSTRACT

Objective: Burn itself is a highly painful phenomenon, but even well after the burn wounds have healed, the resultant disabilities in children continue to tax the patience and the ability to care of the mothers of handicapped children. The present study was conducted to explain and interpret mothers' experiences in caring for children with burn-induced disabilities with the interpretive phenomenological method.

Methodology: The research population included the mothers of children with burn-induced disabilities selected through purposive sampling. Face-to-face unstructured interviews were conducted and recorded with an interview guide, and data saturation was achieved after interviewing six mothers. Data were analyzed based on Dickelman's method.

Results: The analysis of the data extracted from the interviews revealed that mothers' lived experience of caring for children with burn-induced disabilities could generally be divided into five themes: 1) psycho-emotional breakdown, 2) trying to maintain increasing distress, 3) life continuation in the meaning of care and compensation, 4) raising the child in the care bed, and 5) attention and trying to reach the goal despite the disability.

Conclusion: Mothers of children with burn-induced disabilities experience a wide range of emotions, concerns, and experiences. It's important to acknowledge and understand these feelings to ensure the well-being of both the mothers and their children.

Key words: Burns; Care; Disability; Mother; Phenomenology

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1. INTRODUCTION

Burns are a serious public health problem and a primary reason for hospitalization in trauma and surgery units.¹ Burn injury is one of the most damaging, painful, and stressful experiences with disruptive effects on normal life, accompanied by social, economic, and public health outcomes due to the physical consequences and stigma related to disability and disfigurement in many cases.² Burns are a type of local damage with a complex systemic disease. They are difficult to treat and involve

a significant resulting disability.³ Achievement of the proper functioning of body organs is an important goal in treating burn patients. However, fulfilling this goal is not always possible, and the damage caused by burns affects the structure and function of almost every organ.⁴

Functional limitations are a major concern in burn patients that lower their independence and incur more psychological pressure on their recovery process.⁵

Serious burn injuries can cause complications, such as dysfunction of body organs (particularly kidneys and liver), sepsis or septic shock, eye injuries, and even

amputation. As a serious complication of burn injuries, amputation strongly influences various aspects of one's life after a burn experience.⁶ In this respect, the quality of life of these patients is four times lower than other patients suffering only from burns. Burn patients with disability have low self-esteem and poor mental image of the body. These people feel as if they are unattractive to others.⁷ Moreover, burn-induced disabilities have economic effects (e.g., disruptions in productivity, return to work, and financial constraints) and social effects (e.g., stigma, ridicule, and sympathy) from others for burn patients and their families.⁸ Children's burns are a public health problem and the fifth cause of non-fatal injuries worldwide.⁹ Burn injuries represent a stressful experience and cause major concerns in the age group of children.¹⁰ Mortality has been significantly reduced due to advances in the acute stage management of children's burn injuries, including therapeutic fluids, burn wound dressings, antibiotic therapy, and appropriate nutrition. The victims suffer some changes in body appearance and permanent disabilities that chiefly impact their growth, performance, and beauty.¹¹ Hence, returning to society with these disabilities is very stressful for them. Burn experience in childhood may lead to delays in growth and development and behavioral/social problems inside or outside the family; in fact, burns have both psychological and physical consequences.²

Recovery and rehabilitation for severe burns requiring surgical intervention may be time-consuming and accompanied by a prolonged treatment, which can lead to a continuous experience of emotional-psychological tension for injured children and their relatives due to repeated painful medical treatments, recall of the event, and observation on the child's physical conditions.⁹ Overall, burn injuries can lead to severe functional, social, and psychological disabilities.¹² Children with burn-induced disabilities experience less positive emotions, and their social isolation and physical complaints are more than those with burns but without disabilities.⁸

Since parents have the strongest influence on the child's life,¹² they play a unique role in physical care provision and psychosocial improvement of the child in the hospital and after discharge.⁹ Some parents cope mentally and emotionally with the incident and damage and try to manage the situation. Some others show increasing distress over time, affecting their health and other family members.¹³ According to previous studies, parents of children with burns suffer from psychological disorders because parents often deem themselves responsible for the injuries of children's burns.¹⁴ Anxiety (13-47% of cases), depression (23-61% of cases), and post-traumatic stress disorder (30% of cases) are the commonly identified psychological disorders.¹⁵

Having several years of experience in caring for children with burns, the researchers have repeatedly witnessed the impact of child burns and the resulting organ defects on the behaviors, and interactions of parents, and how to care for children with burns. After passing through the acute stage of burns and their recovery, the main concern of parents is how to take care of their child after discharge and returning home, which is more visible in parents with organ defects combined with burns. Parents of children with organ defects caused by burns must deal with their child's organ defects in addition to burns and undertake rehabilitation care because rehabilitation is an integral part of children's burn treatment and its inadequacy can lead to Serious physical and mental damage with lifelong effects.

According to the researchers' experience, parents experience different emotions in the long-term care and rehabilitation of a child with a burn accompanied by a disability. They encounter issues such as financial problems, conflict with their spouses, washing and changing the daily dressing of the burn wound, care for the disability area, medications, normalization of family members' reactions to burns and disabilities, acceptance of appearance changes, and psychological issues of the child and its return to the previous routine of life and presence in the society. Even over-protection of the child may influence the behavior of other children in the family; thus, parents should manage the situation. As the main caregivers of children with burn-induced disabilities, the mothers experience different emotions in caring for their children despite the two crises of burns and the resulting disabilities.

Unlike other acute traumas, burn injuries with extensive wounds, are associated with daily painful and uncomfortable wound care methods, long-term hospitalization, scar formation, lifelong disability, and emotional, psychological, social, and economic disorders resulting from it, which makes a deep investigation on this subject valuable and relevant. Therefore, we aimed to understand and document the mothers' feelings, who simultaneously experience two crises of burns and disabilities of their children.

2. METHODOLOGY

The current qualitative study with a hermeneutic (interpretive) phenomenological approach was conducted to discover the meaning of mothers' care for their children's burn-induced disabilities. The phenomenological method was used as the study aims to discover and represent the perceptions of human experience about the phenomenon.

Hermeneutic phenomenologists interpret human experiences not only from the subjects' perspectives but

also from social and historical influences.¹⁶ The idea of access to people's daily experiences corresponds to Heidegger's philosophy, emphasizing that people's experiences may be understood and interpreted through their language, history, and cultural factors.¹⁷ When Reeder (1985) discusses the specific application of hermeneutics in nursing, he declares its usefulness for research purposes and believes that joining hermeneutics and nursing produces an active ontology.

2.1. Participants

The participants were selected from mothers of children with burn-induced disabilities based on purposeful sampling according to predetermined criteria, including their experience.

In a phenomenological study, the researcher seeks participants who share their experiences about a given phenomenon but are different concerning individual characteristics and experiences.¹⁸ In this pilot study, therefore, the participants were sampled with maximum variety,¹⁹ and burn-induced disabilities, burn levels, burn site, child's age, other burn complications, and the causes of burns were considered in a wide range. Furthermore, the themes encompassed mothers' experience of caring for a disabled child with all these characteristics.

Mothers, who were the main caregivers of the children and were interested in the research participation, could express their feelings and experiences and did not have a disabled child or another chronic disease included in the study. Mothers' experiences were examined after at least one month of the discharge of their children to have a rich experience of care and who could recall their experiences.

Six mothers who cared for their child's burn disability were selected for the study. Their age ranged between 35 and 45 y, with education levels of drop-outs, high school diplomas, and bachelor's degrees. They had 2-3 children in the age range of 6-15 y. Hands, feet, and ears were the sites of children's disability. These organs were damaged by firecrackers, fire, and electrocution. Participant selection was terminated when no additional data were obtained from interviews, and they provided descriptions rich in shared meanings. Saturation occurred during the interview with the sixth participant in this study.

2.2. Data collection

The researcher obtained the code of ethics and permission to attend burn centers, identify the participants, and establish effective communication. The study objectives were explained to participants who agreed with the researcher and presented consent for the time/place of the first meeting. The researcher's contact number and the address of the faculty were provided to

the participants to contact the researcher about questions or for additional interviews. Most of the interviews were conducted at the participant's home, and some others were made at their designated places, such as a park and a hospital clinic. The main data collection method in this research was based on individual interviews. The researcher recorded all the presuppositions and personal mentalities before the interviews to conduct interviews fully informed of the presuppositions and avoid inducing personal mentalities in the participants during the interviews. Throughout the interview process, facial expressions, voice tone, and non-recordable gestures were recorded as notes in the field, and the analysis was performed during the interview and added to the recorded items.

The interview form consisted of two sets of questions: one set of main interview questions and the other set of follow-up questions. For instance, "Can you explain more?" was a follow-up question. Data collection started with an unstructured interview with open questions and continued with a semi-structured interview. During the interviews, the researcher was a listener, did not agree or disagree with the mothers' statements, did not direct their conversations, and used silence at a suitable time to create a comfortable atmosphere and encourage the participant to continue the dialog. Data analysis started after the first interview, and the recorded text was written down verbatim after the interview.

2.3. Data analysis

According to the philosophical basics of the current research, the research data were analyzed using the method of Dickelman, Allen and Tanner (1989). Accordingly, the study focus was on the need to consider the researchers' mental assumptions and experiences in the data interpretation process to achieve the highest level of abstraction in explaining the mothers' experiences of caring for a child with a burn disability. This method is commonly used for data analysis in interpretive phenomenological research.²⁰ Team participation in the data analysis process and the discussion/exchange of opinions among research team members are the remarkable features of this method that enrich the interpretations while creating new insight.²¹

Data were collected and analyzed simultaneously. Finally, based on the hermeneutic circle movement (i.e., part to whole and whole to part), a comprehensive interpretation was obtained from the texts and theme analysis.

To start the hermeneutic analysis, based on the first step of Dickelman's seven-step method, the transcribed texts of the interviews were carefully read several times to achieve a general understanding of the text. Then, the texts of the interviews were sent to respected professors

Table 1: The structural model, themes, sub-themes, and extracted semantic units

Structural model	Themes	Sub-themes	Extracted semantic units
The heavy price for a moment of neglect	Psycho-emotional breakdown	<ul style="list-style-type: none"> - Failure in the role of a mother with negligence - Constant internal dialogue with yourself - Mental erosion 	<ul style="list-style-type: none"> - Self-blame - Tolerating the pressure of self-control - Keeping the incident alive with a constant mental reminder
	Trying to maintain increasing distress	<ul style="list-style-type: none"> - Participation in the care of the lasting pain and suffering of the child - Care without recovery - Full-time care -The growth of care suffering with the growth of the child 	<ul style="list-style-type: none"> - Observing the child's pain in the hospital and after that - Durability of defects - 24-h and non-stop care - Facing the development of the child's disabilities as he gets older
	Continuation of life in the meaning of care and compensation	<ul style="list-style-type: none"> - Compensating the role of an incomplete mother -Atonement 	<ul style="list-style-type: none"> - Being at the service of the child to make up for the lack of motherhood - Doing anything to make up for the fault and negligence
	Raising a child in the context of care and attention	<ul style="list-style-type: none"> - Child support - Child protection - Giving centrality to the child 	<ul style="list-style-type: none"> - Do anything for him/ her - Defending him against others - Trying to protect him/her from people's gaze - Ignoring the child's mistakes - Differentiation from other children
	Trying to reach the goal despite disability	<ul style="list-style-type: none"> - Hope for the child's independence and lack of need - Hope for the success of the child despite the defect 	<ul style="list-style-type: none"> - The child's independence in doing things in the future - Self-sufficiency of the child in the future - The lack of importance of the child's handicap despite the success in the future

as members of the research team to obtain their opinions and guidance on the interview process quality. The received suggestions from the professors were applied in the next interviews.

In the second step of Dickelman's method, an interpretive summary of the text of each interview was written to facilitate a general understanding of the text. Next, the text of each interview was entered into the MAXQDA 2020 software environment to facilitate data management and themes extraction, followed by extracting semantic units (coding in the third step of Dickelman's method), the texts of the interviews were analyzed to identify the themes. At this stage, the interviews and analyses were studied by all research team members, and corrective comments were applied to the analysis text.

In the fourth stage of Dickelman's method, likely contradictions in the analyses and interpretations were resolved by referring to the texts. The participants were

re-interviewed in the case of a need for further explanation and to clarify the ambiguity. In the fifth stage, the texts were compared and contrasted to determine and describe the themes reflecting common meanings. At this stage, five themes were extracted from the participants' interviews. In the sixth stage, the themes were reviewed and compared to identify the structural pattern existing in the texts of all interviews and linking the communication themes. In the seventh (final) stage, a draft of themes and patterns, along with excerpts taken from the texts of the interviews, was provided to the research team. The comments and possible suggestions were applied in the final draft of the findings to prepare the final research report.

3. RESULTS

The analysis of the data obtained from the interviews indicated that the mothers' lived experiences of caring for children with burn-induced disabilities could

generally be classified into a structural model called the heavy price for a moment of neglect with five themes: 1) psycho-emotional breakdown, 2) trying to maintain increasing distress, 3) life continuation in the meaning of care and compensation, 4) raising children in the context of care and attention, and 5) trying to reach the goal despite the disability.

3.1. Psycho-emotional breakdown

A mental breakdown, also known as a nervous breakdown or a mental crisis, is a period of confusion that occurs in response to an external stressor that may be accompanied by physical, psychological, and symptoms related to behavior such as sleep disturbance, reduced concentration, and transformation of mood. The major reason for nervous breakdown is the occurrence of difficult situations that are not expected and predictable for a person.²² The psycho-emotional breakdown theme includes three sub-themes of failure in the maternal role with neglect, continuous internal dialogue with oneself, and mental erosion. These sub-themes were achieved with the meaning units of feeling self-blame, bearing self-control pressure, and keeping the incident alive with continuous mental recall.

The data analysis showed failure in the maternal role with neglect. In this respect, mothers would not forgive themselves due to negligence in performing motherly duties. They have mental rumination or internal dialogue with themselves and constantly think negatively about their fault when caring for their children's disability. In this situation, mothers deem the child's disability indicative of their neglect and feel failure in caring for their children. Mothers of children with disabilities feel a fault in their responsibility and failure in fulfilling their motherly duties. Because some mothers consider themselves the main cause of the child's disability, they are willing even to suffer disability in place of the child. For example, participant 2 said, "*I wish one of my fingers would be amputated, but my son would not have been like this...it is very tough to bear this because I am at fault*". The sense of guilt in some mothers becomes stronger with time as they do not forgive themselves due to neglect and think their mistakes to be irreparable.

Mothers who care for children with disabilities often experience feelings of self-blame. They continually blame themselves for their inadequacy in motherly duties. When mothers take care of a child's disability, they blame themselves by recalling the event and the reaction of their companions. They put themselves on internal judgment as the kid suffers. For instance, participant 3 said that "*It is very tough for me every minute and every second I see him like this, I blame myself*".

In their experiences, mothers point to mental burnout despite enduring the self-control pressure and constant mental recall of the incident during care. Self-control is the ability to regulate one's feelings, thoughts, and behavior when facing negative emotions, leading to positive consequences such as controlling various difficult situations in life.²³ Mothers do not show their feelings and concerns to their children when caring for their child's disability to prevent lowering the child's morale and to control the situation. To return the child to the previous routine, although they pretend the situation is normal to the child, they endure heavy psychological pressure. For example, participant 3 said that "*I hate every time I spend with him, and I tell myself I shouldn't be upset with him although I'm under pressure*".

During the caregiving period, mothers endure physical pressures, such as continued headaches, hypertension, sleep disorder, and low weight, but they do not show the pressures. For instance, participant 1 said that "*I did alone all his work. I always had a headache, I could not sleep well, I had no appetite, but I stood it, I am almost the same now, but there is no other way, I stand*". Mothers endure the burden and care of their child's illness, consider themselves engaged in a compulsory situation, and do not accept new conditions in life. These mothers tolerate the pressure of introjecting emotions and do not feel peace with their children's disability. In this regard, participant 4 said that "*I suffer because of her condition; there is no other way; I have to get along with it ..., I have to get o*".

In their experiences, mothers point to keeping the incident alive with continuous mental reminders during care. Mothers constantly remind the incident and experience severe stress and anxiety near the event. These mothers still remember the details of the incident even several years after the event. In this respect, participant 5 mentioned that "*This tragedy happened to us about 2 years ago; it was a very bad time, it was all agony; I can remember that day second by second*". Participant 1 also stated that "*The entire event is always in front of my eyes; I feel down when getting close to the Wednesday fireworks; I feel like it's going to happen again; I always think about that time as if it was just yesterday*".

3.2. Trying to maintain increasing distress

The theme of trying to maintain increasing distress includes four sub-themes: participation in the care of the child's persistent pain and suffering, care without recovery, full-time care, and the growth of care suffering with the child's growth. These sub-themes were achieved with the semantic units of observing the child's pain by the mother in the hospital and afterward, continued disability, the mother's 24-h and constant

care, and her encounter with the development of the child's disabilities with increasing age.

According to the data analysis, mothers participate in caring for the child's continued pain and suffering by observing the child's pain and suffering in the hospital and later on. Mothers think caring for a child's disability is difficult with suffering and desperation. For instance, participant 3 said that *"It is too tough for me to take care of him, I went through a really bad situation, and even now, I'm not fully at peace"*. Likewise, participant 4 stated that *"When I cared for her, I saw that she was getting hurt and crying; it was too tough for me. When she was in pain, I cried with her and felt sad"* These mothers consider caring for their children's disabilities to be endless and accompanied by distress. Participant 6 stated, *"I care for him forever, and I will suffer from his hand until the end of my life"*.

In their experiences, mothers mention care without achieving the child's recovery due to the permanent disability. These mothers consider it useless to care for disability and express their desperation because the child does not return to the previous routine. For example, participant 2 stated that *"Even if I take care of her all my life, she will not regain those fingers, and there is no hope"*. Similarly, participant 1 said, *"It is taking care of something that will not get better, and you just have to be careful not to get worse"*.

Mothers are usually considered responsible for caring for children, particularly those with disabilities.²⁴ In many cases, the mother gives up her life to concentrate on child care, which chiefly affects her daily life and requires more time and effort.²⁵ The presence of a child with a disability requires long-term attention for psychophysical care, which plays a decisive role in the child's health. In addition to physical care, they pay special attention to the psycho-emotional care of their children. These mothers are always attentive to the child's condition and express sensitivity and precision in providing care. For example, participant 1 stated that *"I didn't sleep at all; I was always taking care"*. Participant 2 mentioned that *"I took care of her myself and did not leave her for a moment; I took care of her 24 h a day"*. Similarly, participant 3 said that *"I didn't sleep at all after the hospital. I always cared for him. I prepared a bed for him that was far from the ground so that I could control he wouldn't get an infection. I also had to support him emotionally"* In this regard, participant 4 stated that *"I used to do everything for her on time, and I would take her to the park not to feel mental pressure"*.

Mothers state the growing caregiving distress as they encounter the development of the child's disabilities with increasing age. These mothers worry about the children's understanding of their disabilities and are afraid of their reaction and adaptation to disabilities.

Mothers are also concerned about the child's lack of independence in the future. In this regard, participant 3 stated that *"I am afraid that he will depend on us for his work until the end of life"*. Similarly, participant 5 said that *"I am afraid that he will grow older and not go along with his disability"*. Participant 2 also denoted that *"I don't know how she will react to her hand when she grows up ... if she can go on with it or not"*.

3.3. Continuation of life in the meaning of care and compensation

The continuation of life theme in the meaning of care and compensation includes two sub-themes of compensation for an incomplete maternal role and fault compensation. These sub-themes were achieved according to the semantic units of service provision to a child to compensate for neglect in the maternal role and struggle to compensate for the fault and negligence on the other's behalf. Mothers with disabled children have found the continuation of their lives in the meaning of care and compensation.

Based on the data analysis, mothers of children with disabilities serve their children to compensate for the neglect in the maternal role. These mothers think of child care as the meaning of their lives. They no longer neglect their motherly duties for compensation, absolutely focus on the child's affairs, and carefully take the child's care responsibility. These mothers have tied maternal duties and roles to care and undertake both mother and caregiver roles. In this connection, participant 3 said that *"I am his gardener; if I leave him alone without watering and do not trim his sides and corners, I feel that he will dry up. I care for him as it should be for a mother"*. Also, participant 2 stated that *"I am a mother and also a nurse besides being a mother, and I have to take care of her motherly"*.

Mothers of children with disabilities have tied their lives to care as their lives pivot around child care. They always pay attention to the child's condition. In this regard, participant 4 stated that *"I am with her in all stages of her life, and I do not neglect her"*.

These mothers undertake full child care to compensate for their faults and negligence, for which they do everything. Accordingly, participant 1 asserted that *"I cheer up him by talking, calming, taking to the cinema or the park, and buying a bicycle; I want to compensate for him"*. Moreover, mothers try to correct their children's disabilities. In this respect, participant 6 expressed that *"I will give him a prosthesis anyway to live comfortably"*.

3.4. Raising a child in the context of care and attention

The theme of raising a child in the context of care and attention includes three sub-themes: 1) child support, 2) child protection, and 3) child centrality. These sub-themes were achieved according to the semantic units of doing everything for the child by the mother, the mother's defense of the child against others, trying to protect the child from people's eyes, ignoring the child's mistakes and other life issues, and the child defense from other children.

The data analysis shows that mothers try to sympathize with the child and heavily support the child emotionally because they take account of the child's mental peace. Mothers are sensitive to their children's lives and try to ensure that nothing is deficient in their children's lives. For instance, participant 4 stated, "*I don't want her to be sad about anything; I won't miss anything for her because she doesn't have a finger*". Participant 2 claimed that "*I do whatever my child wants; I just want her to be happy in this condition*".

The mothers' protect their children's from people's stares and defend them from others. For instance, participant 3 asserted that "*I try to notify my companions to understand his conditions and do not talk about his shortcoming*". Besides, participant 2 mentioned that "*I am always with her outside not being bothered by others. I try to distract her not to see people's eyes on her*". Participant 1 said that "*As long as I live, I will not let anyone make fun of him. I am always careful that others do not bother him with this condition*".

In the data analysis, mothers express their child's centrality in their lives. They ignore the child's mistakes and other issues in life, even discriminate between their children, and focus and prioritize their lives on the disabled child care and attention. For example, participant 5 stated that "*Although I have other problems in my life, I don't let him feel a shortcoming, and I do everything for him on time; I even have an eye on him more than my other kids*".

3.5. Trying to reach the goal despite disability

The theme of trying to achieve the goal despite disability consists of two sub-themes, hope for the child's independence and needlessness and hope for the child's success despite disability. These sub-themes were achieved according to the semantic units of the child's self-sufficiency, doing personal tasks in the future, and no importance of disability despite success in the future.

According to the data analysis, mothers of children with disabilities try to make their children independent to be able to do their tasks in the future, take care of themselves, and not need others' help. In this regard, participants 1 and 5 stated, "*I'm doing my best to raise him/her to become independent and not need anyone in*

the future". Participant 3 said, "*I try to raise him to do personal work by himself, but I know that I am the one who has to take care of him*".

In their experiences, mothers state their hope for their children's success in the future despite their disability. For instance, participant 2 stated that "*Many defective people worse than my child could succeed in their lives, while only her one hand is defective*". Similarly, participant 4 mentioned that "*The most important thing is to do something for her to be a successful person despite this defect in the future, and this condition is not important to her at all*".

4. DISCUSSION

The present study is the first to investigate the lived experiences of mothers in caring for children with burn-induced disabilities. The thematic analysis of the interviews indicated the combined experiences of mothers' positive and negative feelings related to care in the care process of children with burn-induced disabilities. These mothers felt guilty, and anxious, and needed to change the maternal role, which is related to the findings of Kashega et al. research under the title of parents' experiences with children with burns.¹⁵ According to the findings of Rashidinejad's research under the title of 'Psychological and social problems of patients with limb defects caused by burns', these patients have psychological, physical and social problems, including excessive family attention towards them, which is related to the findings of the current research and the mothers brought up the centralization of the child. In a study conducted by Lernevall et al. to investigate the lived experiences of parents regarding their need for support when their child is hospitalized in a burn center, the results of the research revealed that being with the child is one of the needs of parents with a child with burns, which is in line with the findings of the research. Mothers have non-stop care of their children and are always by the child's side.²⁶ In Lernevall's study, the feeling of security and peace of parents was with the care of professionals for their child, while in the findings of the present study, it was found that the peace of mothers is when they are at the service of the child and do everything for him.²⁶ Zamanzadeh et al. studied life experience with burn injury and found that burn patients suffered from the threat and confusion of returning to society and facing others.²⁷ Similarly, the present study indicates that mothers were concerned about the presence of children in society and others' dealing with them and constantly protecting their children in the community. In an investigation analyzing mothers' experiences in caring for a disabled child, Khodabakhshi et al. presented evidence that the mothers presented negative reactions, inability, concern about their children's future, and the stigma of society; these data

are consistent with those of the present study.²⁸ Egberts assessed parents' memories and assessments after children's burn injury and reported positive and negative evaluations of children's conditions denoted by the parents, which is in line with our results. On the one hand, mothers hope for their children's progress and independence; on the other hand, they are worried about facing the children's disabilities along with their growth.²⁹

5. CONCLUSION

The results of this study provide an in-depth understanding of mothers' lived experiences of caring for these children. Data analysis showed that caring for a child with a burn disability could affect mothers' lives differently. Mothers undergo many painful experiences and psychosocial concerns about caring for their children. They keep the accident alive in their minds with constant mental reminders and tolerate the self-control pressure of self-blame. Social stigma, blaming, and accusing mothers by others and the companions' reaction toward the child can be mentioned as mothers' worries. To compensate for and cope with the feeling of guilt and self-blame, they take care of their child incessantly and consider the child the central issue in their lives. Despite their multiple concerns with the child's condition, mothers hope for their children's independence and success in the future. Therefore, it is of paramount importance to be informed of the needs, concerns, and feelings of these mothers because of the impacts on their children's health.

6. LIMITATIONS

Given the high prevalence of burns in the lower social strata, the major limitation during the research implementation included limited or no access to the participants residences, so no access to participants who could talk about their experiences.

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8. Conflict of interest

The authors declare no conflict of interest.

9. Authors' contribution

MS: Write the first draft of the article, Data collection, Data analysis, supervisor

FD: Write the first draft of the article, Data collection, and Manuscript editing

LB: Data analysis, Manuscript editing, methodology supervisor

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