

Thematic Analysis

Challenges Faced by Parents of Pediatric Burn Survivors: A Thematic Analysis

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ABSTRACT

Background: Burn injuries compromise the integrity of skin, its appendages, and underlying tissues due to exposure to various agents including dry and moist heat, corrosive substances, and high voltage electric currents. Particularly in the pediatric population, these injuries not only affect the children but also significantly impact the lives and health of their parents.

Objective: This study aimed to explore the multifaceted challenges faced by parents of pediatric burn survivors at the Burn and Plastic Surgery Center in Hayatabad KPK Peshawar.

Methods: Employing a qualitative case study design, this research involved 10 participants selected via purposive sampling. Data collection was conducted through face-to-face in-depth interviews using a semi-structured interview guide. All interviews were audio-recorded, with non-verbal cues and expressions meticulously documented. Thematic analysis was utilized to derive codes, categories, and subsequently, themes from the data.

Results: Analysis revealed five major themes reflecting the challenges encountered by parents: socio-economic difficulties, psychological distress, physiological and physical health issues, spiritual anxiety with altered religious activities, and domestic violence and abuse. Specifically, 70% of participants experienced significant disruptions in their daily lives and interactions, while 100% reported financial hardships directly affecting their ability to manage the health care needs of their children.

Conclusion: The study underscores the extensive challenges that parents of pediatric burn survivors face, highlighting the necessity for healthcare professionals to adopt a holistic approach in treating burnt children while concurrently addressing parental difficulties. Effective identification and management of these challenges are crucial to improving health outcomes for both the children and their parents.

Keywords: Burn injuries, Care, Challenges, Parents' Experiences, Pediatric Burn Survivors.

INTRODUCTION

Burn injuries, as defined by the American Burn Association (ABA), occur when the integrity of the skin, its appendages, and underlying tissues are compromised due to various agents such as high temperature (both dry and moist heat), contact with corrosive materials (including strong acids and bases), high-voltage electric currents, friction against hard surfaces, and exposure to high-energy radiation from the sun and other sources (1-2). These injuries are commonly categorized as solid, liquid, or flame burns and are classified based on the causative agent, the depth of the burn, the total body surface area (TBSA) involved, and the severity of the tissue damage (3). Health care professionals often classify burns into first, second, third, and fourth-degree burns, depending on the depth of tissue damage (4). The extent of burn coverage is usually assessed using the rule of nines, although this measurement varies according to age and anatomical differences among individuals; burns covering less than 10% TBSA are considered minor, whereas those covering more than 10% are deemed major (5).

The prevalence of pediatric burn survivors is notably higher in developing countries compared to developed ones. The Centers for Disease Control and Prevention (CDC) report that in the United States, unintentional burn-related deaths account for 5% of all such

fatalities among children under 19 years of age, with infants and toddlers experiencing a higher mortality rate from dry heat compared to older children (9). South Asia accounts for 40% of the world's burn injuries, with countries like Pakistan, Bangladesh, Columbia, and Egypt reporting significant rates of temporary and permanent disabilities among children due to burns (10). A case series from the Burn Care Center and Pakistan Institute of Medical Sciences in Islamabad noted that during the winter, the most affected group includes males aged between 3 to 6 years, with a mortality rate of 9.09% among hospitalized burn victims (11).

Various complications can arise from different types of burn injuries, including intense pain, capillary leakage, airway compromise, sepsis, and loss of infection barriers. Post-injury complications may involve delayed wound healing, infections, surgical interventions, scarring, joint contractures, bedsores, and neurological issues such as paralysis, tremors, and numbness (12-15). These complications exert considerable pressure on the parents of pediatric burn survivors, both during and after hospitalization (16). The stress associated with pediatric burns significantly impacts the psychosocial well-being of both the children and their parents, necessitating support from healthcare workers (17-18). Research indicates that parents often experience anxiety, depression, and feelings of guilt, blame, and embarrassment. One study in the Netherlands found that parents of pediatric burn survivors are prone to developing post-traumatic stress disorder (PTSD), which can adversely affect the psychological health of the child (19-20). Moreover, a pilot study highlighted the substantial financial impact of pediatric burns on families, particularly when the injuries involve flames or a larger TBSA (21-22).

Despite the significant challenges faced by parents of pediatric burn patients, the literature reveals a lack of focused research on their experiences, particularly in Pakistan. No studies have been found that address the physical, spiritual, and other challenges these parents endure during and after their child's burn injuries. Additionally, inconsistencies in the findings related to the socioeconomic challenges faced by these parents underscore the need for comprehensive research. This study aims to explore the myriad challenges faced by the parents of pediatric burn survivors in Pakistan, a country marked by limited resources and a general lack of awareness regarding the utilization of health services and proper management of burn patients. This exploration is vital for improving current healthcare practices and providing targeted support to these families.

METHODS

A qualitative case study design was employed to explore the challenges faced by parents of pediatric burn survivors. The research was conducted at the Burn and Plastic Surgery Center in Peshawar from September 2022 to February 2023. Ethical approval for this study was granted by the Ethical Review Board of the Post Graduate Medical Institute (PGMI).

Participants were selected through a purposive sampling technique from the indoor departments, based on specified inclusion and exclusion criteria. The study included both male and female parents of admitted pediatric burn survivors. Parents who were unwilling to participate or whose children had other special conditions such as poliomyelitis or cerebral palsy were excluded.

Informed consent was obtained from all participants prior to data collection. Data were gathered using a semi-structured interview guide during face-to-face, in-depth interview sessions that lasted between 20 to 40 minutes. Each interview was recorded on an electronic audio device, and non-verbal cues and expressions were documented in the field notes.

The data analysis was conducted using the six-step thematic analysis approach as outlined by Braun and Clarke (23). This involved a rigorous comparison of the analyzed data with the transcriptions and field notes to ensure the trustworthiness of the findings. The emergent codes, categories, and themes were carefully aligned with the objectives of the study and substantiated with direct quotes from the participants. This methodological approach facilitated a comprehensive understanding of the psychosocial and economic challenges experienced by the parents, providing valuable insights into their needs and the support required during the recovery process of their children.

RESULTS

In this study, interviews were conducted with 10 participants, consisting of 7 male (70%) and 3 female (30%) parents of pediatric burn survivors. The mean age of participants was 34 years, with a standard deviation of 4.35. Analysis of the data yielded five major themes related to the challenges faced by these parents: socio-economic and psychological challenges, physiological and physical issues, spiritual anxiety with altered religious activities, and domestic violence and abuse.

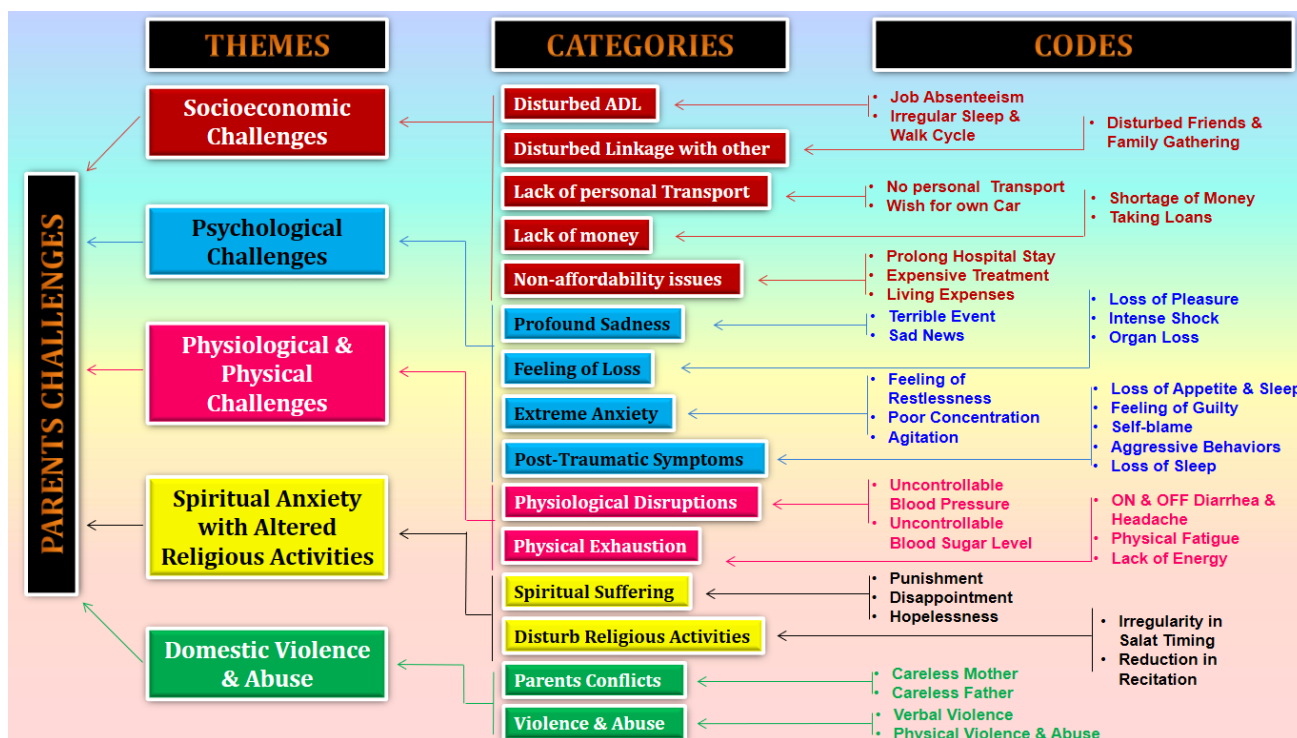


Figure No. 01: Findings of Thematic Analysis

Socio-economic Challenges

The socio-economic hardships encountered by the parents were profound. Participants reported significant disruption in their social interactions and daily activities. One parent noted, "I am a teacher at a private school, and I have not been able to attend work since the accident." This disruption extended to sleep patterns and social life, with one parent lamenting, "My child's needs awaken me at night, as he cannot visit the restroom alone." The requirement for constant care also isolated them from their social circles, as one parent expressed, "My son requires constant attention, preventing me from socializing with friends."

Further exacerbating their challenges were financial constraints. Lack of personal transportation delayed emergency treatment, as one parent recounted, "I had to wait for a taxi because I do not own a vehicle, which delayed getting my child to the hospital." Financial instability was a common thread among the participants, with many expressing difficulty in affording treatment due to the costs associated with long-term care, medications, and potential surgeries. For example, one stated, "We spent a month in the hospital; my husband is a laborer and cannot afford ongoing medical expenses." Another added, "For the first surgery, my husband sold his motorcycle and borrowed money. The doctors have now recommended a second surgery, and I am unsure how we will manage."

Psychological Challenges

Psychologically, parents faced profound sadness, a sense of loss, extreme anxiety, and symptoms indicative of post-traumatic stress (PTS). The initial shock of the burn incident deeply affected their mental health. Parents described feelings of overwhelming sadness triggered by reminders of the trauma. One mentioned, "The decision to amputate my son's leg was devastating, and I find it unbearable." The sense of loss was palpable, with another parent sharing, "I couldn't celebrate my nephew's birth because I was too engrossed in my child's care."

Anxiety was prevalent, manifesting as restlessness, irritability, and concentration issues. One parent admitted, "Since the accident, I've found it hard to focus, often forgetting the names of close relatives." PTS symptoms were also reported, including guilt, blame, and aggression, with a parent confessing, "I feel guilty about the accident as if it was my fault for not being more careful."

Physiological and Physical Issues

Physiological disruptions and physical exhaustion were prominently noted. Parents reported exacerbations of pre-existing health conditions following their child's burn injury. High blood pressure and uncontrolled diabetes were commonly mentioned, with one stating, "My blood pressure soared to 200/100 multiple times post-incident, despite medication." Physical exhaustion was a constant concern, with parents feeling drained from the continuous care required, "The care demands are relentless, leaving me exhausted."

Spiritual Anxiety with Altered Religious Activities

Spiritual suffering and disruptions to religious practices were significant. Parents expressed feelings of punishment and hopelessness, questioning their faith amid the crisis. One parent shared, "I feel this might be a punishment, testing whether we will continue to worship in difficult times." Changes in religious observance were also common, with parents struggling to maintain regular prayer times due to caregiving duties.

Domestic Violence and Abuse

The final theme involved domestic conflicts and blame-shifting related to the burn incident, which sometimes escalated to violence. Accusations of negligence were frequent, with one parent saying, "If my wife had been more careful, this would not have happened." These conflicts often led to prolonged disputes and, in some cases, physical altercations, further complicating the family's dynamics during a period of crisis.

DISCUSSION

The findings of this study illuminate the multi-dimensional challenges faced by parents of pediatric burn survivors, spanning socio-economic, psychological, physiological, physical, and spiritual aspects. Additionally, a novel theme of domestic violence and a pattern of abuse were identified, presenting an overlooked dimension in the existing literature.

Parents reported significant socio-economic difficulties, including disruption in daily activities and financial constraints, which align with previous studies emphasizing the economic burden and social isolation following pediatric burns (23, 24). Psychological challenges were prominent, with parents experiencing profound sadness, a sense of loss, extreme anxiety, and symptoms of post-traumatic stress. These psychological impacts are consistent with existing literature, underscoring the emotional toll of pediatric burn injuries on parents (21, 25, 26).

Physiologically, some parents experienced exacerbations of chronic conditions such as diabetes and hypertension, which were difficult to manage despite adherence to medication, reflecting findings from similar studies in developed contexts (27, 28). Physical exhaustion was also significant, compounded by the demanding care required for their injured children, which resonates with previous research that highlights the physical and emotional toll on parents providing continuous care (29, 30).

Spiritual anxiety was another critical issue, with parents reporting disrupted religious practices and spiritual distress, echoing findings from studies among caregivers of patients with chronic conditions (33). This disruption of spiritual activities often results from the intensive care required by burn survivors, highlighting the profound impact of child illness on parental religious engagement.

The study also unearthed issues of domestic violence and abuse, attributing blame and responsibility for the accident within the household. This finding is particularly significant as it underscores the societal and cultural dynamics that may exacerbate the stress experienced by families, yet is rarely discussed in the literature on pediatric burns.

Despite its insights, this study has limitations. The small sample size and the specific setting limit the generalizability of the findings. Additionally, the study's reliance on self-reported data may introduce bias in the representation of personal and sensitive issues such as domestic violence.

The strengths of the study include its comprehensive approach to exploring the broad range of challenges faced by parents, and its introduction of domestic violence as a critical area of concern, providing a basis for further research in similar socio-cultural settings. Moreover, the study's methodological rigor, with detailed thematic analysis, enhances the depth of understanding of the complex experiences of these parents.

In conclusion, the study contributes valuable perspectives to the understanding of the multi-faceted challenges faced by parents of pediatric burn survivors. It highlights the need for holistic support systems that address not only the physical and psychological needs but also the socio-economic and spiritual well-being of the families. Future research should aim to explore these themes in a broader demographic to enhance the understanding and support mechanisms for families affected by pediatric burns.

CONCLUSION

This qualitative study delved into the myriad challenges faced by parents of pediatric burn survivors, uncovering that socio-economic and psychological distress profoundly impacts these families throughout the treatment journey. Parents grappled with sudden disruptions in daily activities and social interactions, financial strain due to inadequate access to transportation, and the high costs of medical care and accommodations. This financial burden was compounded by significant psychological distress, including profound sadness, stress, and the onset of post-traumatic stress symptoms, often exacerbating chronic conditions like diabetes and hypertension. Moreover, the study highlighted that these pressures adversely affected parents' spiritual and religious practices and escalated to domestic conflicts and violence, primarily driven by perceptions of negligence. This comprehensive insight underscores the urgent need for holistic healthcare approaches that address not only the physical but also the socio-economic, psychological,

and spiritual needs of families, thereby mitigating the compounded stressors they face and fostering a more supportive healing environment for both the child and their caregivers.

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