DOI: 10.52131/pjhss.2024.v12i3.2314

Pakistan Journal of Humanities and Social Sciences

Volume 12, Number 03, 2024, Pages 2616-2628
Journal Homepage:
https://journals.internationalrasd.org/index.php/pjhss

Family Frontiers: Insights into the experiences of having Medical-Technology-Dependent Children at Home

Saba Mumtaz[1], Zara Haroon [2], Mahnoor Abid[3]

[1] Student, Kinnaird College for Women, Lahore (93-Jail Rd), Pakistan. Email: sabnain44@gmail.com
[2] Lecturer, Kinnaird College for Women, Lahore (93-Jail Rd), Pakistan. Email: zara.haroon1@yahoo.com
[3] Student, Kinnaird College for Women, Lahore (93-Jail Rd), Pakistan. Email: mahnoorabid2626@gmail.com

ARTICLE INFO

Article History:

Received:	April 30, 2024
Revised:	August 19, 2024
Accepted:	August 21, 2024
Available Online:	August 22, 2024

Keywords:
Family Experiences
Medical Technology-Dependent
Qualitative
Family Functioning
Interviews
Phenomenological

Funding:
This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

ABSTRACT

The aim of this research is to explore the lived experiences of families providing care at home for medical technology dependent children focusing on its emotional, social and psychological impact along with highlighting how the family members cope with their daily challenges and the strategies they employ to maintain family wellbeing. Medical technology dependent children are those who require special health needs in terms of an external equipment to substitute for the loss of an essential bodily function or to ensure their survival. As an example, they need a complex treatment regimen using devise like mechanical ventilation or tracheotomy (Okido, Zago, & Lima, 2015). This research contributes to the existing literature by deepening the understanding of the caregivers' challenges on looking after such children from a multifaceted perspective within the context of Pakistan. A phenomenological qualitative research design was used (Ho & Limpaecher, 2022). In-depth interviews were conducted from six families having a medical technology dependent child. The data was analyzed using an interpretative phenomenological analysis in a series of steps (Creswell & Poth, 2016). The analysis of the data yielded an overarching theme, major living challenges having the subthemes; psychological factors, social issues, maintaining a family functioning, work related issues and financial constraints. The second major theme was coping strategies having subthemes; self-empowerment, spirituality and social support. The findings revealed that majorly, the coping strategies used by most families during the treatment process were religious and spiritual coping, which is embedded in the cultural norms of Pakistan. Psychological factors were observed more in mothers than in fathers, due to their culturally defined roles. Financial constraints were also a pertinent theme analyzed. This research can empower the individuals who are undergoing similar experiences and future research can focus on the corrective measures as well as policies that can be implemented to assist such families providing them with adequate support sources for home-based care and caregiving burnout.

Corresponding Author's Email: zara.haroon1@yahoo.com

1. Introduction

According to a report published by the World Health Organization (WHO), Pakistan is facing a critical shortage of health care facilities with the doctor to patient ratio 1:1300 being extremely low (Muhammad, Eiman, Fazal, Ibrahim, & Gondal, 2023). This situation appalls for the need for home based medical assistance to address the accessibility challenges. As per research, the use of medical technology in homes has significantly increased over the last 15 years. With the advances being made in the field of medical technology, it is ascertained that more accurate diagnoses of tumors and chronic illnesses are being made (A. D. Kirk et al., 1997). The boils down to the idea that a large number of children are now in a continuous need for medical and nursing care at home along with hospitals. The children therefore need constant care-giving for their special nursing at homes (Glendinning, Kirk, Guiffrida, & Lawton, 2001). The short-term and long-term effects of medical technology on family life can be better understood by families and health care providers through increasing knowledge and awareness in this research area. Despite of the underlying ethical issues, the growing shift from hospital care to care-giving at home showed more favorable conditions (O'Brien, 2001). Some moral, financial and social issues have been explored by the prior literature. Medical technology dependent children are those who "have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." Moreover, they are often overlooked due to the presumption that they're chronically ill or disabled not considering the notion that they need care. They belong to a diverse population and use an array of technologies that varies from being high tech to low tech depending on the illness (Glendinning et al., 2001). These respective groups of patients are not reliant on one single device or technology but rather more than one. This device dependence is not temporary and is thus, there for a long period of time due to its life sustaining and supporting nature (Townsley & Robinson, 2000).

The children with different kinds of illnesses tend to depend on these technologies. The types of respiratory support commonly include supplemental oxygen or mechanical ventilation (with or without tracheostomy). While the medical technologies including mechanisms to support nutrition are gastrostomy and jejunostomy tubes. The most common technologies also include the Semipermanent venous catheters. There are some other examples but these may not have a limitation on enterostomies, renal dialysis and bladder catheterization. A qualified, trained professional tends to regularly monitor the working of these technologies. The children relying on such technologies possess diversity and may develop symptoms related to sequelae of prematurity, genetic syndromes; neuromuscular disorders, congenital anomalies, infections, complications of injury, and other illnesses. Children or adults may have a reliance on number of technologies like mechanical ventilation, urostomy, colostomy, drug or oxygen therapies, artificial nutrition hemodialysis, enteral feeding and tracheostomy (Wagner, 1988).

1.1. Familial perspectives and experiences

Research suggests that parents who dealt with medical technology dependent children in their homes had to endure substantial difficulties (Abbott, Watson, & Townsley, 2005). Existing studies have also showed the significant social, financial and emotional influences inflicted on such families caring for the technology dependent patient (Townsley & Robinson, 2000). The constant need for care-giving can adversely affect the physical and mental wellbeing as well as the quality of life of the caregivers (Kinsella, Dunphy, McCormack, Wilson, & Bennett, 2024). Parents tend to experience an array of challenges in balancing normalcy, family life, household essentials, as well as in managing the medical treatment needs of their medical technology-dependent child (Toly, Blanchette, Al-Shammari, & Musil, 2019). The constant change in the care needs of the technology-dependent child and unpredictability of the child's health status can lead parents to focus excessively on the child's health schedule and routine at the expense of other family roles and responsibilities (Leyenaar, O'Brien, Leslie, Lindenauer, & Mangione-Smith, 2017; Smith, Cheater, & Bekker, 2015). Parents are also liable to manage the technicalities and working of the medical equipment along with resources that are needed for the child's physical and technological needs, leaving them in a highly stressful situation. However, irrespective of these challenges, such families do prefer home instead of hospitals as their place of care (Mitchell, Bray, Blake, Dickinson, & Carter, 2022). The normalcy of family life of a number of families is hampered trying to make sure a challenging care regimen is followed for the medical technology dependent child. Family functioning and normalization is tested by a recent study, families using such procedures over time tend to alter their definitions of normalcy for their scenarios (K. A. Knafl & Deatrick, 2002).

In addition, such families also face a lot of difficulties in providing adequate care to the dependent child in terms attending to them along with struggling to manage to take them for regular treatment follow-ups on time as well as the financial burdens being the ultimate blow (Heyman et al., 2004). The child being reliant on medical technology affects the entire family dynamics and functionality due to special care demands (K. Knafl, Breitmayer, Gallo, & Zoeller, 1996). As a result, such families often become dysfunctional with less stability and predictability, and higher probable physical and mental health risks are posed at the members of such families. Prior researches also suggest that parents of such children tend to develop symptoms of depression that negatively impacts their families. However, it could not be concluded how personal characteristics of parents and their medical technology-dependent children affect parental depressive symptoms, normalization, or family function, providing little evidence for implementation strategies of nursing care to be exercised. This type of knowledge is very important to maintain the psychological health of caretakers and to ensure positive family functioning that directly affects the child's growth, mental and physical well-being (Miles, Holditch-Davis, Burchinal, & Nelson, 1999).

2. Review of literature

In this literature, familial experiences of having a technology dependent child to care for have been reported in a positive as well as a negative framework. Consistent with the findings, Heaton, Noyes, Sloper, and Shah (2005) conducted research on the family experiences of having a medical technology dependent child at home and the findings revealed that technological tools proved to be a reliable support for the health and quality of life of the children. However, the children as well as their families experienced negative consequences as well due to the time demands of the care routines and their incompatibility with other social and institutional timeframes, which limited their involvement in school, work, and social life in general. Parents also suffered from sleep disruptions due to the responsibility of ensuring the working of some medical technologies at night showing that such families have to spend a substantial amount of time caring for medical tech-dependent youngsters at home. The families also do not have access to qualified caretakers who can provide technical care at home or outside the homes so that the parents can take break from their routines.

Moreover, some research studies suggest that parenting a medical technology-dependent child is a drastically different experience. There is a need for professionals to identify how giving excessive attention and care has an impact on the emotional wellbeing of the parents and how they need a platform where they can express their concerns about parenting identity and their bond with their child. Also, the parents' opinions of the nurses’ raised concerns about whether or not they provide adequate care that is tailored to the child's and family's requirements and if parental expertise is credited (S. Kirk, Glendinning, & Callery, 2005). Augmenting the prior research, Wang and Barnard (2004) found the following themes synthesized through the experiences of medical technology dependent children and their families i.e., children and chronic disease, the effects of paediatric home care on children, the special needs of families with medical technology dependent children, and parents' experiences with paediatric home care. The study emphasized on how their experiences led them to redefine their homes, family dynamics, suffer from social isolation, bear financial constraints, shift responsibilities and manage parent-professional relationships. The transition from hospital to home is another challenge for the families that deteriorates the quality of life of the medical technology-dependent children and their families. Long-lasting ventilator support can be provided at to an ever-increasing number of patients with needs of complex health care. Family members' lives are linked and inter dependent, and caregiving has been described as a life contingency that translates into this interdependency within families. Leiter, Leiter, Krauss, Anderson, and Wells (2004) published an article that reports the voices of the women experiencing difficulties at home or employment. They needed to give extra time to their needy children and reduction in working hours had been observed. They had intense and long exhausting hours and their life got unpredictable at the later stage. The odds for dual effect of having a medical technology dependent child were three times greater in terms of complexity.

While, the research on patients chronically dependent on artificial ventilation and their families by Dybwik, Tollåli, Nielsen, and Brinchmann (2011) concluded that despite of a variety of issues associated with respiratory support, they would still choose it and psychosocial assistance is a significant need for chronically ill patients on tracheotomy tube-dependent continuous breathing support. Family members need to provide round the clock availability need support, care and assistance. Further research suggests that the families reported that the complications that arose as a result of raising a medical technology dependent child were related to self-home care of the child and on how to utilize the medical technology mediated devices. The affective state of the families as reported by them made them fall into helplessness, feelings of shock, anxiety, suffering and struggle. The fundamental assistance for these parents and patients would be trainings by qualified professionals on how to use medical technology. Toly, Musil, and Carl (2012) conclude that the family functioning of the mother of the medical technology dependent children posed them at a high risk for clinical depression. Those children with poor functional status and complex care needs required greater home nursing hours that influence a families' normalization.

Similarly, a study conducted by (Chang et al., 2016) on the predictors of stress of the primary caregivers of income oxygen dependent children revealed that the caregivers' overall stress levels peaked and their information needs were scored as the highest among other needs. While they received emotional support from their family and friends, informational support was mostly received from health professionals, but both instrumental and emotional support were important. Levels of stress and caregiver needs were also significantly correlated. The factors predicting stress included the caregiver's poor health status, the child's male gender and the caregiver's hampered financial needs. Another research on the maternal perspectives of the well' siblings well-being residing with a medical technology dependent report that the non-dependent sibling becomes a protector, exhibits altruism and takes on the care-giving role for the dependent sibling and relatively lesser mothers reported mental health issues in such siblings irrespective of the stress of managing the daily health related tasks of the dependent child. (Toly et al., 2019). Another research on the health and well-being of care-givers of medical technology dependent children reveals that 44.3% of the caregivers were at high risk of clinical depression where the child's functional status was associated with greater depressive symptoms in the care-giver. The variable, perceived social support was a moderator in this association and it was conclusive to state that the caregivers of medical technology-dependent children suffer from poor health related quality of life and family functioning. Enhancing the family caregivers' social support sources is profoundly important for their well-being. Chan, Lim, Bautista, Malhotra, and Østbye (2019) A recent study shows that parents do accept and adapt to the medical technologies that their children are dependent upon even though it alters their home environment in terms of its outlook, sound disruptions and feelings of homeness for the members. However, parents perceive it as a valuable support since it helps their medical technology dependent child stay at home as a part of their family (Mitchell et al., 2022).

Similarly, a study was conducted in the US on tracheostomy decision-making for children with medical complexity exploring the supports and resources that the caregivers. The analysis of the semi-structured interviews focus group discussions revealed that the caregivers used 5 domains of resources for tracheostomy decision-making mainly, support from social networks, other parents of children with tracheostomy and health care providers, stimulation labs, internet websites, online health communities and print materials. Thus, the results signify that caregivers need for support and resources wasn't just for decision making but to become knowledgeable and skilled about home-based care and their child's illness along with seeking emotional and spiritual support (Nageswaran, Gower, King, & Golden, 2024). Another recent study on the experiences of parents and caregivers of children who underwent gastrostomy tube insertion was conducted to investigate experiences of decision making, support and adjustment to the transition. The results showed that the major concerns of the caregivers were centered around managing the tube, child's food intake and his feelings associated to it. The findings further showed that the transition brought stress as well as relief to the caregivers along with an array of practical and psychosocial challenges that could be alleviated with peer support (Kinsella et al., 2024). Based on prior literature, which explores the familial perspectives of medical-technology-dependent children extensively, it is to be noted that the consideration of the research in the being conducted in the context of Pakistan remains under-researched in this regard. This gap highlights the need for future studies to better understand, evaluate and address the unique experiences as well as challenges of Pakistani families with medical technology-dependent children.

3. Theoretical framework

The family systems theory emphasizes on the relationship that living beings have with their environment and the behaviors, rules and standards that tend to bring a balance within familial relationships. The family is a single, interrelated system like a triangle and with a special child, it is an illustration of parents being the harmony on the sides of the triangle. A transition affecting one member of the family requires the entire family unit to make adjustments. In our study, because of the medical technology dependent children, their families had to undergo changes and adjustments which led to a disruption for all the members. Thus, it posits towards the idea that environmental stressors challenge familial adjustment and it's important to understanding its impact broadly on the intricate family dynamics (Lang, 2020, May 18). The Family circumplex model by Olson (2000) categorizes family behavior on the grounds of cohesion and adaptability suggesting that balanced family systems are more functional. It identifies how adaptability in the parental roles is crucial for managing stressful situations, in our study the circumstance being caregivers of medical technology-dependent children. The model's hypothesis thus focuses on the idea that that stable family systems manage transitions effectively to bring normalcy and this is what differentiates them with families having dysfunctional dynamics (Masood, Arshad, & Mazahir, 2015). These theories inform a holistic understanding of how families adapt and undergo the transition posed at them as a result of caring for a medical technology dependent child. These frameworks, in integration, provide a solid foundation to explain the findings of the study. The family systems theory highlights how stressors of caring for a medical technology dependent child disrupt the entire family, it aligns with the theme of major living challenges in our study which explains the psychological, social and financial impacts on the family members. While, the family circumplex model focuses on sociological factors of cohesion and adaptation, which resonates with the coping strategies employed by these families. Those who use healthy coping strategies, exhibit greater adaptability. Therefore, both the theories provide us with a thorough lens to understand familial experiences of having medical technology dependent children supporting our derived themes.

3.1. Objectives of this study

1. To explore the family experiences of caring at home for a medical technology dependent child.
2. To find out the social and psychological impact on the care-givers of the medical technology dependent child.
3. To gain an in-depth understanding of how families manage the challenges of living with a medical technology dependent child.

3.2. Research questions

1. How do the family dynamics evolve when living with a medical technology dependent child?
2. What coping strategies do families employ to address the challenges of caregiving for a medical technology dependent child?

4. Research methodology

This study was designed to explore the experiences of families who’re living with medical technology dependent children. A qualitative research design was used for this research along with the utilization of an interpretative phenomenological approach for gaining an in-depth understanding of the lived experiences of the participants. According to Creswell and Poth (2016) interpretative phenomenological research doesn’t only tends to describe but also interprets the meanings of the lived experiences of a phenomenon that people undergo through, in order to arrive at their core universal essence. A sample of 6 participants were recruited using the purposive sampling strategy, which aids in the selection of information rich cases, on the basis of a specified criterion ensuring relevancy (Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2015). Creswell and Poth (2016) suggests that 5 to 25 participants are adequate for phenomenological studies stating that data saturation is about the quality of data and not the quantity of data. The chosen participants were the parents of a medical technology dependent child selected from Combined military hospital, Karachi. 4 males and 2 female participants were enrolled who met the inclusion criteria devised; the child was dependent on 2 more medical technologies for more than a year, the care-givers spoke English or Urdu along with being knowledgeable about the medical technology being used and the child was not consistently dependent on medical technology but for only once or twice a week.

The research instruments used were demographic questionnaires and semi-structured, in-depth interviews. The individual face to face interviews were conducted in Urdu, having a duration of 35-40 minutes and were audio recorded and transcribed. The interview guide was designed to incorporate open ended questions aligned with the objectives of the study pertaining to gain insights into the experiences of the caregivers through asking them about their psychological issues e.g. how do you feel now, years after your child’s medical technology dependency? and how much does the entire treatment process cost? Including probes like, what is your opinion on this? So, this is what you mean to convey, please elaborate etc. Thus, the questions aimed to gain answers on the aspects of the family dynamics of the caregivers and their coping styles, categorizing distinct questions under the heading of each research objective for an in-depth data. About data saturation, researchers argue that in interpretative phenomenological analysis, the aim should be to obtain rich accounts and not saturation, with a focus on individual accounts (Hale, Treharne, & Kitas, 2008). The data analysis was done in steps according to the process defined by IPA (Reading, re-reading, initial noting, developing emergent themes, searching for connections across emergent themes, looking for patterns across cases (Pietkiewicz & Smith, 2014; Smith, Cheater, & Bekker, 2015). Firstly, the transcriptions were thoroughly read and re-read, at least thrice to capture the core essence of the lived experiences of the caregivers. During this process, the initial notes were made by the researcher on the content, its features and initial interpretations in the margins of the transcriptions. Some of the sentences were also highlighted from the transcribed data, which demonstrated distinct emotions. Alongside, a reflective journal was maintained by the researcher to bracket out their own biases from influencing the coding process to ensure transparency. These notes were then converted into emergent themes, in form of short sentences using a different color to code the transcribed data further, grounded in particular in-depth details. Then, the themes were clustered and grouped in points under one descriptive heading. Finally, the write up involved supporting the clustered themes with specific verbatims and the researchers' interpretative analysis. Thus, the derived themes were analyzed and discussed in light of the extracts and verbatims highlighted from the interviews, with rich, thick descriptions being written for each theme and its subthemes. For ensuring validity, this research was peer reviewed by two experts in order to enhance its credibility and quality standards (Herber et al., 2020).

4.1. Ethical considerations

In order to abide by the ethical guidelines, a written informed consent was obtained from the parents and caregivers of the medical technology dependent children, at the very initial stage of the study. They were told about the purpose of the study, that was to explore their lived experiences being caregivers of medical technology dependent children prior to conducting the interviews. They were also educated about how their participation would be beneficial and contribute to a better understanding of their needs, provide resilience to other caregivers and also aid in the development of support programs. The participants were also told that no psychological or physical harm would be inflicted on them in the entire process. However, they were also clarified that they had the right to withdraw from the study at any point if they felt uncomfortable. The confidentiality and anonymity of their data was ensured at every stage, by assigning pseudonyms to each of the parents along with upholding high standards of accuracy in reporting and citing the data, without any manipulation.

5. Results and findings

Based on the analysis, 2 superordinate themes were derived along with their subordinate themes from the process; major living challenges (psychological factors, social issues, work related issues, maintaining family functioning, financial constraints) and coping strategies. Description of the themes:

5.1. Theme 1: Major living challenges

While different people respond differently towards the trauma or adversities they face in their lives, some people as a result of such experiences tend to develop mental health issues. For the parents who have a child dependent on medical technology, it is essential for them to be resilient and healthy in order to deal with their situation in a proactive manner. Their heightened anxiety, stress and frustration levels affect their life orientation and predispose them towards an array of mental health risks. Overthinking about the future of the medical technology dependent child, worrying about his current situation and being pessimistic about development does affect the caregivers detrimentally (Cameron & Frechet, 1991). As the one of them stated, *"Bohat barhe mapley ka shikar hogaye hen hum aur meri bachi, bachi humare hath se gayi."* The parents not only felt physically drained but also mentally exhausted, weak and suffered from sleep deprivation. The parents of children who are dependent on medical technology not only endure greater levels of weariness, daytime sleepiness but also sleep deprivation (Chan et al., 2019). They also reported facing challenges in adjustment, feeling helpless in terms of gaining control of the situation and in trying to divert their attention as one of them stated *"Wo dusray bachon ke samne kamtar mehsoos krta hae"* which augments the idea that they were stuck in their negative and maladaptive thought patterns.

5.1.1. Psychological factors

Psychological stress and problems were prevalent in both the parents due to the burden of looking after a medical technology dependent child. While parental stressors contribute to a deteriorated mental health and low levels of well-being, mothers of such children are more likely to bear a heavy toll on their health (Balbo & Bolano, 2024). This was one of the findings of this study, where the psychological problems were observed more in mothers than the fathers of the medical technology dependent child. Since the mother takes onto the primary care-taker role, spends more time with the child and has to combine her parenting with the routine chores, she has a greater disposition towards suffering from mental health problems. Women, generally tend to display more emotions than men (Brody, 1997). Similarly, the mothers in this study expressed greater emotions and feelings of attachment towards the child. As one of the mothers stated,

'Main har waqt bohat pareshan rehti hun.' Psychological factors like distressing emotions, continued stress and the deterioration in mental well-being affected the mothers of the medical technology dependent child significantly. Some of the parents also felt hopeless and pessimistic while others said that they were still in denial as evidenced by the participants' stance, *'Mein apne bache ke mustaqbil ke bare men bohat pareshan hun.'*

5.1.2. Social issues

Social and environmental factors tend to exert a significant influence on the quality of life, adjustment and support sources of the caregivers. While most of the caregivers reported low-to-moderate levels of social stress, problematic relationship dynamics and issues in family functioning. Some participants reported feeling socially bound and not being able to socialize or attend gatherings due to their medical technology dependent child relying on them for care. They felt neglected and stigmatized by the society, feeling isolated. As one of the participants stated, *'Mein sirf hospital mei doctors ko procedure karte dekhti rehti thi'* which denotes how the social life of such parents was constrained. It is evidenced that being socially constrained due to the excessive caregiving demands of a medical technology dependent child at home makes the parents drown into feelings of social isolation as well as depressive states (Chan et al., 2019). The negative attitudes of people around effects the mental health of such parents. The parents being already burdened by the stress of their child, further the stigmatization by the society effects their behavior negatively where the mothers more frustrated, some of them being physically aggressive while some developing pessimistic views regarding the lives of their children (Friborg, Barlaug, Martinussen, Rosenvinge, & Hjemdal, 2005).

5.1.3. Work related issues

Majority of the participants played a trifecta of roles, being care-givers, parents as well as professional workers. This led them to suffer because many of them reported that they felt having no choice or liberty in taking on caregiving responsibilities. This schema was threefold in caregivers that provide 21 or more hours of care per week. Many of the participants also shared that they had to leave their jobs or limit their working hours due to their medical technology dependent child impacting substantially on their professional as well as familial life. As they said, *"Office ko sath sath manage karna bohat mushkil horha tha"* and that "*ltne kharchon me job chorne ka tu sawal he ni he."*

5.1.4. Financial constraints

Caring for a medical technology dependent child at home appalled for a considerable expenditure. Such children tend to require extensive care including changes in dressing, equipment maintenance and cleaning and buying prescriptive medications which poses the families to bear a hefty financial burden (Pitch et al., 2023). As a participant said, "*Financial situation bohat down ho gai thi*." The economic hardships and imbalance in the family budget led the parents to undergo a financial hardship, especially those parents who were the sole breadwinners of their house.

5.2. Theme 2: Coping strategies

This was one of the major themes that emerged. Different parents used distinct ways of coping with the stressors that their situation posed them with. The use of these strategies differed among the participants depending on their socioeconomic status and the diverse cultural background they belonged to. The use of healthy, adequate coping strategies can alter the impact of stressful situations and lay down a positive impact on the quality of life of the caregiver (Monteiro, Santos, Kimura, Baptista, & Dourado, 2018).

5.2.1. Self-empowerment

The participants focused on their own self growth and adaptation to the situation which helped them to empower themselves and stay hope as they stated*, "ab itna arsa guzarne ke baad isko dekh ker bohat hosla milta he"* and that technology *"ki waja se umeed baandh leti Hun*." Building trust on the medical technological equipment and working on aspects of self-reliance helped the parents get a ray of hope, strength and courage to deal with the situation effectively. The caregivers with a higher socioeconomic status and educational attainment exhibited a greater use of this coping strategy, suggesting that social and cultural factors influence the adaptation to foster resilience. This has been supported by research that, caregivers with better education have access to more information and belonging to a higher socioeconomic status helps them navigate their financial constraints easily, fostering a sense of empowerment in their caregiving role (Oedekoven, Amin-Kotb, Gellert, Balke, Kuhlmey, & Schnitzer, 2017). Through hope one can focus on his capability to find ways and means to achieve desired goals thus the person gets motivated to follow those pathways, effectively managing the caregiving duties (Gerstein, Crnic, Blacher, & Baker, 2009).

5.2.2. Spirituality

There exists strong evidential support for religion and spirituality being linked to psychological wellbeing (Ivtzan, Chan, Gardner, & Prashar, 2013). Every individual uses spirituality as a coping mechanism differently and develops a personal relationship with God. Considering it in the context of Pakistan, majority of the parents reported the use of spiritual coping in their situation. As stated, *"Sirf Allah hi meri madad ker sakta hai"* which denotes that they believed in the blank cheque of power given to them by the higher power. And also, *"sirf Allah k samne dua karne se bohat hosla milta he', "Allah he isko is haal tak le aye hen me yeh ab better he'.* An individual's perspective on his relationship with God may change throughout their lives which is adapted by their own relationships, experiences and sufferings (Baruth & Carroll, 2002). Since the cultural norms in Pakistan reinforce the reliance on spiritual beliefs during times of adversity, majority of the caregivers reported that they resorted to religious practices to cope with their circumstances. Research on indigenous coping strategies among caregivers shows that caregivers frequently tend to engage in prayer and other rituals to fuel their resilience in order to cope up with caregiving stress, which has its roots in culturally embedded values unique to Pakistan (Sahar & Naqvi, 2022). Thus, expressing gratitude towards the divine and adopting an optimistic mindset relying on God was the most common coping style used by the parents of medical technology dependent children.

5.2.3. Social support

The role of social support was very important in this context for the parents of the medical technology dependent child. The familial social support sources were of utmost significance as the participants reported that having a cooperative spouse helped them. Pakistan has a collectivist cultural orientation and this was a fundamental reason behind the caregivers' opinions on the adoption of this coping style. This can be evidenced by research on caregivers of cancer patients conducted in the Pakistani context that revealed, that social support had a significant and positive effect on the caregiver's resilience to care giving burden (Hussain & Ahmad, 2021). Even though the adversity did create a communication gap between the family members, those who managed to cooperate had a normal familial functioning. Their external social support sources also helped them for instance, one of the participants stated, *"Humane bohat se mukhtalif logon se Milna shru kardia'* and that *"doctors ne kafi umeed dilayi thi"* as evidenced by research that it is plausible that the impression of social support functions as a mental stress reliever for caregivers who experience moderate dysfunction and high caregiving responsibilities (Chan et al., 2019).

6. Discussion

This study highlights the diverse experiences of the families living with medical technology dependent children. Such families tend to endure an array of challenges in terms of physical health, psychological well-being as well as social, financial and professional work-related issues. Also, their resilience comes from navigating social support sources, self-empowerment and lastly through spiritual coping, which is very common to the Pakistani cultural context. The research also reveals that among all the family members, the parental figure who is affected the most is the mother, who takes on the primary care-taker role. In societies with a patriarchal family mothers tend to struggle more due to the difficulties posed at them by the caregiving burden since they are responsible primarily for the household work as well as for nurturing the children (Sevgi & Ayran, 2024). This can be applied to the Pakistani society, where the caregiving burden is inflicted on a greater level on mothers evidenced through our study. This has further been evidenced in research by Toly, Musil, and Carl (2012) that the mothers of medical technology dependent children were at a high risk of being diagnosed for clinical depression which substantially affected their family functioning. The participants in this study reported feeling frustrated, hopeless, anxious, prone to pessimism, undergoing difficulties in adjustment, along with being physically exhausted as the challenges that they endured in their daily routines. They had different reactions towards the situation, as Kübler-Ross (1969) explained about stages of grieving that is not a single experience but something that people get stuck in for years. Due to such an unexpected diagnosis of a child, the parents delve into shock and disbelief while some tend to deny it as in line with one of the participant's statements. While the both the parents go through psychological stressors, the mothers reported an increased deterioration of their mental health. They tend to experience depressive symptoms, affecting how they view the situation, a key component of normalization and this in return affects the entire family's functioning (Frankel & Wamboldt, 1998).

There were a lot of social issues endured by the participants including social isolation, stress along with feeling restricted, neglected and stigmatized by the society. The negative viewpoints of the people around were an addition to the grave burden on the caregivers. Caregiving can also have a negative social and financial impact on the caregiver. Fifty- three percent of caregivers reported that caregiving duties tool away from their family and friends, 89.2 % experienced having little or no time for leisure (Irfan, Irfan, Ansari, Qidwai, & Nanji, 2017). Also, the stigmatization tends to elevate the perceived burden among the parents of the caregiving tasks in the parents and they also start to blame themselves for their child's health condition (Mak & Kwok, 2010). The majority of participants reported financial burdens and or professional work-related problems as a result of caring for a medical technology dependent child. While some reported having to bear a substantial burden of responsibility and working overtime, others stated that they had to leave their jobs due to their medical technology dependent child relying on them. Overall, they found it difficult to balance their home and professional life simultaneously. Moreover, they had to bear a hefty expenditure due to the costs associated with the medical technology and the child's health, which posed them with financial hardships. Lai et al. (2012) examined the effects of financial costs on caregiving burden and found out that it was a significant factor contributing to caregiving burden, for both the male and female caregivers.

The other theme focused on coping and participants reported using self-empowerment as one of their most helpful ways of coping. Their self-growth and understanding gave them hope and courage to stay resilient in their most difficult of circumstances. Research by Alexander and Walendzik (2016) revealed that parents who use regenerative coping strategies and used personal growth to cope were less likely to suffer from somatization symptoms and anxiety where intervention programs for care-givers targeting the parent's affective states and knowledge regarding coping strategies proved to be highly beneficial. While others, relied on social support sources within their families or from their friends or support groups. It was explained by one of the mothers that her husband's support after the child's diagnosis empowered her in the upbringing process of her child. In Pakistan, caregivers find living in joint families as their major source of support, with their greatest support being their spouses (Saeed, Malik, Khan, Malik, & Aziz, 2024). Support and assistance of the all the family members and the child's siblings are an important support system as Appleby (2014) explained that peer support, teamwork and sibling support are the factors which tend to lay an effect on the psychological health of families. Lam and Mackenzie (2002) concluded that one of the essential coping strategies used by parents of medical technology dependent children was seeking social support. Majority of the participants also reported holding onto religious and spiritual coping that helped them build optimism, gratitude and a connection to the divine. They stated that having their faith and trust on God regarding their child's life equipped them with the strength and hope to deal and adapt to their situation. It has been stated that in times of uncertainty, hope is crucial for adaptation and enhances one's psychological well-being (Truitt, Biesecker, Capone, Bailey, & Erby, 2012). According to a research, spiritual coping tends to greatly benefit and assist families who are caregivers to cope with their stress and crisis situations in an effective manner using their religious beliefs and practices (Rohmi, Yusuf, Fitriasari, & Agustinus, 2023).

6.1. Limitations

The methodological limitations of this study include having a relatively small sample size affecting the external validity of the research. Moreover, the sample was recruited from only one city in Pakistan, lowering its overall generalizability. This limitation was a result of using the purposive sampling technique, where the chosen participants were not representative of a broader population of caregivers, leading to conclusions based only on a specific stratum of caregivers. Also, the topic being sensitive made the families withhold their true experiences, making the research limited to the analysis of surface level data. Lastly, the constrained timeframe for data collection again augments to the affected depth of the findings.

6.2. Implications

This research provides insights for healthcare authorities to keep into consideration when providing support to families with medical technology dependent children and for future studies to be conducted within the Pakistani context. A greater understanding of these notions can help in the development of policies that assist such families by providing them enhanced hospital care at home without their caregivers having to bear all the burden. Also, the findings of this study also equip mental health care professionals on how to support such families and their children in a better, proactive way. The policy development can ensure that none of such families has to bear a financial strain, through providing subsidized medical equipment and treatment services for a relief. In Pakistan, there are limited mental health support programs for caregivers and the findings of this research highlights its dire need where free counselling services, support groups and community-based workshops on caregiver burnout can be made more available. Moreover, policy makers can make remote work options available for caregivers with flexible working hours to help them maintain their work life and simultaneously, fulfill their caregiving responsibilities as the findings of our study draw a link between

7. Conclusion

This research explored the experiences of families residing with and caring for the medical technology dependent children and highlighted their major living challenges and the coping strategies that they used as the major themes. The first theme, major living challenges comprised of 4 subthemes including psychological factors, social issues, work-related issues and financial constraints. While the second theme, coping strategies had 3 subthemes; social support, spiritual coping and self-empowerment. The parents caring for children with special needs tend to experience stages of grief and crisis, continuously trying to adapt to the situation and be resilient. While the mothers tend to bear a heavier psychological burden being the primary care-givers, being more prone towards experiencing heightened levels of stress, depression and emotional attachment in comparison to the fathers. The responsibilities that come along with the care-giving role tend to alter family functioning and normalcy, due to disruptions in normal daily routines for all the members. Financial hardships were one of issues put forth the most by all the participants. This study aims to bridge the gap between home and hospital care by providing recommendations for the implementation for such measures that redeem such families from undergoing a substantial burden and should be provided with hospital level care at home for their medical technology dependent children.

References

Abbott, D., Watson, D., & Townsley, R. (2005). The proof of the pudding: What difference does multi-agency working make to families with disabled children with complex health care needs? *Child & Family Social Work, 10*(3), 229-238. doi:10.1111/j.1365-2206.2005.00362.x

Alexander, T., & Walendzik, J. (2016). Raising a Child with Down Syndrome: Do Preferred Coping Strategies Explain Differences in Parental Health? *Psychology, 07*(01), 28-39. doi:10.4236/psych.2016.71005

Appleby, J. M. (2014). *Resilience in families of children who have disabilities*: The University of Texas at Arlington.

Balbo, N., & Bolano, D. (2024). Child disability as a family issue: a study on mothers' and fathers' health in Italy. *European Journal of Public Health, 34*(1), 79-84. doi:10.1093/eurpub/ckad168

Baruth, K. E., & Carroll, J. J. (2002). A formal assessment of resilience: The Baruth Protective Factors Inventory. *Journal of individual psychology, 58*(3). doi:https://doi.org/10.21315/eimj2019.11.3.3

Brody, L. R. (1997). Gender and Emotion: Beyond Stereotypes. *Journal of Social Issues, 53*(2), 369-393. doi:10.1111/j.1540-4560.1997.tb02448.x

Cameron, J. F., & Frechet, J. M. J. (1991). Photogeneration of organic bases from o-nitrobenzyl-derived carbamates. *Journal of the American Chemical Society, 113*(11), 4303-4313. doi:10.1021/ja00011a038

Chan, Y. H., Lim, C. Z.-R., Bautista, D., Malhotra, R., & Østbye, T. (2019). The Health and Well-Being of Caregivers of Technologically Dependent Children. *Global Pediatric Health, 6*, 2333794X18823000. doi:10.1177/2333794X18823000

Chang, Y.-S., Lin, M.-H., Lee, J.-H., Lee, P.-L., Dai, Y.-S., Chu, K.-H., . . . Yu, H.-H. (2016). Melatonin supplementation for children with atopic dermatitis and sleep disturbance: a randomized clinical trial. *JAMA pediatrics, 170*(1), 35-42.

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*: Sage publications.

Dybwik, K., Tollåli, T., Nielsen, E. W., & Brinchmann, B. S. (2011). " Fighting the system": families caring for ventilator-dependent children and adults with complex health care needs at home. *BMC health services research, 11*, 1-8. doi:https://doi.org/10.1186/1472-6963-11-156

Frankel, K., & Wamboldt, M. Z. (1998). Chronic Childhood Illness and Maternal Mental Health—Why Should We Care? *Journal of Asthma, 35*(8), 621-630. doi:10.3109/02770909809048964

Friborg, O., Barlaug, D., Martinussen, M., Rosenvinge, J. H., & Hjemdal, O. (2005). Resilience in relation to personality and intelligence. *International Journal of Methods in Psychiatric Research, 14*(1), 29-42. doi:10.1002/mpr.15

Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 981-997. doi:10.1111/j.1365-2788.2009.01220.x

Glendinning, C., Kirk, S., Guiffrida, A., & Lawton, D. (2001). Technology-dependent children in the community: definitions, numbers and costs [1]. *Child: Care, Health and Development, 27*(4), 321-334. doi:10.1046/j.1365-2214.2001.00187.x

Hale, E. D., Treharne, G. J., & Kitas, G. D. (2008). Qualitative methodologies II: a brief guide to applying interpretative phenomenological analysis in musculoskeletal care. *Musculoskeletal Care, 6*(2), 86-96. doi:10.1002/msc.113

Heaton, J., Noyes, J., Sloper, P., & Shah, R. (2005). Families' experiences of caring for technology-dependent children: a temporal perspective. *Health and Social Care in the Community, 13*(5), 441-450. doi:10.1111/j.1365-2524.2005.00571.x

Herber, O. R., Bradbury-Jones, C., Böling, S., Combes, S., Hirt, J., Koop, Y., . . . Taylor, J. (2020). What feedback do reviewers give when reviewing qualitative manuscripts? A focused mapping review and synthesis. *BMC Medical Research Methodology, 20*(1), 122. doi:10.1186/s12874-020-01005-y

Heyman, M. B., Harmatz, P., Acree, M., Wilson, L., Moskowitz, J. T., Ferrando, S., & Folkman, S. (2004). Economic and psychologic costs for maternal caregivers of gastrostomy-dependent children. *The Journal of Pediatrics, 145*(4), 511-516. doi:10.1016/j.jpeds.2004.06.023

Ho, L., & Limpaecher, A. (2022). What is phenomenological research design. *Essential Guide to Coding Qualitative Data.(19.01. 2022'de erişilmiştir: https://delvetool. com/blog/phenomenology)*.

Hussain, M., & Ahmad, D. K. (2021). Spirituality and Social Support as Predictors of Resilience among Elderly Cancer Patients' Informal Caregivers in Punjab, Pakistan. *Journal of Management Practices, Humanities and Social Sciences, 5*(6). doi:10.33152/jmphss-5.6.4

Irfan, B., Irfan, O., Ansari, A., Qidwai, W., & Nanji, K. (2017). Impact of Caregiving on Various Aspects of the Lives of Caregivers. *Cureus*. doi:10.7759/cureus.1213

Ivtzan, I., Chan, C. P. L., Gardner, H. E., & Prashar, K. (2013). Linking Religion and Spirituality with Psychological Well-being: Examining Self-actualisation, Meaning in Life, and Personal Growth Initiative. *Journal of Religion and Health, 52*(3), 915-929. doi:10.1007/s10943-011-9540-2

Kinsella, C., Dunphy, A., McCormack, S., Wilson, C., & Bennett, A. E. (2024). Experiences of Parents and Caregivers of Children Who Underwent Gastrostomy Tube Insertion. *Journal of Patient Experience, 11*, 23743735241272225. doi:10.1177/23743735241272225

Kirk, A. D., Harlan, D. M., Armstrong, N. N., Davis, T. A., Dong, Y., Gray, G. S., . . . Knechtle, S. J. (1997). CTLA4-Ig and anti-CD40 ligand prevent renal allograft rejection in primates. *Proceedings of the National Academy of Sciences, 94*(16), 8789-8794. doi:10.1073/pnas.94.16.8789

Kirk, S., Glendinning, C., & Callery, P. (2005). Parent or nurse? The experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing, 51*(5), 456-464. doi:10.1111/j.1365-2648.2005.03522.x

Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family response to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing, 11*(5), 315-326. doi:10.1016/S0882-5963(05)80065-X

Knafl, K. A., & Deatrick, J. A. (2002). Family matters. The challenge of normalization for families of children with chronic conditions. *Pediatric Nursing, 28*(1).

Kübler-Ross, E. (1969). 2009. On Death and Dying. In: New York: Routledge.

Lai, L., Potts, J. R., Zhan, D., Wang, L., Poh, C. K., Tang, C., . . . Ruoff, R. S. (2012). Exploration of the active center structure of nitrogen-doped graphene-based catalysts for oxygen reduction reaction. *Energy & Environmental Science, 5*(7), 7936. doi:10.1039/c2ee21802j

Lam, L.-W., & Mackenzie, A. E. (2002). Coping with a Child with Down Syndrome: The Experiences of Mothers in Hong Kong. *Qualitative Health Research, 12*(2), 223-237. doi:10.1177/104973202129119856

Lang, D. (2020, May 18). Family Systems Theory. Iastate.pressbooks.pub; Iowa State University Digital Press. Retrieved from https://iastate.pressbooks.pub/parentingfamilydiversity/chapter/the-family-systems-theory/

Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004). The Consequences of Caring: Effects of Mothering a Child with Special Needs. *Journal of Family Issues, 25*(3), 379-403. doi:10.1177/0192513X03257415

Leyenaar, J. K., O'Brien, E. R., Leslie, L. K., Lindenauer, P. K., & Mangione-Smith, R. M. (2017). Families' Priorities Regarding Hospital-to-Home Transitions for Children With Medical Complexity. *Pediatrics, 139*(1), e20161581. doi:10.1542/peds.2016-1581

Mak, W. W. S., & Kwok, Y. T. Y. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine, 70*(12), 2045-2051. doi:10.1016/j.socscimed.2010.02.023

Masood, A., Arshad, R., & Mazahir, S. (2015). Families of children with cerebral palsy: Family functions domains. *Internafional Journal of School and Cognifive Psychology, 2*(1), 1-6.

Miles, M. S., Holditch-Davis, D., Burchinal, P., & Nelson, D. (1999). Distress and Growth Outcomes in Mothers of Medically Fragile Infants:. *Nursing Research, 48*(3), 129-140. doi:10.1097/00006199-199905000-00003

Mitchell, T. K., Bray, L., Blake, L., Dickinson, A., & Carter, B. (2022). 'It doesn't feel like our house anymore': The impact of medical technology upon life at home for families with a medically complex, technology-dependent child. *Health & Place, 74*, 102768. doi:10.1016/j.healthplace.2022.102768

Monteiro, A. M. F., Santos, R. L., Kimura, N., Baptista, M. A. T., & Dourado, M. C. N. (2018). Coping strategies among caregivers of people with Alzheimer disease: a systematic review. *Trends in Psychiatry and Psychotherapy, 40*(3), 258-268. doi:10.1590/2237-6089-2017-0065

Muhammad, Q., Eiman, H., Fazal, F., Ibrahim, M., & Gondal, M. F. (2023). Healthcare in Pakistan: Navigating Challenges and Building a Brighter Future. *Cureus*. doi:10.7759/cureus.40218

Nageswaran, S., Gower, W. A., King, N. M. P., & Golden, S. L. (2024). Tracheostomy decision-making for children with medical complexity: What supports and resources do caregivers need? *Palliative and Supportive Care, 22*(4), 776-782. doi:10.1017/S1478951522001122

O'Brien, M. E. (2001). Living in a house of cards: Family experiences with long-term childhood technology dependence. *Journal of Pediatric Nursing, 16*(1), 13-22. doi:10.1053/jpdn.2001.20548

Oedekoven, M., Amin-Kotb, K., Gellert, P., Balke, K., Kuhlmey, A., & Schnitzer, S. (2017). Caregivers' burden and education level: does subjective health mediate the association? *European Journal of Public Health, 27*(suppl_3). doi:10.1093/eurpub/ckx187.100

Okido, A. C. C., Zago, M. M. F., & Lima, R. A. G. D. (2015). Care for technology dependent children and their relationship with the health care systems. *Revista Latino-Americana de Enfermagem, 23*(2), 291-298. doi:10.1590/0104-1169.0258.2554

Olson, D. H. (2000). Circumplex Model of Marital and Family Systems. *Journal of Family Therapy, 22*(2), 144-167. doi:10.1111/1467-6427.00144

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research, 42*(5), 533-544. doi:10.1007/s10488-013-0528-y

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological journal, 20*(1), 7-14. doi:https://doi.org/10.14691/CPPJ.20.1.7

Pitch, N., Shahil, A., Mekhuri, S., Ambreen, M., Chu, S., Keilty, K., . . . Amin, R. (2023). Caring for children with new medical technology at home: parental perspectives. *BMJ Paediatrics Open, 7*(1), e002062. doi:10.1136/bmjpo-2023-002062

Rohmi, F., Yusuf, A., Fitriasari, R., & Agustinus, H. (2023). What Benefits Might a Family Expect From Using Spiritual Coping Mechanisms When Providing Care for People With Schizophrenia? Literature Review. *SAGE Open Nursing, 9*, 23779608231214935.

Saeed, S., Malik, M. G. R., Khan, M. H., Malik, S. A. R., & Aziz, B. (2024). Care for the caregiver: an exploration of caregiver burden of children with chronic medical conditions at a tertiary care hospital in Karachi, Pakistan – a mixed-methods study. *BMJ Open, 14*(5), e083088. doi:10.1136/bmjopen-2023-083088

Sahar, N., & Naqvi, I. (2022). *Exploration of Indigenous Coping Strategies for Stress Among Caregivers of Substance Users*.

Sevgi, G., & Ayran, G. (2024). Investigating the caregiving burden and stress of mothers with children with special needs. *Journal of Pediatric Nursing*. doi:https://doi.org/10.1016/j.pedn.2024.05.020

Smith, J., Cheater, F., & Bekker, H. (2015). Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health Expectations, 18*(4), 452-474. doi:10.1111/hex.12040

Toly, V. B., Blanchette, J. E., Al-Shammari, T., & Musil, C. M. (2019). Caring for technology-dependent children at home: Problems and solutions identified by mothers. *Applied Nursing Research, 50*, 151195. doi:10.1016/j.apnr.2019.151195

Toly, V. B., Musil, C. M., & Carl, J. C. (2012). A longitudinal study of families with technology-dependent children. *Research in Nursing & Health, 35*(1), 40-54. doi:10.1002/nur.21454

Townsley, R., & Robinson, C. (2000). *Food for Thought: effective support for families caring for a child who is tube fed*: University of Bristol, Norah Fry Research Centre.

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling, 87*(2), 233-238. doi:10.1016/j.pec.2011.08.015

Wagner, D. A. (1988). Appropriate education and literacy in the Third World. *Health and cross-cultural psychology*, 93-111.

Wang, K. W. K., & Barnard, A. (2004). Technology-dependent children and their families: a review. *Journal of Advanced Nursing, 45*(1), 36-46. doi:https://doi.org/10.1046/j.1365-2648.2003.02858.x