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PARENTAL EXPERIENCES AND PSYCHOLOGICAL CHALLENGES IN CARING FOR CHILDREN WITH CONGENITAL MALFORMATIONS: A QUALITATIVE STUDY

Atakulov Jamshed Ostonoqulovich¹, Polikarpova Nataliya Vladimirovna²,
Mirzakarimova Farida Rustamovna³, Nurilloeva Shahodat Nurillo kizi⁴

¹Samarkand State Medical University, Doctor of Medical Sciences, Professor of the Department of Pediatric Surgery No.1, Samarkand State Medical University. Email ID - atakulov.jamshed@gmail.com

ORCHID ID - <https://orcid.org/0000-0003-1338-6873>

²Tashkent State Medical University, Assistant of the Department of Family Medicine No. 2, Clinical Pharmacology, Tashkent State Medical University. Email ID - nataliapolikarpova11@gmail.com

ORCHID ID - <https://orcid.org/0000-0002-7892-1307>

Tashkent State Medical University

³Designation- Assistant of the Department of Family Medicine No. 2, Clinical Pharmacology, Tashkent State Medical University. Email ID - mirzakarimova.f.r@tashmeduni.uz

ORCHID ID - <https://orcid.org/0000-0002-5498-926X>

⁴PhD in Medical Sciences, Bukhara State Medical Institute, Assistant Professor, Department of Internal Medicine in Family Medicine, Bukhara State Medical Institute. Email ID -

shakhodatnurilloeva92@gmail.com

ORCHID ID - <https://orcid.org/009-0002-1220-1187>

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ABSTRACT

Congenital malformations represent a significant public health concern worldwide and often require long-term medical care, placing considerable emotional, social, and financial burdens on parents who serve as primary caregivers. The present study aimed to examine the emotional burden and coping strategies among parents of children with congenital malformations by synthesizing evidence from existing literature. This study adopted a qualitative literature-based approach to develop a comprehensive understanding of the psychological experiences and adaptive mechanisms of parents caring for children with congenital anomalies. Relevant studies were identified through searches of major scientific databases, including PubMed, ScienceDirect, Scopus, Embase, and Medline. The selected studies examined various aspects of parental experiences, including emotional distress, psychological well-being, social support systems, coping mechanisms, and quality of life. The findings from the reviewed literature indicate that parents of children with congenital malformations frequently experience significant psychological distress, including anxiety, depression, fear, and uncertainty following the diagnosis of their child's condition. The long-term caregiving responsibilities, frequent medical interventions, and financial demands associated with congenital conditions further intensify parental stress

and emotional burden. In addition to psychological challenges, parents often encounter social isolation, limited access to healthcare services, and disruptions in family routines and employment. Despite these challenges, many parents develop adaptive coping strategies that enable them to manage the demands of caregiving. Social support from family members, healthcare professionals, and peer networks was identified as a key factor that facilitates parental resilience and emotional adjustment. Informational support, empathetic communication from healthcare providers, and participation in support groups also play a crucial role in helping parents cope with stress and caregiving challenges. The study highlights the importance of implementing family-centered healthcare approaches and integrating psychosocial support services into clinical care for families of children with congenital malformations. Strengthening support systems, improving communication between healthcare professionals and parents, and providing structured counseling programs may significantly enhance parental well-being and caregiving capacity.

KEYWORDS: Congenital malformations, parental experiences, emotional burden, coping strategies, psychological distress, family-centered care Congenital malformations, Genetic research, Minimally invasive surgery, Complications, Rehabilitation.

1. INTRODUCTION

An abnormality in structure or function that develops during fetal development and is apparent at birth is called a congenital malformation or congenital anomaly. Complex medical treatment and interdisciplinary care are sometimes necessary for individuals with these illnesses, which include a broad range of ailments such as congenital heart problems, neural tube defects, craniofacial anomalies, and musculoskeletal abnormalities. Although the prognosis for afflicted infants has greatly improved because to advancements in neonatal medicine and surgical procedures, families, especially parents who take on the main role of caring, typically experience a great deal of psychological and social strain due to the chronic nature of these disorders. According to Chandran et al. (2025) and Gallegos and Cacchillo (2023), the impact of caring for a kid with a congenital defect goes beyond the medical realm and has a significant effect on the mental health of parents, the dynamics within their families, and their ability to function socially.

Parents often experience a range of profound emotions when their child is born with a congenital defect, including shock, bewilderment, sadness, and worry for their child's future. Parents of children with congenital heart disease or cleft lip and palate may experience a range of emotions upon receiving the news of their child's diagnosis, including fear, uncertainty, and a lack of control over their situation (Kumar et al., 2026). Quickly understanding complicated medical information, deciding on tough treatments, and navigating healthcare systems that could be foreign or hard to access are all challenges that parents face. When a child's illness necessitates several hospitalizations or surgical treatments, this process may exacerbate stress, melancholy, and worry, which can cause emotional distress. The emotional reaction is only the beginning of the many issues that come with the long-term caring duties that come with congenital abnormalities. Many parents deal with ongoing worries about their child's well-being, progress in development, and ability to fit in socially. Continual attention, intense medical contacts, and uncertainty define the continual "health journey" that caregivers report in qualitative research of families managing congenital heart disease (Kankaya et al., 2025). Feelings of isolation and exhaustion from caring for a loved one might set in when these responsibilities interfere with one's ability to hold down a job, save money, and maintain social connections. The family's ability to operate and cope psychologically may also be impacted since

parents may find it difficult to meet the requirements of both the afflicted kid and other family members.

Crucially, not all parents' experiences as caregivers are unpleasant. In fact, many report being more resilient, closer to their families, and with more adaptable coping mechanisms. Parental stress and psychological adjustment may be better managed with the help of social support networks, which include healthcare providers, community members, and extended family (Lin et al., 2021; Nemes et al., 2024). Important factors that help parents cope and adjust emotionally include having access to correct information, receiving compassionate communication from healthcare experts, and having peer support from other parents whose children are impacted. However, many healthcare settings still have shortages in psychological support services, especially in low- and middle-income areas where specialist treatment may be hard to come by.

Clinical outcomes and quantitative assessments of caregiver burden have predominated in the current research on congenital malformations, despite growing awareness of the psychosocial aspects of these conditions. Understanding the complex emotional and social realities that parents encounter requires more qualitative research that delves into lived experiences and subjective interpretations. While this kind of study is still relatively scarce, it is crucial. The intricate relationship between medical difficulties and parental psychological experiences may be better understood via qualitative research that records personal narratives, beliefs, and coping mechanisms.

1.2 Background of the Study

Abnormalities in structure or function that develop during fetal development and may be detected during prenatal testing, delivery, or early childhood are known as congenital malformations or congenital anomalies. As one of the top causes of death among children less than five years old, these illnesses have a significant impact on global health. Worldwide, birth defects cause the deaths of around 240,000 infants each year in the first 28 days of life, and many more have permanent impairments that need ongoing medical treatment and rehabilitation (World Health Organization, 2023). Many of these abnormalities need long-term medical intervention and interdisciplinary therapy, and they comprise a broad spectrum of disorders, from cleft lip and palate to congenital heart problems and neural tube defects to musculoskeletal abnormalities. Consequences for the family unit, especially parents who take on the main role of caring for their kid, are typically

substantial when a child is born with a congenital defect. Complex treatment regimens, surgical procedures, long-term monitoring of developmental outcomes, and several hospital visits are common components of caring for a child with a congenital disease. Family routines may be drastically changed by these demands, which can lead to emotional strain, financial stress, and social interaction disturbances (Pelentsov et al., 2015). Dealing with the emotional fallout of their child's diagnosis and navigating the healthcare system may be very taxing on parents' mental health.

The first announcement of the diagnosis is often a very trying time for parents. The confirmation of a congenital defect, whether discovered during prenatal ultrasound screening or after delivery, may often trigger strong emotional emotions including shock, sadness, guilt, and worry over the future health and well-being of the child. When compared to parents of typically developing children, parents of children born with congenital abnormalities are more likely to suffer from psychological distress, according to research (Skari et al., 2006). This is especially true in the early phases after a diagnosis and while treatment plans are being made. Uncertainty about prognosis, possible surgical procedures, and long-term developmental results may amplify these emotional reactions. Parents of children born with congenital defects are more likely to suffer from sadness, anxiety, and caregiver stress, according to empirical research. Caregivers often express feelings of emotional tiredness, chronic stress, and diminished psychological well-being, according to study that examined parental mental health in families of children with congenital disorders (Sundus et al., 2013). When it comes to childcare, housework, and medical caregiving, mothers, who are often the main caregivers, may be more susceptible to psychological anguish. There are several ways in which congenital disorders may affect parents' mental health; for example, dads may worry about their children's future and feel overwhelmed by financial obligations. Caring for a kid born with a congenital defect may be difficult for parents in more ways than one. Parents, especially women, may face shame or guilt in certain cultures due to misunderstandings about the origins of congenital disorders. According to Pelentsov et al. (2015), when people go through these kinds of things, they may feel even more alone and have less access to social support systems, which may make their mental discomfort worse. Parents' openness to seeking psychological treatment or discussing their experiences with others might be impacted by social

stigma as well. Congenital abnormalities impose long-term caregiving obligations on families, yet many families show incredible fortitude in the face of these problems. Support from friends and family, easy access to medical treatment, and open lines of communication with doctors are some of the variables that may help parents adjust their coping techniques over time (Jackson et al., 2018). When parents have access to compassionate healthcare practitioners and a network of supporting family members, they are better able to handle the emotional and practical difficulties that come with their child's illness.

1.3 Purpose of the Study

The focus of this qualitative research is on the social, emotional, and psychological difficulties faced by parents caring for infants born with congenital defects, as well as their lived experiences in providing this care. Constant parental participation in their children's treatment and rehabilitation, as well as long-term medical care, are common outcomes of congenital malformations, which pose a serious threat to world health. World Health Organization data from 2023 shows that congenital defects are still a major contributor to newborn death and morbidity rates, and that families dealing with these issues face significant medical and psychological obstacles.

The diagnosis, treatment, and prevention of congenital abnormalities have received a lot of attention from the medical community, but the psychological experiences of parents who are the children's main caregivers have received much less study. Concerns about their child's health, prognosis, and developmental outcomes may cause emotional discomfort, worry, and ambiguity for parents (Pelentsov et al., 2015). Stress about money, changes in family relationships, and a lack of resources for psychological and social assistance may intensify these problems. Therefore, to fully grasp the larger effect of congenital abnormalities beyond clinical results, it is vital to study family experiences.

1.4 Scope of the Study

Parental experiences and psychological obstacles in caring for children diagnosed with congenital abnormalities are the subject of the current research. Understanding the social, psychological, and emotional aspects of parental caring in the setting of congenital abnormalities is the primary focus of the study. Worldwide Health Organization (2023) reports that these disorders impact family relations and parental well-being due to the long-term medical

treatment and ongoing parental participation typically required for these illnesses, which include a wide range of anatomical or functional abnormalities apparent at birth.

The main focus of this research is on the actual situations that parents face while caring for their children who have congenital defects. The study's overarching goal is to learn more about the mental reactions – such as worry, stress, anxiety, and coping mechanisms – that parents go through after receiving a child's medical diagnosis. Furthermore, the study delves into the ways in which parents adjust to the continuous caregiving duties linked to their children's medical treatments, hospital stays, and long-term health management. The study's overarching goal is to collect parents' first-hand accounts of the difficulties and adaptations they faced while caring for a kid born with a birth defect.

The study's purview also includes investigating how parental caregiving experiences are shaped by social and environmental variables. Factors such as social attitudes about congenital disorders, family support systems, encounters with healthcare providers, and availability of healthcare resources may have a role. To determine what helps and what hinders parents in meeting the challenges of caring, it is crucial to understand these contextual impacts (Pelentsov et al., 2015). The research goes even beyond by looking at how these events affect parents' mental health, adaptability, and resilience.

1.5 Problem Statement

The high rates of infant illness, death, and permanent impairment caused by congenital anomalies also called congenital malformations make them a major international public health concern. Cardiovascular, neurological, musculoskeletal, and craniofacial systems are among those that may be impacted by these disorders, which manifest during fetal development. World Health Organization data from 2023 shows that 240,000 infants die each year as a result of congenital defects, and that many of the children who do survive need continuous medical care, surgery, and rehabilitation. Consequently, congenital malformation therapy goes beyond only medical treatment and sometimes requires families to shoulder long-term caring duties.

The main responsibility for managing a child's healthcare requirements is often carried out by the parents of a kid with a congenital deformity. This may include regular trips to the hospital, specific medical treatments, and ongoing monitoring of the child's developmental progress. Parents may experience significant emotional, psychological, and

social strain as a result of their caring duties. Pelentsov et al. (2015) found that parents of children with congenital disorders often feel more stressed, anxious, depressed, and apprehensive about their child's prognosis and long-term quality of life. Parents may experience a range of emotions, including shock, sadness, and anxiety for what lies ahead, in addition to the complicated medical knowledge that comes with receiving a diagnosis.

The psychological impact of caring for a kid born with a defect is only one of several social and environmental obstacles that parents may face. Medical bills, job losses, restricted healthcare access, and diminished social support are all potential obstacles. Parental guilt, social isolation, and mental suffering may result from misunderstandings about the origins of congenital abnormalities and the related stigma in particular cultural situations. These characteristics might make it even more challenging for parents to manage the stress of caring and keep their mental health in check.

1.6 Emotional Burden And Coping Strategies Among Parents Of Children With Congenital Malformations

Parents typically experience deep anguish after the birth or diagnosis of a child with congenital abnormalities. This is because the event brings along a multitude of emotional, psychological, and social obstacles. The mental health of parents may take a serious hit when their child needs long-term medical treatment, numerous hospital stays, and round-the-clock care due to a congenital defect. Maghahreah et al. (2023) and Santos et al. (2025) found that parents of children with congenital anomalies often suffer from high levels of stress, anxiety, and depression. This is mainly because they have to deal with the demands of long-term caregiving while also not knowing the child's prognosis. Some of these emotional reactions may surface soon after a child's diagnosis, and they may continue all the way through their childhood.



Source:

In the time immediately after a congenital disease diagnosis, parents may feel an even greater emotional load. When asked about their reactions to hearing their child's diagnosis and how it may affect their future, parents often say they are shocked, grieving, terrified, and powerless. According to studies, parents experience more emotional and mental strain when their child's congenital defect necessitates extensive medical treatment or surgery, such in the instance of congenital heart disease (Brosig et al., 2007). Because of their stronger emotional connection to their kid and their greater role in day-to-day caregiving, women often report greater levels of emotional discomfort than dads (Maghaireh et al., 2023) as compared with fathers.

Caring for an infant with a congenital deformity may be very difficult, causing mental pain as well as social and economic difficulties. Financial hardship and diminished engagement in social activities may result from the ongoing need for specialist medical treatment, treatments, and hospital visits. Parents may have diminished quality of life and feelings of loneliness as a result of these circumstances. Caregiving duties may restrict social contacts and raise the incidence of psychological illnesses including anxiety and sadness, according to multicenter research that looked at moms of babies with congenital abnormalities (Santos et al., 2025). Families may already be dealing with a lot of emotional strain due to the prevalence of stigmatization and cultural beliefs about congenital diseases. Although dealing with their child's illness is very difficult emotionally, many parents learn to cope with time. In order to deal with difficult events and keep their mental health in check, people use a variety of coping mechanisms. According to Santos et al. (2025), these techniques may be broadly classified into two main types: problem-focused coping, which is actively tackling the cause of stress, and emotion-focused coping, which entails controlling emotional reactions to stressful situations. Parental resilience and psychological adaptability are both greatly enhanced by the development of effective coping strategies.

Parents of children born with congenital defects have developed a variety of coping mechanisms. A parent's ability to cope with emotional anguish is greatly aided by the social support they get from their family, healthcare providers, and peer networks. Parental confidence in caring may be enhanced when they have access to trustworthy medical information and get supportive communication from healthcare specialists. To help their children cope and adapt emotionally, some

parents turn to spiritual beliefs, positive reframing, and acceptance. Important patterns of coping were revealed in a study of parents dealing with congenital heart disease. These patterns included processing emotions, depending on social support networks, and trying to keep family life normal (Lumsden et al., 2019).

2. LITERATURE REVIEW

This research set out to investigate the lived realities of Ethiopian parents coping with the challenges of caring for children born with birth defects. The parents of infants diagnosed with congenital abnormalities at two tertiary hospitals in South Ethiopia were the subjects of phenomenological research that sought to understand their lived experiences. The in-depth interviews were conducted with a purposeful selection of eighteen parents. We transcribed and translated the interviews once audio recordings were made. Establishing the study's legitimacy, transferability, reliability, and conformability assured its rigor. Using Open Code v4.03, thematic analysis was carried out. Five main ideas surfaced. 'Prior awareness, perception and discovery,' 'burden,' 'support system,' and 'effect of the abnormality' are some of the topics. Because of their child's condition, parents of congenital abnormalities have difficulties in accessing healthcare services, as well as financial and hygiene-related responsibilities. They depend on their small network of family and friends while dealing with emotional and social challenges (Setato, 2026)

This study attempts to compile the most current information available from the literature on the mental health of parents whose children have been prenatally diagnosed with congenital heart abnormalities (CHDs). Researchers looked for research that addressed the mental health challenges experienced by parents whose unborn children were identified with congenital heart defects. We searched many scientific databases to make sure we covered all the bases, including PubMed, Science direct, Embase, Scopus, Medline, and Clarivate. Only research published up to February 2025 was considered. Words like "congenital heart defect" (CHD), "prenatal diagnosis" (PD), "psychological impact," "parental distress," and "coping" were all part of the search approach. For this analysis, 18 research were included, including 673 investigations including parents of fetuses with congenital heart abnormalities. There were 14 qualitative studies and 4 quantitative studies conducted across four continents. Anxiety, despair, stress, PTSD, coping

mechanisms, maternal-fetal bonding, and overall life happiness were the most often reported psychological effects. The two most common mental health disorders were anxiety and depression, with 65% of mothers reporting anxiety and 45.7% reporting depression. Uncertainty over a diagnosis was a typical source of stress. Some parents resorted to healthy coping mechanisms like social support and emotional control, while others fell into unhealthy habits like avoidance. There was an uptick in maternal-fetal attachment after a prenatal diagnosis of CHD, according to one research. The severity of the defect, the amount of social support, the parents' education level, the timing of diagnosis, and the parents' gender were all factors that predicted psychological suffering. Counseling with a structured framework, empathic communication, early psychiatric evaluation, and ongoing emotional support were all suggested as ways to help. The data show that parents consistently experience psychological burden, despite design variation and minimal overall bias. This emphasizes the necessity for comprehensive psychosocial therapy after a prenatal CHD diagnosis. Final thoughts: Prenatal diagnosis of a congenital heart abnormality increases the risk of psychological distress for parents. The best care can be provided when parents are informed about their child's diagnosis, treatments, and possible outcomes by a multidisciplinary team (Tear, 2025)

Acceptance of a child's structural, functional, anatomical, and physical problems as well as the feelings felt by families in response to a child's birth with a congenital defect is an ever-changing and difficult process. In order to assess and integrate the data pertaining to the emotions experienced by parents of children born with congenital defects throughout the puerperal phase. Procedure: This scoping review was carried out using the following question as its guiding principle: "What emotions impact the parents of children born with congenital malformation during the puberty period?" Within the framework of the following databases: BVS (Virtual Health Library), Medline (Medical Literature Analysis and Retrieval System Online), Lilacs (Latin American and Caribbean Literature in Health Sciences), and BDENF (Nursing Database). A total of 693 studies were deemed ineligible for inclusion, with just 19 making it into the final sample. The results of the 19 studies that made up the sample show that parents of children with congenital anomalies experience a wide range of emotions during pregnancy and the postpartum period, including but not limited to: anxiety, depression,

fear, emotional overload, sadness, anger, loneliness, exclusion, surprise, pain, stress, denial, psychopathological symptoms, suicidal thoughts, rejection, uncertainty, insecurity, psychological changes, and infidelity. In order to meet this need in a multi-professional way, the health system must develop public policies and training methods for health personnel (Samersla, n.d.)

Patients and their parents with unusual congenital craniofacial conditions will be the focus of this qualitative systematic study that seeks to shed light on the experience. The research benefited from the involvement of eight patient representatives. A total of 32 papers using qualitative and mixed methodologies with more than 691 individuals were included after a comprehensive search that screened 1,291 research. For the purpose of reporting qualitative evidence synthesis and assessing the reporting of included studies, the ENhancing Transparency in REporting the synthesis of Qualitative research (ENTREQ), COchrane, and Collaborative Criteria for Reporting Qualitative research (COREQ) checklists were used. The majority of studies surveyed parents, and those that did so used mixed-sample diagnostic methods and, on occasion, blended parent and patient viewpoints. The articles' findings sections were subjected to inductive analysis via the use of Thematic Synthesis, which involves line-by-line coding to produce analytical and descriptive themes. First, healthcare experiences; second, raising and growing up; third, character development; fourth, the physical influence of the disease; and fifth, social experiences are the five selected analytical themes that portray experiences and viewpoints. Throughout life, there are many interconnected parts; interactions in all walks of life shape our views; and our experiences might evolve with the passage of time (Faasse, 2025)

A congenital heart disease (CHD) diagnosis may put a parent through a whirlwind of emotions, including worry, stress, and role pressure. The purpose of this research is to better understand the informational, emotional, and practical support requirements of parents whose newborns are born with a congenital heart defect (CHD). Using a narrative synthesis to analyze qualitative literature, this study classifies parents' needs as follows: (1) informational, where parents seek clear guidance due to their overwhelming fear of medical terminology; (2) emotional, where parents need empathy and understanding from healthcare providers and gain strength from peer support; and (3) practical, where parents require help with day-to-day tasks and self-care. The results of this review

highlight the importance of nurses in addressing these demands by providing thorough training, empathetic treatment, and useful tools. As a result, nurses may work together to alleviate parents' worries and create a nurturing atmosphere for families (Tuck, 2025)

This research address this knowledge gap, the current research is concentrating on measuring the well-being of parents who are the main carers for children undergoing neurosurgical treatment for central nervous system congenital abnormalities. In this descriptive cross-sectional research, 44 parents whose children were undergoing neurosurgical treatment for central nervous system congenital abnormalities were evaluated for their quality of life. The data was gathered using the WHO Quality of Life Questionnaire-Short Form (WHOQOL-SF) and the Parent Introduction Information Form. The results were analyzed using SPSS. The social domain had the lowest quality of life ratings among parents who were primary caregivers, whereas the environmental domain had the best. In terms of social quality of life, the child's gender matters much, but in terms of physical quality of life, the kind of diagnosis matters greatly. The quality of life in relation to the environment is impacted by economic position, with low-income households experiencing more severe difficulties. The quality of life for parents is greatly affected by caring for children with central nervous system disorders. Caregiver well-being may be enhanced by focused interventions, such as social and economic assistance, according to the research (Bulut, 2025)

Caregivers of young children undergoing conservative therapy for cardiac abnormalities were the subjects of this study, which intended to assess their quality of life, stress levels, and parental burnout. We surveyed 78 carers, with a median age of 36, whose children, with a median age of 6.0 months, had undergone conservative treatment for congenital heart abnormalities. The children's ages ranged from 6.0 months to 36 months. The Parental Burnout Assessment (PBA), the Perceived Stress Scale (PSS), and the 36-Item Short Form Health Survey (SF-36) were used to gather data at two time points: one immediately after delivery, and six months later, when the congenital illness diagnosis had been made. To determine statistical significance, p-values less than 0.05 were used in paired t-tests, chi-square tests, and Pearson correlation analyses. The average SF-36 score is Material Part At six months, the summary scores had grown considerably from 59.7 ± 11.7 at baseline to 63.5 ± 12.1 ($p = 0.026$). As a result of less felt stress, PSS scores

dropped from 22.9 ± 6.2 to 20.4 ± 5.9 ($p = 0.012$). Evaluation of Parental Burnout Overall, the scores decreased from 44.9 ± 8.5 to 40.1 ± 8.0 , with a p-value of 0.003. Findings from the correlation analyses showed that there were moderate negative associations between the SF-36 categories and both PSS (r range: -0.40 to -0.58) and PBA (r range: -0.34 to -0.52). Final thoughts: Caretakers of children undergoing conservative therapy for heart abnormalities confront complex issues, as our data demonstrate. Clinical monitoring and tailored psychosocial assistance may be beneficial because they improve quality of life while simultaneously reducing perceived stress and parental burnout over a six-month period. Longitudinal patterns could be better understood in future studies by using bigger, multicenter cohorts and longer follow-up periods. Sustaining well-being and improving patient outcome may depend on implementing therapies that alleviate stress and burnout in these families (Dumitru, 2025)

3. METHODOLOGY

3.1 Research Design

The present study adopted a qualitative research design based on a narrative literature review approach to explore the emotional burden and coping strategies among parents caring for children with congenital malformations. A qualitative review methodology was considered appropriate because the objective of the study was not to generate new primary data but to synthesize existing scholarly evidence and provide a comprehensive understanding of parental experiences and psychological challenges associated with congenital anomalies. Qualitative synthesis allows researchers to integrate findings from multiple studies and identify common patterns, themes, and perspectives related to a specific phenomenon (Snyder, 2019).

This study therefore relied on previously published empirical and review studies that examined parental psychological experiences, emotional distress, coping strategies, quality of life, and support systems in families of children with congenital malformations. Through a structured examination of relevant literature, the study aimed to generate a general conceptual understanding of the emotional and psychosocial challenges faced by parents while caring for affected children.

3.2 Data Sources and Literature Search Strategy

To ensure comprehensive coverage of the relevant literature, a systematic search of multiple scientific databases was conducted. The primary databases

consulted for this study included PubMed, ScienceDirect, Scopus, Embase, Medline, and Clarivate Analytics databases. These databases were selected because they provide access to a wide range of peer-reviewed medical, psychological, and public health research related to congenital anomalies and family caregiving.

The literature search was conducted using a combination of keywords and Boolean operators to identify relevant studies. The key search terms included:

- “Congenital malformations”
- “Congenital anomalies”
- “Birth defects”
- “Congenital heart defects”
- “Parental experiences”
- “Psychological distress”
- “Emotional burden”
- “Coping strategies”
- “Parental stress”
- “Caregiver experiences”

These keywords were combined using Boolean operators such as AND and OR to refine the search results and identify studies that specifically addressed the psychological and social experiences of parents caring for children with congenital abnormalities.

3.3 Inclusion and Exclusion Criteria

In order to maintain the relevance and quality of the literature reviewed, specific inclusion and exclusion criteria were established.

Inclusion Criteria:

1. Studies focusing on parents or primary caregivers of children with congenital malformations or congenital anomalies.
2. Research examining psychological, emotional, or social experiences of parents.
3. Qualitative studies, systematic reviews, narrative reviews, and quantitative studies that explored parental coping or mental health.
4. Peer-reviewed articles published in English.
5. Studies published between 2015 and 2026 to ensure the inclusion of recent and relevant evidence.

Exclusion Criteria:

1. Studies focusing solely on medical or surgical treatment outcomes without discussing parental experiences.
2. Studies involving adult congenital conditions without parental caregiving context.
3. Editorials, commentaries, conference abstracts, or unpublished manuscripts.
4. Duplicate articles identified across databases.

3.4 Selection of Studies

The selection process involved an initial screening of titles and abstracts to determine the relevance of each study to the research topic. Articles that appeared relevant were then subjected to a full-text review to ensure that they met the inclusion criteria. After the screening process, a final set of studies was selected for inclusion in the literature review.

The selected studies represented diverse geographical contexts and research designs, including qualitative studies, systematic reviews, and cross-sectional investigations examining parental psychological experiences related to congenital malformations. These studies provided valuable insights into emotional distress, coping mechanisms, social support systems, and the overall well-being of parents caring for affected children.

3.5 Data Extraction and Synthesis

Relevant information from each selected study was carefully extracted and organized for analysis. The extracted data included the following elements:

- Author(s) and year of publication
- Study location and population
- Research design and methodology
- Sample characteristics
- Key findings related to emotional burden and coping strategies

The extracted findings were then analyzed using thematic synthesis, which is commonly used in qualitative literature reviews. This approach involves identifying recurring patterns, concepts, and themes across the selected studies. Through repeated reading and comparison of the findings, major themes related to parental emotional experiences and coping mechanisms were identified and synthesized to provide a broader understanding of the issue.

4. DISCUSSION

The present study synthesized existing literature to understand the emotional burden and coping strategies experienced by parents caring for children with congenital malformations. The findings from the reviewed studies consistently highlight that parents encounter substantial psychological, social, and economic challenges while managing the complex healthcare needs of their children. At the same time, the literature also demonstrates that families gradually develop coping mechanisms and rely on various support systems to adapt to these challenges. The discussion below integrates the major themes emerging from the reviewed studies.

4.1 Psychological and Emotional Burden Among Parents

One of the most prominent findings across the reviewed literature is the significant psychological burden experienced by parents of children with congenital malformations. Parents frequently report emotional reactions such as shock, fear, grief, anxiety, and depression upon learning about their child's diagnosis. These emotions are particularly intense during the early stages of diagnosis when parents are confronted with uncertainty about the child's prognosis and long-term health outcomes (Tecar, 2025).

Studies included in the review indicate that anxiety and depression are among the most common psychological responses among parents. For instance, Tecar (2025) reported that approximately 65% of mothers experienced anxiety and 45.7% experienced depressive symptoms following a prenatal diagnosis of congenital heart disease. Similarly, Samersla (n.d.) found that parents often experience emotional overload, sadness, loneliness, and psychological distress during pregnancy and the postpartum period. These findings suggest that the emotional impact of congenital anomalies extends beyond the initial diagnosis and may persist throughout the child's development.

The emotional burden may also be intensified by the continuous caregiving responsibilities associated with congenital conditions. Parents must frequently manage medical appointments, hospitalizations, and long-term treatments, which can lead to chronic stress and emotional exhaustion. This aligns with the findings of Dumitru (2025), who observed significant levels of parental stress and burnout among caregivers of children undergoing treatment for congenital heart conditions.

4.2 Social and Economic Challenges

In addition to psychological distress, parents of children with congenital malformations often face substantial social and economic challenges. The literature reviewed indicates that caring for a child with a congenital condition may disrupt family routines, employment opportunities, and social relationships.

Setato (2026) found that parents in Ethiopia experienced difficulties accessing healthcare services, along with financial strain associated with medical expenses and hygiene-related caregiving responsibilities. These challenges were particularly pronounced in resource-limited settings, where access to specialized healthcare services and social support systems may be limited.

Economic factors also play an important role in shaping parental experiences. Bulut (2025) reported that parents from low-income households experienced lower environmental quality of life due to financial constraints and limited access to healthcare resources. These findings highlight that socioeconomic status can significantly influence the level of stress experienced by parents and their ability to effectively manage caregiving responsibilities.

Furthermore, social isolation is another major challenge reported by parents. Many parents reduce their social interactions due to the intensive caregiving demands placed upon them. As a result, parents may experience feelings of loneliness and reduced social support, which can further exacerbate emotional distress.

4.3 Coping Strategies And Parental Adaptation

Despite the considerable challenges associated with caring for children with congenital malformations, many parents gradually develop coping strategies that help them adapt to their circumstances. The literature suggests that coping strategies may vary depending on individual, social, and cultural factors.

Several studies indicate that social support plays a crucial role in helping parents cope with emotional stress. Setato (2026) reported that parents often rely on close family members and friends as their primary support network when facing emotional and social challenges. Similarly, Tuck (2025) emphasized the importance of informational, emotional, and practical support provided by healthcare professionals, particularly nurses, in assisting parents to manage caregiving responsibilities.

Adaptive coping strategies identified in the literature include seeking social support, gaining knowledge about the child's condition, maintaining hope, and developing emotional resilience. These strategies enable parents to gradually accept their child's condition and develop a sense of competence in managing caregiving responsibilities.

However, the literature also indicates that some parents may adopt maladaptive coping strategies, such as avoidance or emotional withdrawal, particularly during periods of high stress (Tecar, 2025). These coping patterns may increase the risk of long-term psychological distress if appropriate support systems are not available.

4.4 Role Of Healthcare Professionals And Support Systems

The reviewed studies consistently emphasize the

critical role of healthcare professionals in supporting parents of children with congenital malformations. Healthcare providers serve as an important source of information, emotional reassurance, and practical guidance for parents navigating complex medical situations.

Tuck (2025) highlighted that parents often require three primary forms of support: informational support, emotional support, and practical assistance. Informational support helps parents understand the medical condition and treatment options, while emotional support allows them to express their fears and concerns. Practical assistance may include guidance on caregiving techniques, hospital procedures, and access to community resources.

In addition, multidisciplinary care teams consisting of physicians, nurses, psychologists, and social workers can play a vital role in addressing the diverse needs of families. Tecar (2025) recommended structured counseling programs, empathetic communication from healthcare professionals, and early psychological interventions to reduce parental distress following a diagnosis of congenital anomalies.

5. CONCLUSION

The current research aimed to synthesize information from previous studies in order to get a thorough comprehension of the emotional strain and coping mechanisms faced by parents caring for children with congenital abnormalities. The analyzed research show that parents' mental, social, and financial health are greatly impacted by the identification and treatment of congenital abnormalities. Anxiety, despair, dread, uncertainty, and emotional anguish are common reactions among parents, especially in the time immediately after their child's diagnosis. Uncertainty about the child's future health and growth, frequent medical treatments, and long-term caring duties might amplify these emotional emotions. The research goes on to say that mental anguish is only one of many difficulties parents confront. Intense caring duties may lead to social isolation, financial pressure from continuous medical treatment, interruptions in career and family routines, and restricted access to healthcare services in certain places. Whether parents have enough support depends on a variety of variables, including their financial status, level of education, and access to healthcare.

Despite these obstacles, the research we looked at also show that parents learn to cope with the responsibilities of caring for children with congenital defects in their own unique ways. When parents are

emotionally overwhelmed, it is essential that they have social support from people they trust, such as friends, family, and healthcare providers. Parents' ability to adjust and bounce back may be greatly enhanced with the help of informative assistance, compassionate communication from healthcare professionals, and psychological treatment. In order to adapt to their caregiving tasks, parents may use effective coping mechanisms include reaching out to social support, learning as much as they can about their child's illness, and keeping their emotional resilience strong.

Supporting parents throughout their caregiving journey is a crucial role that healthcare systems and multidisciplinary teams play, according to the results. Doctors, nurses, psychiatrists, and social workers, among others, may help parents cope better with their child's illness and treatment by being there for them with answers to their questions, words of encouragement, and detailed explanations of what to expect. Parents' emotional well-being and ability to cope may be further improved by family-centered healthcare treatments and structured counseling programs.

5.1. Recommendations

- **Strengthening Psychological Support Services:** Healthcare institutions should integrate structured psychological support services for parents whose children are diagnosed with congenital malformations. Counseling programs and mental health interventions should be made available immediately after diagnosis and continue throughout the treatment process.
- **Enhancing Communication between Healthcare Providers and Parents:** Effective communication between healthcare professionals and parents is essential for reducing uncertainty and emotional stress. Medical professionals should provide clear, accurate, and understandable information regarding the child's diagnosis, treatment options, and prognosis. Training programs for healthcare professionals should emphasize empathetic communication skills so that parents receive emotional reassurance and support during critical stages of diagnosis and treatment.
- **Development of Family-Centered Healthcare Programs:** Hospitals and healthcare systems should implement family-centered care approaches that actively involve parents in the decision-making process regarding their

child's treatment. Such programs can help parents develop confidence in managing their child's condition while also promoting collaboration between families and healthcare professionals.

- Establishment of Parental Support Groups: Support groups for parents of children with congenital malformations should be established within healthcare institutions or community settings. These groups can provide opportunities for parents to share experiences, exchange coping strategies, and receive emotional support from others facing similar challenges. Peer support networks can play an important role in reducing feelings of isolation

and strengthening parental resilience.

- Provision of Financial and Social Support Programs: Government agencies and healthcare organizations should develop policies and support programs that provide financial assistance and social support for families caring for children with congenital anomalies. The high cost of medical treatments and long-term care often places a significant financial burden on families, particularly those with limited economic resources. Financial aid programs, insurance coverage, and community-based services can help alleviate this burden.

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