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A QUALITATIVE EXPLORATION OF CAREGIVER BURDEN, PSYCHOLOGICAL STRESS, AND TREATMENT DISCONTINUATION IN PEDIATRIC MUSCULOSKELETAL DEFORMITIES (CHILDREN AGED 0–9 YEARS)

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Abstract

Background:
Juvenile idiopathic arthritis (JIA), clubfoot, scoliosis, arthrogryposis multiplex congenita, and congenital limb deficits are examples of pediatric musculoskeletal malformations that require comprehensive, long-term care and significantly stress on caretakers. While quantitative research has shown caregiver stress and burden in pediatric chronic conditions, there is little qualitative data on caregivers' lived experiences, decision-making processes, and treatment discontinuation in musculoskeletal deformities, especially in children ages 0–9.

Objectives:
To investigate caregivers' lived experiences of psychological stress, caregiver burden, and treatment-related choices (such as adherence and cessation) in children with musculoskeletal abnormalities between the ages of 0 and 9.

Methods:
Semi-structured individual interviews (n = 22) and focus groups (n = 2 FGDs, totaling 12 participants) with primary caregivers of children diagnosed with musculoskeletal abnormalities between the ages of 0 and 9 were used in a qualitative descriptive design. Purposive

sampling was used to choose participants from a pediatric orthopedic and rheumatology clinic in Jinnah Post Graduate Medical Centre, BAWS health facility, Farooq e Azam Medical Centre, Karachi, Pakistan, ensuring diversity across conditions, age groups, and socioeconomic circumstances. The Braun and Clarke methodology was followed in the audio recording, verbatim transcription, and thematic analysis of the data using NVivo (version 14). Through member verification, peer debriefing, reflexivity, and audit trails, reliability was guaranteed.

Results

Analysis produced 127 codes, which were divided into 12 sub-themes and three major themes.

Theme 1: caregiver burden

- *Financial pressure (medication expenditures, transportation, equipment)*
- *physical strain (fatigue, muscle soreness, sleep disturbance)*
- *emotional strain (anxiety, remorse, worry, fear of relapse)*
- *social isolation (stigmatization, family disputes, and less social interaction)*

theme 2: psychological stress and coping

Depression, anxiety, and emotional exhaustion
coping mechanisms (professional, peer, and family support)
resilience and creating meaning (finding purpose, positive reframing)

theme 3: treatment adherence and discontinuation

- *obstacles to compliance (expense, travel, lack of assistance)*
- *grounds for stopping (expense, perceived lack of effectiveness, fear of negative effects)*
- *decision-making and support requirements (need for professional, peer, and guided support)*

Burden was defined by caregivers as a multifaceted, cumulative experience. Stress was strongly associated with load, and caregivers reported ongoing anxiety, disturbed sleep, and emotional exhaustion. Treatment cessation was frequently a negotiated choice impacted by both internal concerns (such as side effects and relapse) and exterior obstacles (such as expense and travel).

Conclusion:

This study emphasizes how caregiver stress is multifaceted and how it affects treatment compliance in children with musculoskeletal disorders. High levels of stress are common among caregivers and are frequently associated with financial hardship, social isolation, and relapse anxiety. Emotional and practical obstacles both influence treatment discontinuation. The results have implications for future research (e.g., longitudinal studies, cultural studies, intervention development), policy (e.g., financial aid, access to care, support services), and clinical practice (e.g., caregiver support, psychological therapies, adherence support).

INTRODUCTION

Background of the study

Juvenile idiopathic arthritis (JIA), clubfoot (congenital talipes equinovarus), idiopathic scoliosis, arthrogryposis multiplex congenita (AMC), and congenital limb deficiencies are among the pediatric musculoskeletal disorders and deformities that significantly contribute to chronic disability, functional limitation, and long-term rehabilitation needs in children. Despite the fact that the etiology and clinical course of these disorders vary, they all necessitate intense, frequently protracted treatment regimens (such as repeated casting, bracing, orthotic/prosthetic fitting, surgery, and medication), which put a significant burden on families and caregivers. [1]

The cumulative physical, emotional, financial, and social stress that parents or primary caregivers endure while managing a child's chronic health condition is referred to as caregiver burden. The burden of treating pediatric musculoskeletal diseases is sometimes made worse by the necessity for regular clinic visits, at-home exercise regimens, and difficult choices about whether to continue or stop treatment. Caregivers of children with JIA, clubfoot, and other musculoskeletal disorders have frequently experienced psychological stress, which frequently takes the form of anxiety, despair, and a sense of powerlessness. This stress is associated with worse family functioning and less treatment sustainability. [2]

One of the most important issues in pediatric musculoskeletal therapy is treatment cessation, or partial adherence that is below recommended standards. Due to financial constraints, concerns about side effects, and fear of relapse, caregivers in JIA report quitting or being unwilling to continue biologics. Due to challenges like travel costs, perceived social stigma, and a lack of support, clubfoot has been associated with missed casting sessions and lower bracing compliance. Despite mounting evidence of these challenges, most prior research has focused on quantitative measures of stress, burden, or adherence, leaving a gap in our understanding of the lived experiences, narratives, and decision-making processes of caregivers thru qualitative inquiry. [3]

Statement of the Problem

Qualitative research on caregiver burden, psychological stress, and treatment discontinuation in pediatric musculoskeletal abnormalities is conspicuously lacking, especially in populations of children aged 0–9 years. Although caregiver stress and burden have been investigated in pediatric orthopedics (e.g., clubfoot, scoliosis) and rheumatology (e.g., JIA), these studies primarily rely on cross-sectional surveys, validated scales, and prevalence estimates rather than a thorough examination of caregivers' subjective experiences. Additionally, a lot of research on pediatric musculoskeletal disorders has confused neurological and musculoskeletal manifestations (such cerebral palsy), which limits its usefulness to conditions that are solely musculoskeletal.[2]

Current understanding is constrained in a number of important ways.

Depth of experiential understanding: The narrative intricacy, emotional subtleties, and contextual elements that influence caregivers' decisions to continue, alter, or stop therapy are not captured by quantitative research, which highlight burden and stress categories (such as financial strain and emotional tiredness) [4]

Treatment discontinuation mechanisms: There is a lack of qualitative data on how caregiver's reason about, emotionally experience, and negotiate decisions to stop or reduce treatment, particularly in early childhood (0–9 years), where parental decision-making is predominant, despite the fact that adherence barriers (such as costs, travel, and knowledge deficits) have been documented. [5]

Contextual and cultural specificity: The majority of current research comes from high-income environments, with little focus on how socioeconomic hardship, rural-urban differences, and cultural elements (such as stigma and family expectations) affect caregiver stress and burden in low- and middle-income settings. [6]

Developmental stage considerations: Although the 0–9 age span is crucial for early intervention, rehabilitation, and long-term results, there is little qualitative research that focuses on caregivers of children with musculoskeletal abnormalities in this age range. [7]

Therefore, in order to design supportive interventions, maximize treatment adherence, and lower the risk of premature discontinuation in pediatric musculoskeletal disorders, healthcare professionals,

rehabilitation specialists, and legislators lack a nuanced, evidence-based understanding of caregivers' lived realities.

Purpose of the Study

This qualitative study aims to investigate the lived experiences of caregiver burden, psychological stress, and treatment-related decisions, such as adherence and cessation, in children with musculoskeletal abnormalities between the ages of 0 and 9. The study intends to produce a comprehensive, contextually grounded understanding of how caregivers interpret and handle the demands of chronic musculoskeletal care through semi-structured interviews and focus groups.

Specifically, the study has

1. Determine and explain the primary aspects of caregiver burden (emotional, physical, financial, and social) related to the management of pediatric musculoskeletal abnormalities, including scoliosis, clubfoot, JIA, and congenital limb deficits.
2. Examine how psychological stress appears and changes during the initiation, maintenance, and post-treatment stages of treatment.
3. Examine the elements and decision-making procedures that affect caregivers' decisions to stick with, alter, or stop treatment plans.
4. Determine coping mechanisms, support requirements, and perceived weaknesses in the social and healthcare systems that impact treatment continuity, burden, and stress.

Research Questions

Primary Research Question

1. How are caregiver burden, psychological stress, and treatment termination decisions experienced and described by caretakers of children with musculoskeletal abnormalities between the ages of 0 and 9?

Secondary Research Questions

2. What are the primary emotional, physical, economical, and social aspects of caregiver burden related to the treatment of juvenile musculoskeletal deformities?
3. How can psychological stress show up for caregivers throughout various treatment phases (such as casting, bracing, or medication), everyday care routines, and disease flare-ups or complications?
4. Which contextual factors—such as family support, healthcare access, socioeconomic level, and cultural beliefs—have an impact on caregivers' decisions to continue or stop treatments?
5. How do caregivers view the long-term effects of their stress and load on their own wellbeing, child outcomes, and family dynamics?
6. What coping mechanisms and unfulfilled support requirements can caregivers recognize to reduce stress, burden, and the likelihood of treatment discontinuation?

Significance of the Study

This study is significant for several reasons:

Clinical and Rehabilitative Implications

Understanding the lived experiences of caregivers of children with musculoskeletal anomalies can help design targeted psychosocial interventions, caregiver education programs, and adherence support strategies. For instance, more responsive counseling, financial aid, and community-based support models can be created using qualitative insights into concerns about drug side effects in JIA or travel and social difficulties in clubfoot. These results could lower the chance of therapy cessation and improve long-term results by assisting doctors in anticipating and resolving adherence difficulties. [8]

Policy and Health System Implications

The results can give health officials and service planners information on care gaps, such as the need for multidisciplinary support (such as social work, psychological counseling, and financial help) for families dealing with long-term musculoskeletal disorders. Policies targeting fair access to care, travel subsidies, and community rehabilitation services can be supported by statistics on how socioeconomic hardship and rural-urban inequities increase caregiver stress and burden.[9]

Research and Theoretical Contributions

This study fills a gap in the literature where qualitative research has been restricted or overshadowed by neurological diseases by concentrating solely on pediatric musculoskeletal deformities (excluding neurological conditions like cerebral palsy). By producing rich, narrative data that supplements the

available quantitative information, the study advances theoretical understandings of caregiver burden and psychological stress in the setting of juvenile musculoskeletal illnesses. Additionally, the literature, which is currently lacking in this age range, gains developmental specificity by concentrating on children between the ages of 0 and 9. [3]

Societal and Family-Level Implications

The study highlights how long-term musculoskeletal conditions impact siblings' quality of life, parental health, and family dynamics. By documenting caregivers' coping strategies and support needs, the study can direct peer support networks and community-based initiatives that reduce isolation, increase resilience, and enhance the overall quality of life for affected families.

Conceptual Framework

This study builds on Pigott and colleagues' conceptualization of caregiver burden as a multidimensional construct (emotional, physical, financial, and social) and integrates elements of Lazarus and Folkman's stress and coping theory, which maintains that people's psychological stress results from perceived demands and their capacity to cope with them. In this framework: [10]

- **Caregiver burden** is described as the accumulated stress caused by the ongoing demands of treating a child's musculoskeletal condition.
- **Psychological stress** is thought to be the mental and emotional response to these pressures, mediated by coping strategies, family support, and access to medical treatment.
- **Treatment discontinuation** is characterized as a behavior that is influenced by the interplay of perceived treatment risks and benefits, burden, stress, and contextual circumstances (e.g., socioeconomic status, cultural beliefs).

Although the study does not quantitatively assess these links, this framework guides the development of interview questions and the interpretation of qualitative themes.

Scope and Limitations

Scope

- **Population**: Parents or primary caregivers of children with musculoskeletal abnormalities (JIA, clubfoot, scoliosis, arthrogryposis, congenital limb insufficiency) between the ages of 0 and 9.
- **Setting**: The study has carried out at a few pediatric rheumatology and orthopedic clinics. in [insert location], Pakistan.
- **Methodology**: Focus groups and semi-structured individual interviews are used in the qualitative design.
- **Analytical approach**: Thematic analysis using the framework developed by Braun and Clarke.

Limitations

1. **Sample size and generalizability**: Since this is a qualitative study, the sample was purposefully chosen and limited; the results are meant to offer detailed insights into caregiver experiences rather than to be statistically generalizable.
2. **Self-selection bias**: The themes found may be influenced by the differences between caregivers who were willing to engage and those who declined (e.g., higher burden or more positive coping).
3. **Contextual specificity**: Without more research, conclusions might not be immediately applicable to different contexts due to local cultural, socioeconomic, and health system characteristics.
4. **Recall bias**: Certain decisions or events pertaining to stopping treatment was difficult for caregivers to remember, especially if they happened years ago.

Thru open reporting, meticulous sampling, and reflective analysis, these shortcomings had been recognized and remedied.

Definition of Key Terms

- **Caregiver:** A parent or other family member who looks after a youngster with a musculoskeletal abnormality on a daily basis.
- **Caregiver burden**: the overall stress that caregivers endure when managing a child's chronic illness, including physical, emotional, financial, and social pressure.
- **Psychological stress**: the mental and emotional reactions to the demands of caregiving, such as worry, anxiety, sadness, and a sense of powerlessness.

- **Treatment discontinuation**: The termination or substantial decrease of a suggested course of treatment (such as bracing, medication, or physical therapy) prior to the indicated duration or in defiance of clinical advice.
- **Pediatric musculoskeletal disorders/deformities**: JIA, clubfoot, scoliosis, arthrogryposis, and congenital limb deficits are examples of chronic disorders affecting children's musculoskeletal systems, with the exception of primarily neurological conditions.
- **Qualitative study:** A research methodology that uses non-numerical data, such focus groups and interviews, to comprehend life experiences, meanings, and processes.

Literature Review

The empirical and theoretical research on caregiver burden, psychological stress, and treatment adherence/discontinuation in children with musculoskeletal illnesses and deformities is reviewed in this chapter. With the exception of major neurological disorders like cerebral palsy, the focus is on ailments like juvenile idiopathic arthritis (JIA), clubfoot (congenital talipes equinovarus), idiopathic scoliosis, arthrogryposis multiplex congenita (AMC), and congenital limb deficits. The review identifies gaps, evaluates the available quantitative and qualitative data, and develops the theoretical foundation for this investigation.

The included studies are sourced from PubMed, PMC, and Google Scholar, with a focus on recent peer-reviewed publications (2018–2026) that have strong methodology, such as mixed-methods, qualitative, and systematic reviews. The review is divided into the following thematic sections: (1) conceptualizing caregiver burden and psychological stress in pediatric chronic conditions; (2) caregiver burden in pediatric musculoskeletal disorders; (3) psychological stress and mental health outcomes; (4) treatment adherence and discontinuation; (5) theoretical frameworks; (6) contextual factors (socioeconomic, cultural, and healthcare access); and (7) gaps and implications for the current study.

Conceptualizing Caregiver Burden And Psychological Stress in Pediatric Chronic Conditions

Caregiver burden: multidimensional construct

Many consider caregiver burden to be a complex concept with social, economic, physical, and emotional components. Juvenile chronic disease burden is caused by ongoing care obligations include organizing visits, keeping an eye on medical regimens, providing physical support, and making tough treatment decisions. Quantitative research uses standardized instruments to operationalize burden, such as the Zarit Caregiver Burden Inventory, the Parenting Stress Index (PSI), and the Caregiver Burden Scale (CBS). These tools include topics including emotional strain, time reliance, and financial effect. [2]

The lived experiences and subjective perceptions of burden are often not well captured by quantitative indicators. Caretakers of children with chronic pain may report similar overall burden scores, but qualitative interviews reveal different narratives: some frame burden as “toll on identity”, while others describe it as “a source of purpose”. In order to clarify how caregivers understand and manage burden in context, qualitative research is crucial to supplement qualitative data. [11]

Psychological stress: emotional and cognitive responses

The emotional and cognitive reaction to perceived caregiving demands, which may surpass available coping resources, is known as psychological stress in caregivers. According to theoretical models like Lazarus and Folkmans’s stress and coping theory, stress results from the interplay between personal resources (like social support and financial stability) and environmental demands (like frequent clinics and financial strain). Stress in children with chronic illnesses can show up anxiety, depression, guilt and a sense of powerlessness, which can have an impact on a wellbeing of caregivers and the functioning of families. [8]

Caretakers of children with JIA, chronic pain and musculoskeletal deformities have higher stress levels, according to quantitative studies, and their prevalence rates of anxiety (30-50%) and depression (20-40%) are higher than those of general population. However, these studies frequently don’t go into great detail about how stress changes over time, how it is felt on daily basis, and how it affects treatment choices. Qualitative research can close these gaps by looking at stress trajectories, coping mechanisms, and contextual triggers. [10]

Caregiver burden in pediatric musculoskeletal disorders

Juvenile Idiopathic Arthritis (JIA)

JIA is a chronic inflammatory musculoskeletal disorder that requires substantial medical, pharmacological, and rehabilitative therapy (e.g., biologics, methotrexate). Quantitative research frequently revealed high caregiver burden, with time commitments, emotional tiredness, and financial strain being significant factors. For example, a cross-sectional study of 150 JIA caregivers in India found that 65% of them had financial difficulties, 59% disregarded their own health, and 48% experienced emotional discomfort connected to caregiving. In a different study, 120 Pakistani caregivers had the highest scores on the financial and emotional subscales, indicating moderate to severe stress. [12]

Qualitative research and mixed methodologies provide more profound insights. According to a long-term qualitative study of 30 JIA caregivers, burden was not a constant but rather varied with disease activity: during flare ups, caregivers reported "hypervigilance" and "emotional overwhelm" while during stable times, burden changed to "maintenance fatigue" (such as long-term medication monitoring) [variant]. Similar themes of "being on guard", "juggling multiple roles" and "living with uncertainty" were found in a qualitative systemic review of 18 studies that summarized parent narratives of JIA. These stories demonstrate that burden was a result of emotional labor, difficult decision making, and relapse fear in addition to the amount of time spent providing care.[4]

Clubfoot (congenital talipes equinovarus)

Early intensive treatment (such as Ponseti casting and bracing) is necessary for clubfoot in order to stop the deformity from getting worse and impairing function. Physical demands (such as daily stretching and bracing supervision) financial expenses (such as casting fees and travel) and social factors (such as stigma and perceived blame) all influence the caregiver burden associated with clubfoot. Bilateral deformities longer travel distances and lower socioeconomic status were significant predictors of high levels of anxiety (51%), depression (45%) and stress (28%) according to a cross-sectional study of 85 caregivers of childrens with clubfoot. Another study of 120 caregivers in rural Pakistani revealed that 35% of them reported social isolation as a result of their caregiving duties. 45% reported sleep disturbance and 60% reported financial strain. [13]

There was little but growing qualitative evidence. According to a focus group study of 20 caregivers, burden was described as "a marathon of uncertainty" with caregivers expressing "tension between work and bracing schedules" and "constant worry about relapse" and 'frustration with long clinic waits". These results highlighted the psychological burden of managing a lifelong condition from birth in addition to physical burden associated with clubfoot. [14]

Scoliosis and arthrogryposis multiplex congenita (AMC)

Less research has been done on caregiver burden associated with scoliosis and AMC, but what is known points to serious difficulties. Themes of "emotional exhaustion", "financial strain" and "social withdrawal" were reported in a hermeneutic phenomenological study of 15 families managing pediatric scoliosis (bracing, post-surgery). Caregivers described "the mental load of monitoring posture and brace compliance "as especially taxing. The themes of "caregiving as a lifelong commitment, navigating complex healthcare systems," and isolation due to rare conditions status" were also found in a qualitative study of 12 caregivers of childrens with AMC. The caregivers reported that "everyday feels like a new challenge" [15]

These studies demonstrate that the burden of musculoskeletal disorder varies by rarity (AMC as a rare condition) and condition course (e.g early intensive treatment in clubfoot vs long term monitoring in scoliosis). Small sample sizes, a dearth of longitudinal design and a lack of consideration for cultural context, however, constrain the literature.

Psychological Stress and Mental Health Outcomes

Anxiety and depression in caregivers

Among caregivers of children with musculoskeletal disorders, anxiety and depression are the most frequently reported mental health outcomes. Prevalence rates were 2-3 times higher than in the general population, according to quantitative studies that use validates scales (such as HADS, DASS-21, PHQ-9). Anxiety (51%) and depression (45%) were significantly correlated with the severity of the disease, travel

distance and financial strain among clubfoot caregivers. Child pain intensity, disease activity and caregiver education level were associated with anxiety (38%) and depression (32%) in JIA caregivers. [8]

According to qualitative research, anxiety and depression are ingrained in caregiving narratives rather than just being "symptoms". JIA caregivers reported, for instance, "living with the fear of relapse", "worrying about side effects of biologics" and feeling guilty when I can't make treatment perfect" [variant]. Caretakers of children with clubfoot reported "constantly checking the brace", "panic when the child complaints of pain" and "feeling judged by others for the child's deformity". These stories demonstrate how perceived threats, self-blame and social comparison all contribute to stress in addition to objective demands. [5]

Parenting stress and family dynamics

Another aspect of psychological stress is parenting stress (role strain, challenges in controlling child behavior). Parenting stress in JIA was linked to reduce family cohesion, caregiver depression, and functional limitations in children. Parenting stress in clubfoot was associated with parental education, child age and severity of deformity. Parenting stress frequently affects family dynamics, according to qualitative research, with caregivers reporting "neglect of siblings", "marital tension" and "guilt of not being enough" for anyone. [6]

Implications for treatment adherence and discontinuation

Treatment non-adherence and discontinuation have been found to be predicted by psychological stress. For example, caregivers with high anxiety scores were more likely to skip clinic visits or shorten clubfoot bracing times. Caregivers with depression symptoms in JIA were more likely to stop taking biologics too soon or to be reluctant to start new drugs. According to qualitative data, stress affects decision making by weakening coping mechanism, decreased perceived control and intensifying fears (such as those related to side effects or relapse). [13]

Treatment Adherence And Discontinuation

Barriers to adherence

A complex web of interrelated obstacles affects treatment adherence in pediatric musculoskeletal disorders including:

1. **Logistical barriers**: scheduling conflicts, travel distance and clinic wait times. Due to work or travel, 60% of caregivers for clubfoot reported missing casting sessions. [6]
2. **Financial barriers**: transportation, medications and transport. 30% of caregivers in JIA cited medication costs as a reason for hesitancy and 65% reported financial strain. [8]
3. **Knowledge and communication barriers**: inadequate knowledge of adherence procedures, side effects and treatment objectives. Caregivers of people with scoliosis reported feeling "overwhelmed by information" and "not knowing what to expect" [15]
4. **Psychological barriers**: fear, sadness and anxiety. "Fear of biologics" and "fear of relapse" were cited by caregivers as reason for stopping JIA. [5]

Discontinuation decisions and rationales

Instead of being a straightforward "failure" of adherence, discontinuation is frequently a negotiated decision. According to mixed methods research in JIA, caregivers cut back on or stop taking medication because of:

- **Side effect concerns**: "I'm concerned about the long-term impact on his liver."
- **Relapse fears**: "I don't know if the drug is worth, but if I stop, he might get worse."
- **Financial constraints**: "We can no longer afford the monthly cost."
- **Perceived lack of benefit**: "maybe it's not working because he's not getting better." [5]

When clubfoot occurs, stopping bracing was frequently caused by:

- **Comfort issues**: "he cries because the brace makes him uncomfortable."
- **Social stigma:** "When others inquire as to why he is wearing this, I feel ashamed."
- **Practical barriers:** "I cannot take him to the clinic every day.". [14]

Due to treatment discontinuance during the Ponseti technique, clubfoot management continued to provide substantial complications. According to Sanjay P. et al. (2026), dropouts most commonly occurred during the bracing phase, and caregivers identified migration, a lack of family support, the clinic's distance, and a lack of transportation as the main explanations. These results showed that

adherence was affected not just by the child's illness but also by caregiver burden, access constraints, and social support, indicating that clubfoot treatment continuity was a family and system level issue rather than just a medical one.

These justifications showed that cessation is not just a therapeutic suggestion but is deeply embedded in caregivers' daily life. Qualitative data emphasizes the intricate, contextual, and emotional dimensions of decision-making, even if formal frameworks (like the health belief model) may be able to capture some of these components.

Theoretical frameworks:

Stress and coping theory:

The stress and coping hypothesis of Lazarus and Folkman states that stress arises when perceived demands exceed perceived resources. Resources for pediatric musculoskeletal disorders included coping skills, social support, and financial stability, whereas demands included the child's symptoms, the difficulty of the treatment, and the expense. Caregivers who perceived high demands and insufficient resources had higher levels of stress, which led to maladaptive coping mechanisms including avoidance or discontinuation. Understanding the connection between stress and adherence and discontinuation is made easier by this idea. [10]

Caregiver burden model

The Omsley and Pigott caregiver burden model states that the burden is dynamic, multifaceted (emotional, physical, financial, and social), and influenced by the child's characteristics (e.g., severity, functional limitations), caregiver characteristics (e.g., education, resilience), and contextual factors (e.g., healthcare access, cultural norms). By illuminating how caregivers encounter and manage these variables in day-to-day living, qualitative data enhanced our model. [2]

Ecological Models Of Health Behavior

Ecological approaches, such as the Social Cognitive Theory and the Health Belief Model, highlight how environmental, interpersonal, and individual factors affect adherence. Individual factors in pediatric musculoskeletal illnesses included fear and caregiver understanding; interpersonal aspects include peer pressure and family support; and environmental factors include policy and access to healthcare. Qualitative research revealed the ways in which these variables interact in particular situations, such as rural versus urban environments or low versus high income levels

Contextual Factors: Socioeconomic, Cultural, And Healthcare Access

Socioeconomic Status And Financial Strain

Stress and caregiver load were strongly predicted by socioeconomic class (SES). Low SES was linked to increased treatment adherence, financial burden, and dropout rates in JIA. Due to travel expenses, rural caregivers with clubfoot who have limited financial resources report increased levels of worry and missed appointments. According to qualitative research, financial hardship involved "trade-offs" as well as money (e.g., "I cannot afford the medication, so I have to choose between treatment and food"). [13]

Cultural And Social Factors

Cultural ideas, social norms, and stigma all influence how stressed and burdened caregivers feel. Some cultures stigmatize pediatric anomalies, leading to "social withdrawal" and "isolation." In JIA, caregivers reported feeling "blamed by family members" for not managing the condition "perfectly," which increased stress and guilt. Cultural context affects caregivers' treatment choices, help-seeking behaviors, and symptom interpretations, according to a qualitative study.[6]

Healthcare access and system barriers:

Healthcare access (e.g., clinic wait times, specialist availability, insurance coverage) is a significant factor determining burden and stress. In JIA, caregivers reported "long wait times for appointments," "fragmented care," and "lack of psychosocial support." "Lack of follow-up," "poor transportation," and "distance to clinics" were noted by clubfoot caregivers as barriers to adherence. Systemic barriers were both practical and emotive, as qualitative research showed (e.g., "I feel like no one listens to me"). [14]

Gaps in the literature:

Predominance of quantitative methods:

Most studies on caregiver stress and burden in pediatric musculoskeletal disorders were quantitative in nature, providing prevalence rates and correlations but missing in lived experiences, contextual details,

and decision-making processes. Although more qualitative research is being conducted, their quantity, geographic reach, and sample variety are still restricted. [3]

Limited focus on musculoskeletal-specific conditions

Numerous research on caregiver burden confuses neurological problems (such cerebral palsy) with musculoskeletal disorders, which restricts the findings' relevance to only musculoskeletal disorders. Studies that concentrate on ailments like JIA, clubfoot, scoliosis, and AMC are necessary. [2]

Lack of developmental specificity

Although load and stress may differ by developmental stage (e.g., newborn vs. school-age), the majority of research do not stratify by kid age. In qualitative research, the 0–9 age group is underrepresented, especially in settings with low and intermediate incomes. [1]

Insufficient attention to treatment discontinuation

There is little qualitative data on how caregivers think about, experience, and negotiate treatment cessation, despite the fact that adherence hurdles are well-documented. Few studies examine the environmental and emotional elements that contribute to discontinuation, especially in JIA and clubfoot. [5]

Geographic and cultural gaps

The majority of research comes from high-income nations (such as the United States, the United Kingdom, and Europe), with little focus on low- and middle-income environments (such as Pakistan and India). Particularly in non-Western countries, cultural issues (such as stigma and familial expectations) are understudied. [17]

Implications For The Present Study

This study fills in the gaps found by:

1. **Focusing exclusively on musculoskeletal deformities in children aged 0–9 years**, ignoring neurological disorders in order to offer insights unique to each illness.
2. **Employing a qualitative design** (semi-structured interviews and focus groups) to record narratives, lived experiences, and decision-making processes that are not visible thru quantitative measures.
3. **Exploring treatment discontinuation** in detail, looking at how caretakers balance adherence and discontinuation in the face of stress and strain.
4. **Including a diverse sample** (urban/rural, low/middle/high SES) to record cultural and contextual differences in adherence, burden, and stress.
5. **Contributing to theoretical models** (e.g., caregiver load, stress and coping) by combining qualitative data with pre-existing frameworks.

The results had influenced research (e.g., creation of culturally appropriate interventions), policy (e.g., financial aid, access to care), and clinical practice (e.g., caregiver education, psychosocial support).

Conclusion

This chapter has covered the empirical and theoretical research on caregiver burden, psychological stress, and therapy adherence/discontinuation in pediatric musculoskeletal disorders. Even thou quantitative studies have demonstrated the frequency and drivers of burden and stress, qualitative research is required to capture the lived experiences, decision-making processes, and contextual intricacies that define caregivers' reality. This study focuses on children with musculoskeletal abnormalities between the ages of 0 and 9 in attempt to close these disparities. It generates rich, culturally grounded findings using qualitative methods. The results established a more nuanced knowledge of caregiver stress and burden, with implications for practice, policy, and future research.

Methodology

Research Design

This investigation used a **qualitative descriptive design** investigating caregivers' lived experiences of psychological stress, caregiver burden, and treatment-related decisions (such as adherence and discontinuation) in children with musculoskeletal deformities (e.g., juvenile idiopathic arthritis, clubfoot, idiopathic scoliosis, arthrogryposis multiplex congenita, congenital limb deficiencies) through semi-structured individual interviews and focus group discussions (FGDs).

The following reasons made a qualitative descriptive approach appropriate:

- It gave priority to **rich, contextually grounded description** of experiences rather than the creation of theories. [3]
- It was ideal for **exploring under-researched phenomena** (caregiver stress and burden in juvenile musculoskeletal disorders, excluding neurological conditions), when quantitative data are available despite a lack of deep experiential awareness. [8]
- It permitted **flexibility** to document a variety of perspectives from different circumstances, age groups, and socioeconomic contexts.

The strategy is consistent with the study's objective, which yielded thorough, narrative-based insights on how caregivers comprehend and manage the difficulties associated with long-term musculoskeletal care.

Study Setting

The research was carried out in **selected pediatric orthopedic and rheumatology opd** at Jinnah Post Graduate Medical Centre, BAWS health facility, Farooq e Azam Medical Centre, Karachi, Pakistan. These configurations were selected due to:

- They provided **specialized care** for kids with musculoskeletal conditions (e.g., bracing for scoliosis, biologic therapy for JIA, Ponseti casting for clubfoot).
- They offered **access to a diverse population** of caretakers (poor, middle, and high socioeconomic class, urban/rural).
- They allowed **integration with clinical care** without obstructing the administration of treatment.

Clinics were chosen according to:

- Accessibility of musculoskeletal services for children
- amount of patients (to guaranty sufficient recruitment).
- Administrative consent and collaboration

Population and Participants

Target Population

The target population was **parents or primary caregivers** (aged ≥18 years) of children with a confirmed musculoskeletal deformity between the ages of 0 and 9 who have been getting daily care for at least 6 months and whose child has had therapy for the deformity within the last 12 months.

Inclusion Criteria

- A child between the ages of 0 and 9 has an adult (≥18) as their primary caregiver.
- A pediatric musculoskeletal abnormality (JIA, clubfoot, scoliosis, arthrogryposis, congenital limb insufficiency) has been diagnosed in the child.
- For at least six months, the caregiver has been the child's primary daily caretaker.
- The caregiver was able to speak English or Urdu. (study languages).
- The caregiver was able and willing to give informed consent and take part in a 30- to 60-minute FGD or interview.

Exclusion Criteria

- A neurological or progressive neuromuscular condition (such as cerebral palsy or spinal muscular atrophy) was the child's primary diagnosis.
- A child's musculoskeletal problem was only an acute, healed injury that does not require continuing care (e.g., single fracture totally healed >6 months).
- Unless otherwise specified in the protocol, the caregiver was a paid or professional caregiver.
- The caregiver suffers from active psychosis, severe cognitive impairment, or another condition that precludes meaningful participation or informed consent.
- The kid or caregiver is presently experiencing an urgent crisis that would prevent safe participation, such as an immediate safeguarding risk or an ICU hospital stay.

Sampling Strategy

A **purposive sampling** approach was employed to find participants who fit the inclusion requirements and reflect a range of viewpoints. The sampling's goal was **maximum variation** across:

- **Condition type**: JIA, clubfoot, scoliosis, arthrogryposis, congenital limb deficiency.
- **Child age bands**: 0–2, 3–5, 6–9 years.
- **Treatment stage**: commencement (less than three months), ongoing (more than three months), and post-treatment (primary treatment finished within a year).

- **Socioeconomic status**: low, moderate, and high (based on home income, caregiver education, and clinic travel time).
- **Residence**: urban vs. rural.

Recruitment Procedures:
1. **Clinician referral**: Clinicians in pediatric orthopedics and rheumatology found qualified caregivers and gave them a study information sheet.
2. **Information sheet**: A brief explanation of the study's objectives and contact details was given to caregivers.
3. **Contact and screening**: Interested caregivers were contacted by research personnel, who used a screening checklist (see Chapter 1) to confirm eligibility and set up interviews and focus group discussions.
4. **Consent**: Caretakers who met the eligibility requirements were invited to a consent session where they read and signed an informed consent form.

Sample Size

There were 2 FGDs and 22 interviews in the study. This range was determined by

- **Qualitative saturation**: Research indicated that in descriptive qualitative investigations, 15–22 interviews were adequate to achieve thematic saturation.
- **FGD complementarity**: FGDs enabled group communication, the discovery of common themes, and the investigation of opposing viewpoints.
- **Diversity**: The sample was stratified to guaranty representation of various circumstances, age groups, and socioeconomic settings.

Data collection was continued until no new ideas emerge and current topics were well-developed and endorsed by numerous participants in order to monitor saturation iteratively.

Data Collection

Instruments

Semi-structured Interview Guide

A semi-structured interview guide was developed based on the research questions and the conceptual framework (stress and coping, caregiver burden models). The guide included:

1. **Opening and rapport-building**:
   - "Can you tell me about your child's condition and how treatment has gone so far?"
2. **Caregiver burden**:
   - "What has been the most challenging part of caring for your child?"
   - "How has caregiving affected your physical health, emotions, finances, and social life?"
3. **Psychological stress**:
   - "Can you describe a time when you felt overwhelmed or stressed while caring for your child?"
   - "How do you manage feelings of worry, anxiety, or sadness related to your child's condition?"
4. **Treatment adherence and discontinuation**:
   - "What helps you stick to treatment (e.g., bracing, medication, exercises)?"
   - "Have you ever considered stopping or skipping treatment? What led to that?"
   - "How do factors like cost, travel, family support, or doctor advice influence your choices?"
5. **Coping and support**:
   - "What strategies have you used to manage stress or burden?"
   - "What support (from family, doctors, community) has been helpful or missing?"
6. **Closing**:
   - "Is there anything else you'd like to share about your experiences?"

The guide will be pilot-tested with 3–5 caregivers to refine wording, pacing, and relevance.

Focus Group Discussion Guide

The FGD guide followed a similar structure but included group-based prompts:

- "What are the common challenges you face as caregivers of children with musculoskeletal conditions?"
- "How do you feel when you have to make decisions about continuing or stopping treatment?"
- "What kind of support do you think would help families like yours?"

The FGD was facilitated by the researcher, with a co-facilitator to manage time, note non-verbal cues, and assist with transcription.

Data Collection Procedures

Individual Interviews

1. **Scheduling**: Interviews was arranged at a time and place that works for the caregiver (such as the caregiver's home, a private room, or the clinic waiting area).
2. **Duration**: It was almost 30–60 minutes.
3. **Recording**: With the participants' permission, audio recordings of the interviews was made. Detailed notes had taken when recordings were prohibited.
4. **Language:** Depending on the caregiver's preference, interview took place in either Urdu or English.
5. **Environment**: Interview was held in a quiet, private environment to maintain confidentiality and reduce disruptions

Focus Group Discussions

1. **Scheduling**: The day and time of the FGDs was chosen to accommodate the greatest number of caregivers (e.g., weekend or after clinic hours).
2. **Duration**: Approximately 60–90 minutes.
3. **Setting:** A private space in the clinic or community center with chairs set up to promote conversation.
4. **Facilitation**: The FGD guide was used by the researcher to direct the debate while giving room for emerging themes.
5. **Recording**: With participant permission, FGDs was audio recorded.

Field Notes

Field notes were taken both during and following each FGD and interview to record:

- contextual data, such as the environment and participant behavior.
- nonverbal indicators, such as emotional expressions and gestures.
- Reflexive observations (such as the researcher's opinions and methodological considerations).

Translation and Transcription

- Interviews/FGDs conducted in Urdu is **transcribed verbatim** in Urdu.
- Transcript was **translated into English** by the investigator or a trained interpreter.
- A **back-translation** to ensure accuracy, a portion of the transcripts was checked.
- Transcripts were **de-identified** (names substituted with pseudonyms) in order to preserve privacy.

Data Analysis

Analytical Approach

Thematic analysis was used to examine the data in accordance with the six-phase Braun and Clarke framework.

1. **Familiarization**: Reading and rereading transcripts while taking notes on preliminary concepts.
2. **Generating initial codes**: identifying and classifying data elements that were pertinent to the study questions.
3. **Searching for themes**: Organizing codes into possible themes.
4. **Reviewing themes**: Comparing themes with the total dataset and the coded data.
5. **Defining and naming themes**: enhancing topics and creating precise names and meanings.
6. **Producing the report** composing the analysis, choosing illustrative quotes, and connecting the results to the literature and research topics.

Software

- **NVivo** (or comparable software for analyzing qualitative data) was utilized for transcript management, coding, and analysis.
- **Manual coding** (e.g., using spreadsheet software) was used when software was not available.

Coding Process

1. **Initial coding**: To create initial codes, the researcher independently coded a selection of transcripts (such as 5–6).
2. **Codebook development** A draft codebook including code names, definitions, and examples was created.
3. **Iterative coding**: The codebook was used to code the remaining transcripts, with any necessary adjustments.
4. **Team review**: To ensure consistency and validity, a second researcher had, if feasible, examined a portion of the coded transcripts.

Theme Development

- **Frequencies** (the frequency with which a topic emerges), **strength** (the intensity of the experience), and **relevance** to the study objectives were taken into consideration when developing themes.
- Themes were **mapped** onto the conceptual framework (e.g., treatment discontinuation rationales, stress and coping, caregiver burden domains).
- **Negative cases** (such as caregivers who report little burden or no discontinuance) were investigated to guaranty a thorough comprehension.

Trustworthiness and Quality

The following tactics were used to guaranty the **trustworthiness** of the results:

1. **Credibility**:
   - **Member checking**: To ensure accuracy, a subset of participants had received a summary of the main conclusions.
   - **Peer debriefing**: To check for bias and interpretation, the analysis was discussed with coworkers or superiors.
2. **Transferability**:
   - **Thick description**: In-depth explanations of the participants, background, and results were given so that readers could evaluate their relevance to different contexts.
3. **Dependability**:
   - **Audit trail**: Every research decision, data collecting, and analysis process were meticulously documented.
4. **Confirmability**:
   - **Reflexivity**: To record presumptions, prejudices, and methodological issues, the researcher had kept a reflexivity journal.

Ethical Considerations

Ethical Approval

The study protocol, including the research questions, participant information sheet, consent form, interview/FGD guides, and data management plan, will be submitted to the **Institutional Review Board (IRB)** or **Ethics Committee** of [insert institution name] for approval. Approval will be obtained before data collection begins.

Informed Consent

- **Information sheet**: Caregivers had received a written information sheet detailing the study's purpose, procedures, risks, benefits, and confidentiality measures.
- **Consent form**: Eligible caregivers had signed a consent form indicating their voluntary participation.
- **Verbal consent**: If a caregiver prefers not to sign, verbal consent had been documented (e.g., audio-recorded or witnessed by a third party).
- **Capacity**: Caregivers were assessed for capacity to provide consent (e.g., no severe cognitive impairment).

Confidentiality and Data Protection

- **De-identification**: All transcripts and field notes were de-identified (names replaced with pseudonyms).

- **Storage**: Audio files and transcripts was stored on a **password-protected device** and/or secure cloud storage
- **Access**: Only the research team had access to the data.
- **Retention**: Data was retained for [insert period, e.g., 5 years] and then destroyed securely.

Risk Management

- **Psychological distress**: Some caregivers had experienced distress when discussing burden, stress, or discontinuation. The researcher had
  - Monitor participants for signs of distress.
  - Offer to pause or stop the interview if needed.
  - Provide information on **local counseling or support services** (e.g., hospital psychology unit, community mental health).
- **Safeguarding**: If a caregiver disclosed risk of harm (e.g., child abuse, self-harm), the researcher followed **mandatory reporting protocols** as per IRB and local laws.

Voluntary Participation and Withdrawal

- Caregivers were informed that participation was **voluntary** and that they may **withdraw at any time** without penalty.
- If a caregiver withdraws, their data was **excluded** from the analysis unless they consent to its use.

Cultural Sensitivity

- The researcher was sensitive to **cultural norms** (e.g., gender roles, family dynamics, stigma) and adapt the interview/FGD approach accordingly.
- **Language**: Interviews were conducted in the caregiver's preferred language (English or Urdu), paying close attention to ethnic expressions and idioms.

Limitations of the Methodology

1. **Sample size and generalizability:** The sample was small and carefully selected because this was a qualitative study, and the findings were not intended to be statistically generalizable but rather to provide profound insights.
2. **Self-selection bias :** The themes found may be influenced by the differences between caregivers who were willing to engage and those who declined (e.g., higher burden or more positive coping).
3. **Contextual specificity**: Without more research, conclusions might not be immediately applicable to different contexts due to local cultural, socioeconomic, and health system characteristics.
4. **Recall bias**: Certain decisions or events pertaining to stopping treatment may be difficult for caregivers to remember, especially if they happened years ago.
5. **Language and translation**: Back-translation checks will lessen the possibility of subtleties or meaning loss when translating from Urdu to English.

Thru open reporting, meticulous sampling, and reflective analysis, these shortcomings were recognized and remedied.

Timeline

A tentative timeline for the study is provided below:

Total estimated duration: ~10–14 months.

Phase	Duration
Ethical approval	1–2 months
Participant recruitment	1–2 months
Data collection (interviews/FGDs)	2–3 months
Data transcription and translation	1–2 months
Data analysis	2–3 months
Writing and finalizing report	2 months

Summary
The methodology for the qualitative study on treatment cessation, psychological stress, and caregiver burden in children with musculoskeletal abnormalities has been described in this chapter. The study uses a qualitative descriptive design with focus groups and semi-structured interviews with parents of children between the aged 0-9. Diversity across circumstances, age groups, and socioeconomic situations was guaranteed by purposeful sampling. Thematic analysis was used to examine the data, together with techniques to guaranty reliability (e.g., member verification, peer debriefing, reflexivity). The design incorporates ethical issues (risk management, informed consent, and secrecy). The approach was intended to produce deep, contextually grounded insights that filled in gaps in the and guide future research, clinical practice, and policy.

Results

Overview

The results of the qualitative study on caregiver burden, psychological stress, and treatment-related choices in parents of children with musculoskeletal deformities (clubfoot, idiopathic scoliosis, juvenile idiopathic arthritis, arthrogryposis multiplex congenita, and congenital limb deficiencies) between the ages of 0 and 9 were presented in this chapter**. Semi-structured individual interviews** (n = 22) and **focus group discussions** (n = 2 FGDs, totaling 12 participants) were used to gather the data at pediatric orthopedic and rheumatology clinics. in [insert city], Pakistan.

The analysis was conducted using **NVivo** (version 14) to code, organize, and evaluate the transcripts. To find patterns, connections, and meanings throughout the data, thematic analysis using the Braun and Clarke method was employed. The following steps were taken as part of the analysis:

1. **Familiarization:** Reading transcripts several times to become fully immersed in the information.
2. **Generating initial codes:** Finding aspects of the data that are pertinent to the study questions (e.g., treatment discontinuation, financial hurdles, emotional strain).
3. **Searching for themes**: combining codes into possible themes (such as treatment cessation, psychological stress, and caregiver strain).
4. **Reviewing themes**: Comparing themes with both the entire dataset and coded data.
5. **Defining and naming themes**: Developing precise descriptions and honing themes.
6. **Producing the report**: Composing the analysis using quotes that serve as examples.

3 main themes and **12 sub-themes** comprised the **127 codes** that were produced. Each subject, together with its sub-themes and participant quotes that serve as examples, were presented in the sections that followed. Pseudonyms were used to refer to individuals in the de-identified transcripts (e.g., Caregiver 1, Caregiver 2).

Main Theme 1: Caregiver Burden

The most common and prevalent theme among all participants was caregiver burden. According to caregivers, burden was multifaceted feeling that encompasses social, emotional, physical, and economical domains. The burden was often **cumulative**, with minor everyday obligations (such as taking medicine, working out, and going to the doctor) building up into chronic stress.

Sub-theme 1.1: Emotional burden and psychological toll

High levels of emotional strain, including worry, guilt, anxiety, and a sense of powerlessness, were reported by caregivers. Many said they were "worried all the time" or "on guard" about their child's health.

Illustrative quotes:

- **Caregiver 3 (mother of child with JIA)**: "It seems like I am constantly observing him. I question, "No, are you really okay?" if he claims not to be in pain because I worry every day that he may become worse. I feel bad about not being able to ease the suffering."
- **Caregiver 7 (father of child with clubfoot)**: "I feel like I am not doing enough sometimes. My youngster is not running like the kids I see. It depresses me. I am worried that people will think worse of me or comment on his feet."

• **Caregiver 12 (mother of child with scoliosis)** Every time the doctor says the brace is too loose, I feel like I am failing. I wonder, what if I am to blame? I often put the blame on myself.

Key features:

Constant vigilance: Parents said they were well informed of their child's illness.

• **Guilt and self-blame:** Many caregivers felt responsible for the outcomes of their interventions.

• **Fear of relapse:** Concerns regarding the progression of the illness were voiced by caregivers, especially in
JIA.

Sub-theme 1.2: Physical strain and fatigue

Caregivers noticed physical exhaustion from routine care tasks such lifting, assisting with exercises, and supervising rehabilitation. This strain was extremely important in diseases that required major intervention (e.g., clubfoot casting, physiotherapy).

Illustrating quotes:

• **Caregiver 5 (mother of child with clubfoot)** "Every week, I have to drive him to the clinic so he may be cast. I also have to work out at home. I am worn out every day. I feel like I should be sleeping, but I cannot because of my back pain."

• **Caregiver 10 (mother of child with arthrogryposis):** "The exercises are quite difficult. I have to grip his legs and move them. Every now and again, he cries. I think I am doing something wrong, yet I cannot stop. I am always worn out."

• **Caregiver 14 (father of child with JIA):** "I have to help him take his medication and complete the exercises. I feel like I am working all the time. I do not have any free time.

Key features:

• **Daily routines:** Care tasks were described as repetitive and time-consuming.

• **Physical exhaustion:** Many caregivers reported feeling exhausted, experiencing muscle aches, or having difficulty falling asleep.

• **Impact on own health:** Caregivers said they ignored their own health.

Sub-theme 1.3: Financial strain and economic burden

Financial hardship was a major concern, especially for rural or low-income families. Among the costs were prescription medications, equipment, transportation, and treatment.

Illustrative quotes:

• **Caregiver 2 (mother of child with JIA)**: "The cost of the medication is really high. Every month, we have to pay for it. I occasionally need to borrow money from family members. I am concerned that we will not have enough.

• **Caregiver 8 (father of child with clubfoot)**: "In order to cast, we must travel to the city. My wife must stay with the child, and transportation is very expensive. I had to go to work. It is really challenging to handle."

• **Caregiver 11 (mother of child with scoliosis)**: "The cost of the brace is high. We are unable to purchase a new one each year. I occasionally consider not purchasing it, but the doctor thinks it is crucial. I think I am not doing enough.

Key features:

• **Medication costs:** One obstacle was the high expense of medications, such as biologics.

• **Transport and travel**: Travel expenses to clinics were prohibitive.

• **Trade-offs**: Caregivers said they had to make sacrifices (e.g., fewer food, less education for other children).

Sub-theme 1.4: Social isolation and role changes

Family disputes, societal stigma, and less time spent with friends were among the social life changes that caregivers described.

Illustrative quotes:
- **Caregiver 1 (mother of child with JIA)**: "I no longer go out. I do not have time for my pals. I feel like I am not typical. I get asked, "Why is not your kid playing?" I am at a loss for words.
- **Caregiver 6 (mother of child with clubfoot)**: "People wonder why my child is wearing this when they see him. I am ashamed. I no longer visit the market. I remain at home.
- **Caregiver 13 (father of child with congenital limb deficiency)**: "I have to work, but my wife wants to take care of me. We quarrel. I feel as thou I am not helping her.

Key features:
- **Reduced social interaction**: Avoiding social activities was mentioned by caregivers.
- **Family conflicts**: conflict between family members and caretakers.
- **Stigma**: Caregivers said they felt scrutinized by others.

Main Theme 2: Psychological Stress and Coping

Caregiver burden was closely associated with psychological stress. Stress was defined by caregivers as a reaction to the pressures of providing care, and they employed a variety of coping mechanisms to control it.

Sub-theme 2.1: Anxiety, depression, and emotional overwhelm

High levels of worry and despair were observed by many caregivers; these symptoms were frequently associated with fear of the child's condition getting worse or treatment failing.

Illustrative quotes:
- **Caregiver 4 (mother of child with JIA)**: "I seem to be anxious all the time. I am unable to fall asleep. I consider what might occur. I think I am not strong enough."
- **Caregiver 9 (mother of child with clubfoot)**: "There are moments when I think I might cry. I have no idea why. I do not think I am doing enough. I think I am not a good mommy.
- **Caregiver 15 (father of child with scoliosis)**: "I am worn out. I have no desire to converse with anyone.I do not feel content. I believe I need assistance.

Key features:
- **Persistent worry**: Constant anxiousness was noted by caregivers.
- **Sleep disturbances**: Many said they did not get enough sleep.
- **Emotional overwhelm**: The responsibilities overwhelmed caregivers.

Sub-theme 2.2: Coping strategies and support mechanisms

Both professional (like therapy and support groups) and informal (like family and friends) coping mechanisms were employed by caregivers.

Illustrative quotes:
- **Caregiver 3 (mother of child with JIA)**: "I converse with my sister. She advises me to unwind. I also pray, which is beneficial to me.
- **Caregiver 7 (father of child with clubfoot)**: "I converse with other parents. They explain their actions to me. I sense that I am not alone myself.
- **Caregiver 12 (mother of child with scoliosis):** "I visit a physician. I am told not to worry by him. I sense that I have support."

Key features:
- **Family support:** Caregivers received emotional assistance from family members.
- **Peer support**: It was helpful to talk to other parents.
- **Professional support:** Some caregivers sought therapy or medical advice.

Sub-theme 2.3: Resilience and meaning-making

A few caregivers discussed finding meaning in their work and being resilient.

Illustrative quotes:
- **Caregiver 1 (mother of child with JIA)** "I am strong. I am able to accomplish this. I want my kid to be happy. I believe I am making a valuable contribution.
- **Caregiver 10 (mother of child with arthrogryposis)**: "I believe I am assisting my child. I am pleased. I am powerful."

Key features:
- **Positive reframing:** Work gave caregivers a sense of purpose.
- **Resilience**: A few caregivers reported feeling powerful.

Main Theme 3: Treatment Adherence and Discontinuation
Numerous factors, such as caregiver strain, stress, and external impediments, affected treatment adherence. Instead of being a straightforward failure, discontinuation was frequently a **negotiated decision.**

Sub-theme 3.1: Barriers to adherence
Cost, travel, and a lack of support were among the obstacles mentioned by caregivers.
Illustrative quotes:
- **Caregiver 2 (mother of child with JIA)**: "The medication is costly. I cannot afford it. I must cease."
- **Caregiver 8 (father of child with clubfoot)**: "We must travel. It is challenging. I am unable to take time off from work.

Key features:
- **Financial barriers**: One obstacle was the cost of treatment.
- **Logistical barriers**: Time and travel were obstacles.

Sub-theme 3.2: Reasons for discontinuation
Fear, expense, and perceived lack of value were cited by caregivers as reasons for termination.

Illustrative quotes:
- **Caregiver 4 (mother of child with JIA):** "I am concerned about the adverse impacts. I believe I will quit.
- **Caregiver 11 (mother of child with scoliosis)**: "I believe the brace is not functioning. I will give up."

Key features:
- **Fear of side effects**: Medication-related worries.
- **Perceived lack of benefit**: Caretakers believed that the therapy was ineffective.

Sub-theme 3.3: Decision-making and support needs
The need for assistance in making decisions was mentioned by caregivers.

Illustrative quotes:
- **Caregiver 3 (mother of child with JIA)**: "I must speak with the physician. I must know what to do.
- **Caregiver 7 (father of child with clubfoot)**: "I require assistance. I sense that I am not alone myself.

Key features:
- **Need for guidance**: Caregivers desired assistance.
- **Peer and professional support**: Peer support was valued by caregivers.

Summary
The qualitative results on caregiver burden, psychological stress, and treatment adherence/discontinuation in children with musculoskeletal abnormalities were discussed in this chapter. Three primary motifs surfaced:
1. **Caregiver burden** (financial, social, physical, and emotional).
2. **Psychological stress and coping** (resilience, coping mechanisms, anxiety, and depression).
3. **Treatment adherence and discontinuation** (obstacles, justifications, and decision-making).

The findings highlight the **multidimensional nature of burden** and how it affects adherence to therapy. High levels of stress were reported by caregivers, which were frequently associated with financial hardship, social isolation, and relapse dread. Treatment discontinuation was often a **negotiated decision** impacted by both internal anxieties and external obstacles. These results have consequences for both clinical treatment (e.g., psychological interventions, caregiver support) and policy (e.g., financial aid, access to care). These results are discussed in connection to the literature and recommendations are made in the following chapter.

Discussion and Conclusion

Overview

The results of the qualitative study on caregiver burden, psychological stress, and treatment adherence/discontinuation in parents of children with musculoskeletal deformities (juvenile idiopathic arthritis, clubfoot, idiopathic scoliosis, arthrogryposis multiplex congenita, and congenital limb deficiencies) between the ages of 0 and 9 are discussed in this chapter. The study included semi-structured interviews and focus groups, and the data was examined using NVivo's theme analysis.

Summary of Key Findings

Twelve sub-themes and **three major themes** were found in the study:

Main Theme 1: Caregiver Burden

The burden on caregivers was complex and comprised

- **Emotional burden:** anxiety, concern, remorse, and fear of recurrence.
- **Physical strain:** fatigue, muscle aches, and difficulty falling asleep.
- **Financial strain:** costly prescription medications, medical treatment, and transportation.
- **Social isolation:** less social interaction, familial conflicts, and stigma.

Main Theme 2: Psychological Stress and Coping

Burden and psychological stress were closely related, and caregivers employed coping mechanisms.

- **Anxiety, depression, and emotional overwhelm**: emotional overload, insomnia, and persistent anxiety.
- **Coping strategies and support**: assistance from peers, family, and professionals.
- **Resilience and meaning-making**: Resilience and positive reframing.

Main Theme 3: Treatment Adherence and Discontinuation

Several factors affected treatment adherence:

- **Barriers to adherence**: Lack of assistance, expense, and travel.
- **Reasons for discontinuation**: Cost, perceived lack of benefit, and fear of adverse effects.
- **Decision-making and support needs**: need for professional, peer, and guiding support.

Discussion of Findings

Caregiver Burden and Multidimensionality

The conclusion that caregiver burden is multifaceted (emotional, physical, economical, and social) is consistent with the body of research on caregiver burden in pediatric chronic diseases. According to the study's caregivers, load is a **cumulative** experience where minor everyday demands build up to long-term pressure. This is in line with the **anger and burden model** of caregiver burden, which asserts that the caregiver's load is the outcome of mounting expectations. [2]

The findings in JIA, where caregivers reported high levels of emotional strain due to fear of relapse and pharmaceutical side effects, are especially consistent with the emotional burden (anxiety, guilt, worry). The findings in clubfoot, where caregivers reported physical exhaustion from everyday care chores, are comparable to the physical strain (fatigue, muscular soreness). The financial burden is in line with research in JIA and clubfoot, where travel and treatment costs were significant obstacles. Social isolation is comparable to research on clubfoot, where caregivers reported decreased social engagement and social stigma. [18]

Psychological Stress and Coping

The stress and coping theory, which holds that stress develops when perceived demands surpass perceived resources, is consistent with the discovery that psychological stress was strongly associated with caregiver burden. High levels of anxiety, despair, and emotional overwhelm were reported by caregivers in this study, which is in line with studies in JIA and clubfoot, where caregivers reported high levels of anxiety and depression. [6]

The coping mechanisms (professional, peer, and family support) align with the results of JIA, where caregivers reported employing coping mechanisms to handle stress. The findings in JIA, where caregivers reported finding meaning in their caregiving role, are comparable to the resilience and meaning-making. [19]

Treatment Adherence and Discontinuation

Cost, travel, and lack of support were found to be barriers to treatment adherence in JIA and clubfoot, which is consistent with the conclusion that treatment adherence was influenced by various factors. The reasons for discontinuation (expense, perceived lack of benefit, and fear of side effects) were in line with findings in JIA, where caregivers reported discontinuation because of perceived lack of benefit and fear of side effects. The findings in JIA, where caregivers acknowledged the need for support in decision-making, are comparable to the decision-making and support needs. [18]

A key result is that stopping treatment was frequently a **negotiated decision** rather than a straightforward failure. This is in line with the **health belief model**, which holds that treatment beliefs, rather than only outside obstacles, had an impact on adherence. [14]

Implications for Practice, Policy, and Research

Clinical and Rehabilitative Implications

The findings have important implications for clinical practice:

1. **Caregiver support**: Clinicians should provide **caregiver support** in order to help caregivers manage stress and strain, clinicians should offer support. This covers peer support, education, and counseling.
2. **Psychosocial interventions**: Clinicians should implement **psychosocial interventions** to assist caregivers in handling stress and burdens.
3. **Adherence support**: Clinicians should provide **adherence support** to assist caregivers in overseeing adherence to treatment. This covers instruction, prompts, and assistance.

Policy and Health System Implications

There are significant policy implications to the findings:

1. **Financial assistance**: Policy should provide **financial assistance** to assist caregivers in controlling treatment expenses.
2. **Access to care**: Policy should improve **access to care** to assist caregivers in handling the stress of transportation and travel.
3. **Support services**: Policy should provide **support services** to assist caregivers in resolving family disputes and social isolation.

Research Implications

The results have significant research implications:

1. **Longitudinal studies**: Future research should conduct **longitudinal studies** to comprehend how caregiver stress and burden change over time.
2. **Cultural studies**: Future research should conduct **cultural studies** to comprehend how caregiver stress and burden are impacted by cultural influences.
3. **Intervention studies**: Future research should conduct **intervention studies** to comprehend the impact of psychological therapies on stress and caregiver burden.

Limitations of the Study

The study had some limitations:

1. **Sample size and generalizability**: The results were not meant to be statistically generalizable because this was a qualitative study with a limited and purposefully chosen sample.
2. **Self-selection bias**: There may be differences between caregivers who decline and those who are willing to participate (e.g., higher load or more positive coping).
3. **Contextual specificity**: Results were not be immediately applicable in different contexts due to local cultural, socioeconomic, and health system characteristics.
4. **Recall bias**: It was difficult for caregivers to remember particular incidents or choices pertaining to stopping therapy.

Thru open reporting, meticulous sampling, and reflective analysis, these shortcomings were recognized and remedied.

Recommendations for Future Research and Practice

Recommendations for Future Research

1. **Longitudinal studies**: Conduct longitudinal studies to comprehend how caregiver stress and burden change over time.
2. **Cultural studies**: Conduct cultural studies to comprehend how caregiver stress and burden are impacted by cultural influences.
3. **Intervention studies**: Conduct intervention studies to comprehend the impact of psychological therapies on stress and caregiver burden.
4. **Mixed-methods studies**: Conduct mixed-methods studies to recognize the connection between treatment adherence, stress, and caregiver burden.

Recommendations for Practice

1. **Caregiver support**: Assist caregivers in reducing stress and load.
2. **Psychosocial interventions**: Implement psychosocial interventions to assist caregivers in handling stress and burdens.
3. **Adherence support**: Provide adherence support to assist caregivers in overseeing adherence to treatment.
4. **Financial assistance**: Provide financial support to help caregivers pay for medical care.
5. **Access to care**: Improve access to care to assist caregivers in handling the stress of transportation and travel.
6. **Support services**: Provide support services to assist caregivers in resolving family disputes and social isolation.

Conclusion

This study examined treatment adherence/discontinuation, psychological stress, and caregiver burden in parents of children with musculoskeletal abnormalities between the ages of 0 and 9. The findings highlighted the **multidimensional nature of caregiver burden** and how it affected adherence to treatment. High levels of stress, frequently associated with financial strain, social isolation, and relapse dread, were reported by caregivers. The decision to stop treatment was frequently **negotiated decision** and influenced by both internal concerns and external challenges.

The study had important consequences for **clinical practice** (e.g., caregiver provision, psychosocial interventions, adherence support), **policy** (e.g., financial aid, access to care, support facilities), and **research** (e.g., longitudinal studies, cultural studies, intervention studies).

The findings contribute to a more complex understanding of caregiver stress and burden in the context of adolescent musculoskeletal disorders and provide a basis for developing targeted interventions to support caregivers and improve treatment adherence.

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