

Experiences and Needs of School Children with Rheumatic Heart Disease and Their Caregivers at Kenyatta National Hospital, Nairobi City County, Kenya

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Abstract

A qualitative descriptive study was conducted to explore the lived experiences of school-age children with rheumatic heart disease (RHD) and their caregivers at Kenyatta National Hospital (KNH) in Nairobi, Kenya, as well as the barriers encountered. RHD remains a substantial health and socioeconomic burden in many low-resource settings and is compounded by delayed diagnosis, limited access to treatment, and financial strain, all of which negatively affect patient outcomes. The purpose of this study was to identify the medical, psychological, and social challenges that these children face due to RHD and to help determine the types of support they require from their caregivers. Semi-structured interviews were used to collect data, which were then analyzed using thematic analysis. Triangulation was used to increase the credibility of the findings. Four main themes emerged: financial hardship, social isolation, physical/emotional burden, and systemic healthcare issues. This shows there is a complex relationship between the medical and social aspects of the experiences of families living with children with RHD. The findings from this study should inform the development of targeted, integrated, and necessary interventions to improve the delivery of healthcare to these families and the overall quality of life of the children and their caregivers.

Keywords: *Rheumatic heart disease, experiences of children living with RHD, caregivers.*

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1. Introduction

Rheumatic Heart Disease (RHD) is a serious health burden that affects mainly children aged 5-14 years in low- and middle-income countries. According to the World Heart Federation, RHD is responsible for a large portion of heart-related deaths among children around the world (154,000 deaths; Watkins et al., 2018). The disease is often preceded by acute rheumatic fever (ARF), which results from streptococcal bacterial infections that are not properly treated or treated quickly enough to prevent complications (Arvind & Ramakrishnan, 2019). RHD rates have decreased greatly in high-income countries due to better access and prevention methods, but continue to be a major source of illness and death among children in parts of Sub-Saharan Africa and Southeast Asia (Baker et al., 2023). The worldwide difference between RHD rates

in high-income and low- and middle-income countries creates a situation where RHD is less of an epidemic in the developed world than it is in developing countries. Accordingly, there is a need to develop targeted interventions and research designs to address the social determinants of health associated with the persistence of RHD in these populations.

Rheumatic Heart Disease (RHD) is a major public health concern in Kenya, especially among children in the school-age group. They have to deal with obstacles accessing healthcare services, often waiting a long time after getting sick before being treated, and have few options when it comes time for them to receive treatment for RHD (Muhamed et al., 2019). The number of kids with RHD in Nairobi reflects the general pattern of RHD throughout the area, where the disease is compounded by things like poverty and lack of access to medical care (Mocumbi, 2015a). At the Kenyatta National Hospital (KNH), the largest referral facility in Kenya, by the time many kids are seen by a doctor there, they have already developed a great deal of the disease and require several expensive, complicated levels of care. This research will look at how the experiences of and needs expressed by school-aged children with RHD and their caregivers relate to the way the disease is managed and their overall outcomes.

1.1 Problem Statement

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) continue to be public health crises in Kenya, especially for school-aged children who experience barriers to accessing appropriate health services, including timely diagnosis of disease, and access to effective treatment (Muhamed et al., 2019). Prevalence levels of RHD in children in Nairobi mirror regional trends; difficulties associated with social determinants of health, such as extreme poverty and limited access to health services, further compound the issues surrounding disease outcomes due to rheumatic fever (Mocumbi, 2015a). At the Kenyatta National Hospital (KNH), Kenya's largest referral facility, children with RHD frequently present in advanced stages of disease, requiring invasive and costly treatments. The aim of this study was to examine the treatment experiences and health care needs of school-aged children with RHD and their caregivers in Nairobi, and how these factors affect the management of RHD and health outcomes for this population

Many of the children with RHD who present at KNH do so because they are already in advanced disease stages. This reflects that RHD has not been managed appropriately through early intervention and treatment. Over 60% of these children require surgical intervention or complex medical treatment, both of which are costly and require significant resources (Mocumbi, 2015a). The situation is further complicated by limited resources and inadequate specialized care, resulting in longer hospital stays and increased caregiver burden. In addition, the lack of comprehensive care for both the child and the caregiver exacerbates management challenges and overall patient outcomes. To address these concerns, there needs to be a focused assessment of RHD-affected children's and families' experiences, priorities, and needs in order to improve the delivery of care and outcomes at KNH and worldwide.

1.2 Research Objectives

1.2.1 Broad Objective

To explore the experiences, challenges, and needs of parents and school-aged children with RHD and their caregivers at KNH, Nairobi.

1.2.2 Specific Objectives

1. To explore the experiences of children living with RHD in school-aged children and their caregivers at KNH.
2. To explore the challenges experienced by school-aged children living with rheumatic heart disease (RHD) and their caregivers at Kenyatta National Hospital (KNH).
3. To explore the support needs of caregivers and school-aged children with RHD at KNH.

2. Literature Review

2.1 Theoretical Review

Urie Bronfenbrenner's ecological model comprises five systems that positively or negatively influence children's growth and development. Each of the systems is interconnected and influences the others. The five systems are microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Bronfenbrenner, 1979).

Microsystems are the immediate environments in which children develop. Examples of microsystems include family, school, medical service provider environments, and peer groups. Children's experiences in each of these systems are essential to everyday life, and each can have a positive/negative impact on a child's physical, emotional, and social development.

The mesosystems are the relationships between the various strands of the microsystem (e.g., family/school). The quality of the relationships within the mesosystem ultimately impacts the overall well-being of the child.

The exosystem consists of larger social organizations that a child may experience indirectly. The exosystem includes transportation systems and community support services. Children are not directly involved in the exosystem; however, the way it is structured can be beneficial/harmful to a child, as seen in access to care, financial resources, and resource availability.

The macrosystem includes the larger culture, economy, and society in which we live. An example of a macrosystem comprises the people's perceptions of the treatment and control of chronic diseases, such as rheumatic heart disease (RHD), and the belief systems of the representative policymakers that create, ratify, and enforce laws.

The chronosystem adds a new dimension to the bioecological model by introducing time as an extra dimension. The chronological system illustrates how different developmental time frames affect an individual's development. Various time frames of development include: transitions in life, changes in one's environment, and changes in history; and how these transitions occur at both the individual level (e.g., progression of disease, multiple hospitalizations, changes in schooling) and broader levels (e.g., changes to healthcare systems, changes to policies, changes to the economy). When assessing chronic diseases like rheumatic heart disease (RHD), the cumulative effects of long-term illness from time elapsed due to delayed diagnosis and continual treatment impact both children with long-term illnesses (e.g., RHD) and caregivers over time.

The bioecological model provides a comprehensive framework for evaluating the developmental outcomes of school-age children with rheumatic heart disease (RHD) at Kenyatta National Hospital (KNH). At the microsystem level, the interactions among school-

age children, their caregivers or family members, healthcare providers, and educators provide a context for managing their illnesses. At the mesosystem level, the interactions among these microsystems and how they work together to support the management of the school-age child with RHD, such as through care coordination during hospitalization and assistance with school attendance. The exosystem includes things such as healthcare policy, the availability of healthcare resources, and community support systems that impact a child's access to care. The macrosystem represents the cultural attitudes towards chronic illness, poverty, and equity as they relate to healthcare. The chronosystem defines how the development of RHD, through ongoing healthcare provision and encounters, changes numerous aspects of the child's experience, both in the short term and in anticipated long-term outcomes.

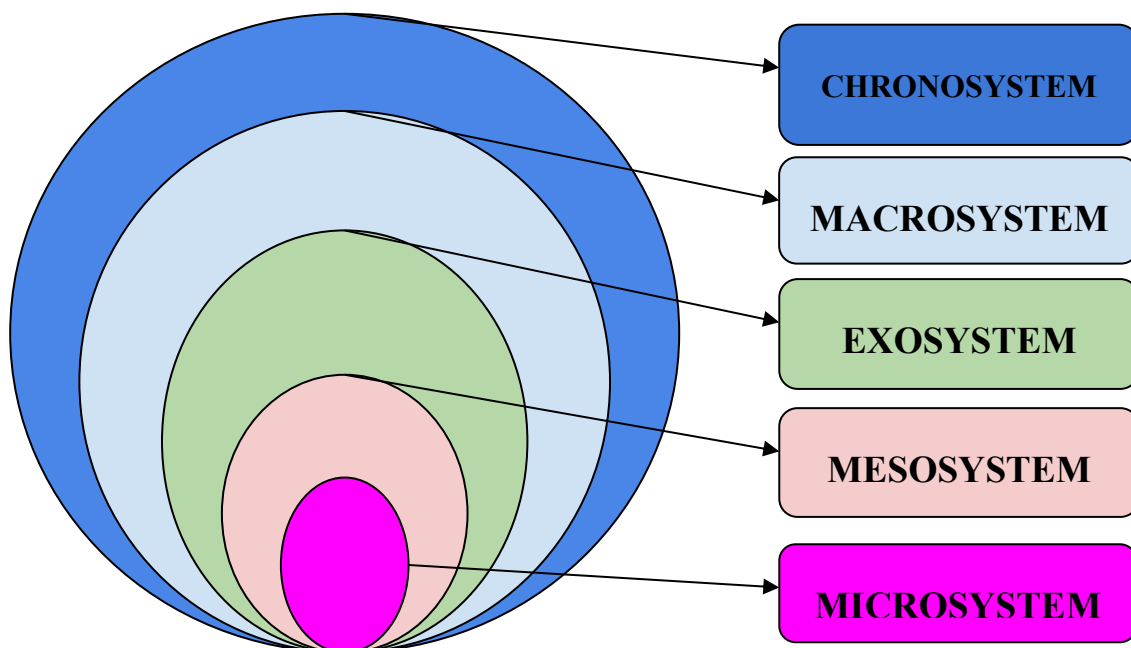


Figure 1: Theoretical Framework

2.2 Empirical Review

2.2.1 Exploring the Daily Experiences of RHD patient and their caregivers

School-aged children living with rheumatic heart disease (RHD) experience many challenges due to their health condition and the limited health-care resources available to them. Barriers to managing their disease effectively have been documented, including limited access to regular medical care, difficulty adhering to treatment protocols, and physical symptoms (Arvind & Ramakrishnan, 2020; Bitar et al., 2000). In Kenya, specifically at Kenyatta National Hospital (KNH), systemic issues such as inadequate health-care infrastructure and financial difficulties exacerbate these barriers (Watkins et al., 2018). The broader context at KNH suggests that targeted interventions and strategies for supportive care are needed to accommodate the unique needs of children living with RHD in low-resource countries.

Despite advances in medical treatment, RHD continues to have a broad impact on many different areas of life for children with the disease. Hospitalizations, interruptions in schooling, and social isolation due to their condition are just some of the ways RHD affects children

(Haynes et al., 2022). The connections among all these factors illustrate the need for comprehensive management solutions that address both medical needs and educational and social disruptions. According to the literature, little is known about these factors as they relate to children living with RHD in Kenya; this study will explore children's lived experiences of RHD at KNH to address this gap.

2.2.2 Psychological Challenges of Living with Rheumatic Heart Disease.

Children who suffer from rheumatic heart disease (RHD), a chronic illness, are at a greater risk of developing psychological disorders, such as anxiety and depression (Cooper et al., 2024; Livermore et al., 2023), as a result of the prolonged nature of the illness. Ongoing medical interventions and disease-related limitations can lead to feelings of frustration, helplessness, and a lack of feeling “normal.” In addition to psychological challenges, KNH, the main provider of cardiology treatment for children with RHD in Kenya, responds to the global health concern created by the chronicity of the illness through integrated care.

The strain of RHD on children affects their families as well, generating cycles of emotional and social stress and strain on the family structure, affecting family dynamics and coping mechanisms (Baker et al., 2023b). Compounding the difficulty of the families coping with the stress and strain created by the lack of mental health resources, low-resourced settings such as KNH have a dearth of comprehensive mental health services available to assist with these circumstances, underscoring the need for integrated care approaches covering the physical and mental health complications of RHD. This review demonstrates a significant gap in the existing literature on the psychological effects of RHD on Kenyan children, a gap that will be crucial to the development of efficient support systems and interventions.

2.2.3 Social Challenges of Living with Rheumatic Heart Disease

The parents of RHD pediatric patients play an important role in their care, and they frequently struggle with many forms of support while caring for their child. Studies show that parents of children with chronic illness, including RHD, experience high levels of stress, anxiety, and caregiving burden (Livermore et al., 2016; Min et al., 2020). In addition to limited healthcare resources in the KNH context, the logistical and emotional difficulties parents face in balancing caregiving and other roles add to the overall burden (Essop & Nkomo, 2005).

Consequently, it is essential for both parents and children to have access to comprehensive and accurate disease information, psychological counselling, and practical help with how to care for their child (Read et al., 2023). However, literature regarding parental support needs specific to the Kenyan context is very limited; thus, this study will address this gap by exploring how parents at KNH experience the health care system and the support they need to effectively manage their child's RHD. Ultimately, this investigation will help develop targeted services that could better support families in caring for their children's RHD.

Children with RHD have unique needs, such as the need for emotional support, fitness opportunities to ensure social inclusion, and to ensure educational continuity. Therefore, these children require intervention strategies that address their unique physical and psychosocial needs while coping with a chronic illness (Sara et al., 2020a). Identifying and addressing the needs of RHD children will positively affect their quality of life and holistic development.

3. Methodology

The qualitative descriptive design was chosen as the research method for this study. The study was conducted at KNH, Nairobi City County, Kenya. The participants were children between the ages of 6 and 18 years, who had been diagnosed with Rheumatic Heart Disease (RHD), and their primary caregivers at Kenyatta National Hospital (KNH). The participants were recruited from the Pediatric Cardiology Outpatient Clinic, where children attend regular follow-up appointments for evaluation and management of their cardiac condition, and from the Pediatric Medical Wards, where children may be admitted for either acute or long-term management of their RHD. The study focused on children currently receiving treatment for RHD and their caregivers, who play a significant role in providing daily care and support and in facilitating treatment adherence. Purposive sampling was used to select participants for this study. The final sample size was 28, consisting of 14 school-age children and their caregivers. The primary data collection tool was a set of semi-structured interview guides. A pilot study was conducted at Kenyatta National Hospital (KNH), specifically in the Pediatric Medical Ward, to help ensure the clarity, relevance, and feasibility of the data collection tools and procedures. Thematic analysis was used to analyze the data.

4.0 Results and Discussion

4.1 Sociodemographic Characteristics

The study sample comprised 14 participants, including children with RHD and their primary caregivers, who were recruited from Kenyatta National Hospital in Nairobi. The sample demographics revealed a varied composition, as shown in Table 1.

Table 1: Demographic Characteristics

Variable	n	%
Age (years)		
8–10	5	36
11–13	7	50
14–17	2	14
Sex		
Male	6	42.9
Female	8	57.1
Child's Level of Education		
Primary school (Grades 1–6)	11	78.6
Secondary school (Form 1–2 / Grade 9)	3	21.4
Duration of Diagnosis		
≤1 year	2	14.3
2–5 years	6	42.9
>5 years	6	42.9
Treatment Plan		
Monthly penicillin injections only	7	50
Penicillin + other medications (enalapril, Lasix, digoxin)	6	42.9
Surgery done	1	7.1

Clinic Attendance		
Regular (every 2 weeks–monthly)	4	28.6
Occasional (2–3 times/year)	5	35.7
Rare (≤ 2 times/year)	5	35.7
Activity Level		
Limited physical activity	9	64.3
Active/Regular participation	5	35.7
Guardian Relation		
Mother	7	50
Father	3	21.4
Sister	1	7.1
Grandmother	3	21.4
Guardian Marital Status		
Married	9	64.3
Single	3	21.4
Widowed (grandmothers assumed)	2	14.3
Guardian Education		
Primary (Class 4–8)	5	35.7
Secondary / Form 4	6	42.9
Higher/None specified (assumed secondary level for gaps)	3	21.4
Guardian Occupation		
Housewife	3	21.4
Farmer	2	14.3
Driver	3	21.4
Student (older sibling)	1	7.1
Casual labourer	5	35.7
Monthly Income (KES)		
<10,000	7	50
10,000–20,000	3	21.4
20,000–30,000	4	28.6

4.2 Findings

The findings are presented under four main themes: (1) Lived Experience of the Illness, (2) Challenges of Managing the Illness, (3) Social Challenges of Living with RHD, and (4) Systemic Gaps in Knowledge, Attitudes, and Support. In Table 2, “CL” denotes the child, and “CG” denotes the caregiver.

Table 2: Themes, Sub-Themes, and Categories Identified from Pediatric RHD Narratives

Theme	Sub-theme	Representative Quote (Verbatim)
Personal Burden of Illness in Child-Caregiver Dyad	Physical Suffering and Functional Limitations	“It hurts a lot... when she gets really sick, it hurts a lot.” (CL1, 14 years)
	Intense Caregiver Distress and Trauma	“I was shocked. I thought it was the end of my life.” (CG5)
Psychological Strain with Future Uncertainty	Helplessness and Emotional Exhaustion	“I can’t sleep at night because of my child’s pain.” (CG10)
	Fear of the Future and Illness Uncertainty	“I worry about my device getting old and needing another surgery.” (CL11, 13 years)
Social Alienation with Community Disintegration	Social Exclusion and Lack of Understanding	“Peers don’t understand and sometimes they push me roughly.” (CL13, 10 years)
	Disruption of Social Roles and Daily Life	“When I am sick, I cannot attend classes.” (CL1, 14 years)
Systemic Gaps with Support Deficits	Financial Hardship and Resource Constraints	“I don’t have money... money is a problem. Traveling is a problem? Yes. Getting food is a problem? Yes.” (CG12)
	Gaps in Healthcare Delivery and Need for Support Systems	“When I take them to the hospital, they don’t believe me.” (CG2)

4.2.1 Theme 1: Personal Burden of Illness in the Child - Caregiver Dyad

This theme demonstrates how children with RHD and their caregivers experience physical, emotional, and functional challenges. Because of their child's limitations, caregivers are burdened with caregiving responsibilities and emotional stress, ultimately reinforcing those burdens.

4.2.1.1 Sub-theme 1.1: Physical Suffering with Limited Function

Children with RHD frequently experience chronic pain, fatigue, and decreased physical function. As a result, they are unable to participate in typical daily activities, including school and recreation. Caregivers witness their child's limitations and support them to perform self-care, therefore experiencing emotional stress related to their child's suffering.

“It hurts a lot. ... when you get really sick, it hurts a lot.” (CL1, 14y)

“I often feel too tired to walk.” (CL14, 9y)

“I feel my heart beating fast, and then I can’t breathe well.” (CL6, 12y)

“My legs used to swell until I couldn't wear my shoes.” (CL8, 10y)

4.2.1.2 Sub-theme 1.2: Caregiver Distress stemming from Emotional Trauma

Because caregivers of children with RHD have experienced significant shock, fear, and emotional distress at the time of diagnosis, the continual witnessing of their child's suffering creates stress, helplessness, and social isolation for them.

"I was shocked. I thought it was the end of my life." (CG5)

"I felt very bad and was stressed to the point of getting sick myself." (CG14)

"I didn't expect it... I didn't know what to do because other moms who have had this disease had told me that I shouldn't be worried too much" (CG1)

4.2.2 Theme 2: Psychological strain exacerbated by pressure of future uncertainty

This Theme reflects the emotional and cognitive challenges experienced by children and caregivers. Feelings of helplessness, anxiety, and worry regarding how the disease will progress, the child's long-term health, and the uncertainty of how the child will turn out have detrimental effects on mental wellness and day-to-day life.

4.2.2.1 Sub-theme 2.1: Helplessness and Emotional Exhaustion

Caregivers feel a sense of helplessness when they are unable to relieve the pain and suffering of their child. This creates an emotional strain that manifests itself through disturbances in sleep patterns, chronic fatigue, and persistent emotional stress and strain, which negatively impact their mental health and day-to-day activities.

"I can't sleep at night because of my child's pain." (CG10)

"Obviously, I felt bad. But you know, there's nothing I can do. I just have to accept." (CG4)

4.2.2.2 Sub-theme 2.2: Fear of Future Health

Anxiety regarding how the disease will progress, how surgery will affect their child, and the long-term outcome of their child's health generates anxiety and worry for both children and their caregivers. Children are fearful that their device will fail or that they will have to undergo another surgery, while caregivers experience anxiety regarding an abrupt decline in health and an uncertain prognosis for their child, and thus experience ongoing anxiety.

"I worry about my device getting old and needing another surgery." (CL11, 13y)

"I know with this condition, anything can happen. I wonder what is next." (CG14)

"I desire a clear road map... to know what to expect with this condition." (CG9)

4.2.3 Theme 3: Social Disruption with Isolation

RHD causes problems in social relationships and roles. Children deal with stigma from peers, being isolated from their friends, and their routines being interrupted. Caregivers also feel disconnected from their community, have limited support, and participate less in daily social activities.

4.2.3.1 Sub-theme 3.1: Social Exclusion with Limited Understanding

Children experience stigma, do not get along with peers, and are isolated from peers. Their caregivers report limited empathy from teachers and community members. Because social barriers impede social interaction, children will be isolated and unable to have regular social contact.

“Peers don’t understand, and sometimes they push me roughly.” (CL13, 11y)

“At school... they don't want to play with me, because I rest often.” (CL4, 9y)

“I am afraid my child will be sick. There are teachers who don’t understand my child.” (CG12)

4.2.3.2 Sub-theme 3.2: Disrupted Social Roles with Daily Routine

Due to their school absences and disrupted childhood routines, RHD has caused caregivers and children to become socially isolated. Therefore, caregivers limit their community attendance, reducing the contacts and interactions of both the caregiver and their child.

“When I am sick, I cannot attend classes.” (CL1, 14y)

“My social life, including going to church and women’s group, everything stopped.” (CG13)

“Now I am the only one with this child... I don't have anyone I can go to.” (CG2)

“I cannot go to work freely... my school attendance is affected by her physical symptoms” (CG14)

4.2.4 Theme 4: Health System Barriers with Unmet Support Needs

This theme illustrates the difficulties facing families that inhibit their ability to provide care for their children due to additional constraints on their ability to provide adequate care, such as financial stressors (or lack of resources), inability to access appropriate pediatric services, and inadequacy of psychosocial supports, which create barriers to both compliance with treatment and general well-being for these children.

4.2.4.1 Sub-theme 4.1: Financial Burden with Resource Limitations

Caregivers are financially burdened by the costs of care, transportation, and nutrition associated with their child’s treatment, which impacts the child's overall health. Financial stress creates barriers to accessing care and increases caregiver psychosocial burden.

“I don’t have money... traveling is a problem... food is a problem.” (CG12)

“We don't have the money... I don't have any income.” (CG3)

“I sold my only cow to pay for the first deposit at the hospital.” (CG7)

“I don't have a job... I didn't have money.” (CG1, child 14y)

4.2.4.2 Sub-theme 4.2: Healthcare Gaps including Support Needs Deficits

Children and families experience delays in receiving care, under-utilization of healthcare services, and poor communication with medical personnel regarding available resources to support families and children receiving medical care. Healthcare providers have identified the

need for enhancing the availability of psychosocial support services for families; lack of structured information and peer support programs have contributed to stress and reduced coping abilities for families and children while receiving care.

“When I take them to the hospital, they don't believe me.” (CG2)

“Emotional support is like talking to other parents who have this.” (CG4)

“I would like them to talk to me. So, I don't have to worry.” (CG10)

4.3 Discussion

4.3.1 Discussion of Theme 1: Personal Burden of Illness in the Child - Caregiver Dyad

Children with RHD are faced with chronic physical pain, restricting their mobility, their ability to participate in school, and their ability to engage in social events. Due to these functional limitations, children are often removed from age-appropriate play and socialization, creating an additional burden of dependence on others and fewer opportunities to form social bonds with peers. In addition, these limitations create barriers to educational achievement that enhance the ongoing chronic physical and emotional vulnerability of the children.

Caregivers experience extraordinary psychological distress from the time of diagnosis, and this level of distress continues long after the diagnosis, creating an ongoing emotional burden. The continual demands of being a caregiver impact both physical and emotional health and provide further evidence that the family system is affected by RHD, in addition to the child. The caregiver is left emotionally fatigued, fearful, and constantly worried, illustrating the extent of the non-clinical consequences associated with RHD (Arvind & Ramakrishnan, 2020; Haynes et al., 2022).

4.3.2 Discussion of Theme 2: Psychological Strain with Future Uncertainty

The psychological strain that caregivers undergo can be quite profound due to the emotional tiredness from feeling helpless and overwhelmed by many life stressors. Additionally, social supports are low, healthcare is often limited, and financial resources are often extremely limited; all of which contribute to high levels of distress. Children are also affected as they, too, have anxieties related to the progression of their disease(s), and worry about the interventions that will happen in the future related to their health status.

Structural barriers such as delayed diagnosis, limited access to follow-up care after being diagnosed, and variable outcomes from treatment increase the level of stress for both caregivers and children. The level of uncertainty regarding each person's illness trajectory and the provision of healthcare services creates barriers to achieving emotional stability for both parties; therefore, clarity, direction, and predictability in care pathways are critically needed (Nalubwama et al., 2023; Leal et al., 2019).

4.3.3 Discussion of Theme 3: Social Alienation with Community Disintegration

RHD may contribute to social disconnection and stigma, thereby limiting the ability of children affected by RHD to interact socially with their peers. Also, fear of being judged by adults, such as teachers, limits children's interactions with others beyond the home or school environment. Disruptions in the daily routines of children affected by RHD, as a result of missing school,

often as a result of RHD, limit the social opportunities they have to develop socially, as well as to achieve academically.

Caregivers of children with RHD also experience social isolation from social networks or community resources because of the demands of caring for their children, further compounding their vulnerability (both economically and emotionally). Because the caregivers of children with RHD are relatively socially isolated, they have limited access to emotional and/or tangible resources; therefore, the cycle of poverty and illness continues (Watkins et al., 2018; Baker et al., 2023).

4.3.4 Discussion of Theme 4: Systemic Gaps with Support Deficits

A primary barrier to accessing healthcare, medications, and adequate nutrition for children suffering from RHD is financial hardship. Catastrophic costs of accessing these basic needs often force difficult choices for families, which, in turn, negatively affect both the continuity and quality of care received.

Weaknesses within the healthcare system (e.g., communication issues; delays in receiving services; a lack of post-operative support) further exacerbate these challenges and can create anxiety for caregivers. Caregivers need proactive guidance, structured care plans, and psychosocial support to effectively navigate the healthcare system and provide optimal care to their children. When integrated, these supports may reduce the physical and emotional burden associated with RHD (Arvind & Ramakrishnan, 2020; Nalubwama et al., 2023).

5. Conclusion

Pediatric RHD is much more than simply receiving medical management; it comprises psychological, social, and financial components. RHD is a syndetic disease, as the pathophysiological process associated with the disease coexists with poverty and systemic deficiencies to create detrimental results.

Stress and decreased quality of life for families occur primarily due to the inability to access quality and affordable health care rather than the cardiac lesions themselves. Families are faced with ethical dilemmas and financial burdens; therefore, many are left feeling powerless about the future due to high levels of anxiety, social isolation, and disconnectedness with their communities. The effective management of RHD requires access to specialized cardiac care, social welfare support, financial assistance, and early intervention programs within the community.

6. Recommendations

6.1 Reducing Financial Stress

- A. RHD National Fund: Create financial sources to assist with medications, prophylactic antibiotics, dietary supplements, and travel costs for children with RHD.
- B. Caregiver Economic Support: Provide vocational training or micro-grants to lessen the financial burden of caring for someone with RHD.

6.2 Increasing Healthcare Capacity

- A. Primary Care Screening: Add inexpensive echocardiogram/clinical scoring at primary health facilities for early diagnosis and prevention of disease progression.

- B. Postoperative and Transition Care: Develop structured discharge plans, make immediate access to medications available, and schedule follow-up visits to reduce patient abandonment.

6.3 Providing Psychological/Social Support

- A. Clinic-based Psycho Social Services: Provide counseling to caregivers and families at the time of diagnosis and throughout their ongoing care to help them cope with their trauma and chronic stress.
- B. Peer Support Networks: Create parent/caregiver support groups to reduce feelings of isolation, to offer practical information, and to reconnect families to the community.

6.4 Use Improving Patient Education and Guidelines

- A. Standardized RHD Resource for Patients: Produce educational resources to help explain the different phases of treatment and identify milestones, so that patients will have less anxiety when they receive treatment and learn what to expect along the way.
- B. Employment and School Education Resources: Provide educational resources to employers, educators, and other professionals to create understanding and supportive environments for children living with RHD.

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