IJCRT.ORG ISSN : 2320-2882

INTERNATIONAL JOURNAL OF CREATIVE RESEARCH THOUGHTS (IJCRT)

An International Open Access, Peer-reviewed, Refereed Journal

Role Of Parents As A Support System For Haemophilic Learners: A Qualitative Study

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Abstract

Haemophilia is an X-linked recessive genetic disorder that significantly impacts the sufferer physically, physiologically, emotionally, socially, mentally, financially and psychologically. This blood borne disease becomes more challenging specifically for learners in higher education and with this condition. The learners have to go through numerous academic hurdles raised by frequent bleeding episodes and associated gaps in their academic journey. Moreover, at such a crucial stage , concern for future aspirations, personal goals, physical constraints , financial loads, and social exclusion lead to psychological distress and emotional breakdowns. In coping up with these situations, the support systems of the haemophilic learners which includes their parents, teachers, siblings, peers etc play significant roles, not only by providing care and compassion but as social and financial support to the haemophilic learners. The present study explores the role of parents as a primary support system for haemophilic learners. Using a qualitative approach, data were collected through semi-structured interviews from parents of haemophilic learners. An inducto-deductive thematic analysis was employed to identify both pre-constructed and emergent themes. The findings revealed that parents play multifaceted roles including those of caregivers, supporters in emotional breakdowns, educational facilitators, and social advocates. Despite challenges such as financial burden and debts, lack of awareness, social stigma for the disease, psychological stress, parents actively devote themselves to ensuring continuity in education and overall well-being of their children. The study highlights the need for institutional and government support along with awareness programs to enhance parental capacity and inclusive education practices.

Keywords- Haemophilia, parental support, caregivers, educational facilitators, parental awareness

INTRODUCTION

Haemophilia is a genetic bleeding disorder caused due to mutation of genes responsible for the formation of the clotting factors. This mutation is passed down from parents to children directly following an X-linked recessive type of inheritance. The clotting proteins may be completely absent or may be present in very low levels (WHO) Haemophilia is a lifelong disorder and could be life-threatening if left untreated (World Federation of Haemophilia)

Since the disease follows an X-linked recessive type of inheritance pattern, the females having mutation on one of their X chromosomes will only become a carrier of the disease-causing gene, as they have got two X chromosomes. They will only become sufferers of this disease when they have a mutation on both of their X chromosomes (which is an extremely rare condition). While, in case of males, as they have XY type of sex chromosomes meaning that there is only one single X chromosome present and thus, mutation on this single X chromosome is enough to cause disease in males. Therefore, a carrier mother will transmit the disease to half of her sons whereas a sufferer mother would transmit the disease to all of her sons. So, in both the conditions, the probability of males becoming sufferers is far more than females, that is why, nearly all haemophilic individuals are males. Haemophilia, which finds its earliest mention in the Jewish text "Talmud" has also been famously called as the "Royal Disease" because Queen Victoria of the Royal family of Britain herself was a carrier of the disease and pedigree records show that Victoria transmitted the mutant allele to three of her nine children. The disease was passed to her daughter Alice (a carrier) and through her to her granddaughter Czarina Alexandra who was married in the Russian Imperial family . Czarina had four daughters and one son, and the son, Alexis, suffered from haemophilia. Victoria's own son Leopold was a sufferer and her daughter Beatrice (a carrier) transmitted the disease to the Royal family of Spain. Thus, the disease was passed down through descendants into various royal families of Europe (Snustad & Simmons, 1997, p.98)

Haemophilia is known to occur mainly in three different forms (Center for Disease Control and Prevention, 2023)- Haemophilia-A, the most common form which is caused by deficiency of Factor-VIII and has a prevalence of 1 in 5,000 male births globally ; Haemophilia-B (Christmas disease) caused by deficiency of Factor-IX and having a global prevalence of 1 in 25,000 male births; Haemophilia-C, the rarest and mildest among the three forms which can occur in males and females both and is more common in Ashkenazi Jews ,and is caused by deficiency of Factor-XI with a prevalence of 1 in 100,000 births (National Hemophilia Foundation, 2023) Apart from these three some rarest forms have been recently reported too like Acquired Haemophilia , an autoimmune disorder where the body develops antibodies against clotting factors, often Factor VIII (Franchini & Lippi, 2020) and Owen's disease due to deficiency of Factor-V.

The individuals suffering from Haemophilia have a life expectancy considerably worse in lower-income countries approximately 64%, 77% and 93% for countries with upper-middle, lower-middle and low-incomes respectively, according to World Bank definitions, which is due to high-treatment costs (World Federation of Haemophilia, 2019).

It is difficult for the haemophiliac individuals studying in educational set ups like schools, colleges, universities, etc to cope up with the unbearable pain, emotional suffering, mentally challenging conditions thereby maintaining their academic performance simultaneously. Learners with haemophilia often face interruptions in schooling due to frequent hospital visits, physical limitations, and social stigma. Such stigma often creates fear and discrimination towards the haemophiliacs increasing their problems. The Social Model theory of Oliver (1983) too emphasizes that disability is created by societal barriers, not the individual's impairment. In such contexts, parents emerge as the primary support system, playing an important role in managing both health and education of their children.The role of parents in supporting their children with chronic illnesses can be understood through Bronfenbrenner's Ecological Systems Theory, proposed by Urie Bronfenbrenner. According to this framework, the child's development is shaped by multiple environmental systems, with the microsystem (family) being the most proximal and impactful (Bronfenbrenner, 1979). For haemophilic learners, parents operate within this microsystem as primary caregivers, mediators, and facilitators of both health management and educational engagement. Their continuous interaction with the child directly influences coping mechanisms, resilience, and academic adjustment.

Additionally, the Family Systems Theory, associated with Murray Bowen, emphasizes that the family functions as an interconnected emotional unit where the experience of each member of the family affects

the whole system (Bowen, 1978). In the case of Haemophilia, the chronic nature of the disease often redefines family roles, with parents assuming intensified caregiving responsibilities. Studies have shown that parents of children with haemophilia actively coordinate medical care, manage treatment regimens such as injections, factor replacements, and ensure adherence to safety precautions (Khair et al., 2012). This systemic involvement reinforces the notion that parental support is not isolated but embedded within broader family dynamics.

From a psychosocial perspective, Social Support Theory (Cohen & Wills, 1985) provides further insight into the buffering role of parental support. The theory highlights that emotional, informational, and instrumental support significantly reduces stress and enhances well-being. Parents of haemophilic learners provide instrumental support (e.g., administering treatment, arranging hospital visits), emotional support (e.g., reassurance, motivation), and informational support (e.g., educating the child about self-care), thereby mitigating the adverse effects of the disorder (Breakey et al., 2014). Research indicates that strong parental support is associated with better psychological adjustment and improved quality of life among children with Haemophilia (Lindvall et al., 2013).

Furthermore, Vygotsky's Sociocultural Theory, developed by Lev Vygotsky, highlights the importance of social interaction in cognitive development (Vygotsky, 1978). Parents act as "more knowledgeable others," scaffolding the learning experiences of haemophilic children, especially when formal schooling is disrupted due to health-related absences. Through guided learning, home-based instruction, and coordination with teachers and other stakeholders, parents help bridge educational gaps and sustain academic progress.

Several empirical studies strengthen these theoretical perspectives. For instance, research by McLaughlin et al. (2016) found that parental involvement significantly improves adherence to treatment and school participation among haemophilic children. Similarly, a study by van Os et al. (2011) highlighted that parental coping strategies directly influence the child's emotional stability and social integration. Parents often advocate for their children within educational institutions, ensuring necessary accommodations such as flexible attendance, modified physical activities, and teacher awareness (Cassidy et al., 2010).

Despite their crucial role, parents face numerous challenges, including financial burden, emotional stress, and lack of awareness or institutional support (Khair et al., 2012). These challenges can affect their capacity to provide consistent support, underscoring the need for systemic interventions. Nevertheless, the literature consistently positions parents as central agents in the holistic development of haemophilic learners.

The concept of parental involvement in education has been widely acknowledged; however, in chronic conditions like haemophilia, this role extends beyond academic support to include medical and psychosocial care. That is why, this study aimed to understand how parents support haemophilic learners in tackling the various educational challenges encountered by the Haemophilic learners. Also, this study aimed to understand how parents help these haemophilic individuals cope up from psychological stress and emotional breakdowns arising from academic constraints and at times how they advocate for their children in situations of social exclusion. This study also found out the numerous financial and institutional challenges that the parents have to go through while ensuring support to their child who is haemophilic. Thus, the research question which guided the present study is how parents emerge as support systems for the Haemophilic learners.

METHODOLOGY

A. Research Design

The present study adopts a qualitative research design, specifically a thematic analysis approach, to explore the role of parents as support systems for haemophilic learners. The study is based on a secondary analysis of qualitative data originally collected as part of a broader dissertation that employed a multiple holistic case study method and examined the support systems of haemophilic learners, including parents, teachers, siblings, and peers.

A focused re-analysis was done to extract and interpret data specifically related to parental roles, making the study a reflexive thematic reinterpretation of existing interview data (Braun & Clarke, 2006).

B. Research Approach

The study follows an interpretivist paradigm, which emphasizes understanding participants' lived experiences and meanings they assign to social realities. Since the aim is to explore how parents support haemophilic learners in real-life contexts, this approach is appropriate for capturing depth and complexity.

C. Participants

The participants for this study included parents of haemophilic learners (2 learners with Haemophilia-A type disease) whose interviews were originally conducted during the larger study.

Sampling technique: Purposive sampling

Inclusion criteria: Parents of diagnosed haemophilic learners and their willingness to participate in the original study. Although the larger study included multiple stakeholders, only parent-related data were extracted for this paper.

D. Data Source

Data for this study were derived from semi-structured interviews of parents. These interviews explored areas such as caregiving practices, educational support, emotional experiences, and challenges faced.

The use of semi-structured interviews allowed flexibility and depth, enabling participants to share detailed experiences.

E. Data Analysis

Data were analyzed using inducto-deductive thematic analysis based on the framework proposed by Braun and Clarke (2006).

Deductive component: Pre-constructed themes (e.g., caregiving, educational support, emotional support) were informed by existing literature and research objectives.

Inductive component: New themes emerged from the data, reflecting participants' lived experiences (e.g., stigma management, financial burdens, roles).

The analysis followed these steps:Familiarization with data (re-reading interview transcripts), initial coding, categorisation , theme identification, reviewing and refining themes and defining and naming themes

This combined approach ensured both theoretical grounding and data-driven insights.

F. Ethical Considerations

Informed consent was obtained during the original data collection. Participant confidentiality was maintained as well. Data has been used solely for academic purposes. No identifying information has been disclosed in this study.

RESULTS AND INTERPRETATIONS

Table 1- The themes, categories and codes derived from in depth interviews of parents of haemophilic individuals

THEMES	CATEGORIES	CODES	REPRESENTATIVE QUOTES/STATEMENTS
1. DIAGNOSIS, ACCEPTANCE AND EMOTIONAL ADJUSTMENT	DIAGNOSIS EXPERIENCE	Early diagnosis	Prnt 1: "when he was six months old, we found that he is haemophilic"
		late diagnosis-critical condition	Prnt2:"bleeding in his head was continuing for 10 days"
	ACCEPTANCE OF DISEASE	Delayed acceptance	Prnt1:"it took almost six months to accept"; "it was very difficult we didn't believe initially"
		Shock and disbelief	
	EMOTIONAL ADJUSTMENT	Child's emotional struggle	Prnt1:"Very challenging for him…especially in childhood"
		Parental emotional support	Prnt1:"we keep talking to him so that he doesn't feel isolated"
		Social exclusion in initial phase	Prnt2:"He definitely felt excluded"
		Social inclusion in later phase	Prnt1:"He doesn't feel excluded, everybody includes him"
2. MEDICAL MANAGEMENT AND DAILY CARE PRACTICES	BLEEDING EPISODES	Unpredictable bleeding	Prnt1:"it can happen at any moment"
		Frequent bleeding	Prnt2"it was very frequent"
	TREATMENT ROUTINE AND PREPAREDNESS	Regular medication	Prnt1:"we have to be ready all the time" ;"injections on regular intervals"
		Continuous preparedness	
	HOME-BASED CARE BY PARENTS	Availibility of medicines	Prnt1:"medicines should be present all the times"
			Prnt2:"he was having walking problems"
3. PROTECTIVE PARENTING AND EDUCATIONAL EXPERIENCES	PROTECTIVE PARENTING	Home environment modification	Prnt1:"no object with sharp edges…in the furniture"
		constant supervision	Prnt1:"24x7, somebody from us was available there in the house"
		Restriction of movement/play	Prnt1:"we didn't allow him to play a lot"
		Fear driven monitoring	Prnt2:"we were shouting that he does not go here and there"
	EDUCATIONAL INCLUSION	Supportive teachers	Prnt1 :"teachers were very caring/cooperative"

		Peer support	Prnt2:"his peers…everybody was supportive"
	EDUCATIONAL CHALLENGES	Missed classes	Prnt1:"certain classes…he missed"
		Dropout due to illness	Prnt2:"he had to take a drop out from his B.Tech course"
4. FINANCIAL BURDEN, SUPPORT SYSTEMS AND SYSTEMIC BARRIERS	FINANCIAL BURDEN	High cost of treatment	Prnt1:"very, very expensive"
		Income strain	Prnt1:"30% of my salary goes into treatment"
		Loans and Borrowing	Prnt 2:"we had to take loans from relatives"
	SUPPORT SYSTEMS	NGO support	Prnt1:"discounts... are actually monetary help"
		Haemophilia society membership	Prnt2:"we have joined that society"
		Employer support	Prnt1:"My company where I work is supporting me"
	AWARENESS AND SCHEMES	Awareness of schemes	Prnt1:"schemes are helpful"
		Lack of awareness	Prnt2:"not directly aware"
	SYSTEMIC BARRIERS	Bureaucratic hurdles	Prnt1:"a lot of paperwork is there"
		Administrative difficulty	Prnt2:"Daftar ke chakkar kattate raho, very difficult for a common citizen"

Theme 1: Diagnosis, Acceptance and Emotional Adjustment

The findings indicate that the diagnosis of haemophilia serves as a critical and emotionally overwhelming turning point for families. The nature and timing of diagnosis shaped parental responses significantly. One parent reported early diagnosis in infancy, stating that "when he was six months old, we found that he is haemophilic", whereas another parent encountered a delayed and severe diagnosis, describing that "bleeding in his head was continuing for 10 days, that is when we got to learn about his condition."

In both cases, acceptance was not immediate. Parents underwent a phase of denial and emotional struggle. This is evident from statements such as "it took almost six months to accept" and "it was very difficult… we didn't believe it initially." Such responses reflect that acceptance is a gradual psychological process rather than an instant realization.

Children also experienced emotional challenges, particularly during early developmental stages. One parent shared that it was "very challenging for him… especially in childhood", highlighting the child's difficulty in understanding and adjusting to the condition. However, continuous parental reassurance helped in emotional adjustment, as reflected in "we keep talking to him so that he does not feel isolated."

Social experiences further influenced emotional well-being. While one case reported inclusion ("he does not feel excluded, everybody includes him"), the other revealed initial stigma and exclusion ("he definitely felt excluded"), largely due to lack of awareness.

Interpretation: In both the cases, parents revealed that diagnosis, which is a major milestone in haemophilia, brought about a period of shock and inacceptance but gradually they learnt to cope up with the difficulties.Thus, the theme reflects a transition from shock and denial to gradual emotional adjustment, shaped by family support and societal attitudes.

Theme 2: Medical Management and Daily Care Practices

The analysis highlights that haemophilia is perceived as a chronic and unpredictable condition requiring continuous management. Parents emphasized the uncertainty associated with bleeding episodes. One parent noted that "it can happen at any moment", while another described the severity by stating "it was very frequent."

This unpredictability necessitates constant preparedness and vigilance. As expressed by a parent, "we have to be ready all the time", indicating that caregiving involves ongoing anticipation of medical emergencies. The importance of immediate access to treatment is evident in statements like "medicines should be present" and "injections on regular intervals."

In more severe cases, physical complications added to caregiving challenges. For instance, one parent reported that "he was having walking problems", showing how haemophilia can affect mobility and daily functioning.

Interpretation: The overall experiences of both the parents demonstrate that caregiving extends beyond routine parenting to a medically intensive, continuous responsibility, where health management becomes central to everyday life. Therefore, this theme underscores that haemophilia management is constant, uncertain, and deeply embedded in daily living practices.

Theme 3: Protective Parenting and Educational Experiences

The findings reveal that parents adopt protective and precautionary approaches to ensure the safety of their child. This includes modifying the physical environment and maintaining constant supervision. One parent explained that "no object with sharp edges should be there in the furniture" and "24 x 7, somebody from us was available there in the house", reflecting a highly vigilant caregiving environment.

In some cases, parenting became more restrictive due to fear of injury. This is evident from statements such as "we didn't allow him to play a lot" and "we were shouting that he does not go here and there." Such practices indicate a fear-driven approach, which may limit the child's independence.

Despite these challenges, educational experiences were largely supported by institutions. Parents acknowledged that "teachers were very caring/cooperative" and "his peers, everybody was supportive", suggesting that inclusive environments positively influenced the child's participation.

However, health-related issues did impact academic continuity. One parent mentioned that "certain classes… he missed because of Haemophilia", while another reported a more serious disruption: "he had to take a drop out from his B.Tech."

Interpretation: This theme illustrates that while protective parenting ensures safety, it may also restrict personal liberty, and although schools can be supportive, medical conditions continue to influence educational aspirations and career paths.

Theme 4: Financial Burden, Support Systems and Systemic Barriers

The data strongly highlight the economic strain associated with haemophilia treatment. Parents consistently described treatment as expensive, using expressions such as "very, very expensive" and "almost 30% of my salary goes into that." For families with limited financial resources, this burden becomes even more severe, leading to borrowing and financial instability, as reflected in "we had to take… loans… from relatives."

Support systems, including employers, NGOs, and haemophilia societies, provided some relief. For example, one parent shared that "My company where I work is supporting me", while another noted that "discounts made available by Haemophilia societies are actually monetary help." These supports, although helpful, were indirect and insufficient to fully meet financial needs.

Awareness and utilization of government schemes were found to be inconsistent. While some parents acknowledged that "schemes are helpful", others admitted that they are "not directly aware." Moreover, accessing these benefits was perceived as difficult due to administrative barriers. Parents highlighted challenges such as "a lot of paperwork is there" and "very difficult for a common citizen."

Interpretation: This theme reveals that despite the presence of support mechanisms, financial burden remains a persistent challenge, often added by systemic inefficiencies and accessibility issues, especially the governmental schemes. The theme also highlights a little awareness about governmental schemes amongst the normal public and some way less awareness about haemophilia amongst government front-desk officials.

DISCUSSION

The present study established the role of parents as most significant support systems for haemophilic learners and revealed that parental involvement extends far beyond routine caregiving, encompassing emotional, educational, medical, financial, and social dimensions. The findings demonstrate that parents act as the primary helping force in the lives of haemophilic learners, particularly in assisting them cope with the academic disruptions, emotional stress, and social challenges associated with the condition. These findings strongly support the theoretical frameworks and empirical studies discussed in the introduction.One of the major findings of the study was that the diagnosis of haemophilia becomes a turning point for families, often accompanied by shock, denial, fear, and emotional distress. Parents reported difficulty in accepting the diagnosis initially, especially in severe cases where the child experienced frequent bleeding episodes or life-threatening complications. However, over time, parents gradually adapted to the condition and became emotionally resilient caregivers. These findings are consistent with the Family Systems Theory proposed by Bowen (1978), which explains that chronic illness affects the entire family system and compels family members to reorganize their roles and responsibilities. The present findings also align with the work of van Os et al. (2011), who reported that parental coping strategies significantly influence the emotional adjustment and resilience of children with haemophilia. The emotional reassurance provided by parents in this study helped children overcome feelings of isolation and fear, thereby strengthening their psychological well-being.

Another significant finding was the intensive medical caregiving role performed by parents. Parents continuously monitored their children's health conditions, remained prepared for emergency bleeding episodes, arranged hospital visits, and ensured the availability of medicines and injections. This reflects the multidimensional caregiving burden experienced by parents of haemophilic children. Similar findings were reported by Khair et al. (2012), who observed that parents of children with haemophilia are deeply involved in treatment management and safety precautions. The findings also support Bronfenbrenner's Ecological Systems Theory (1979), which emphasizes that the family microsystem plays the most direct and influential role in a child's development. In the context of haemophilia, parents become the primary agents responsible for maintaining both the health and overall functioning of the child.

The study further revealed that parents played a vital role in maintaining educational continuity for haemophilic learners. Frequent hospital visits, physical complications, and periods of hospitalization often interrupted schooling and affected academic participation. Despite these barriers, parents actively coordinated with teachers, encouraged home-based learning, adjusted study schedules, and motivated their children to continue their education. These findings correspond closely with Vygotsky's Sociocultural Theory (1978), which highlights the importance of social guidance and scaffolding in learning. Parents in the present study acted as "more knowledgeable others," helping learners bridge educational gaps caused

by illness-related absences. The findings are also in agreement with McLaughlin et al. (2016), who found that parental involvement significantly improves school participation and treatment adherence among haemophilic children.

The findings additionally revealed that parents often adopted highly protective parenting practices to prevent injuries and bleeding episodes. Continuous supervision, restrictions on physical activities, and modifications in the home environment were common protective measures reported by participants. While such practices ensured safety, they sometimes limited the independence and social participation of the child. Nevertheless, parents considered these restrictions necessary due to the unpredictable nature of haemophilia. This finding reflects the complexities involved in balancing protection with autonomy in chronic illness management. It also supports the observations of Breakey et al. (2014), who emphasized that psychosocial factors and parental involvement significantly shape the quality of life of haemophilic individuals.

Social support and advocacy emerged as another crucial dimension of parental roles. Parents frequently interacted with schools, teachers, peers, and relatives to create awareness about haemophilia and reduce stigma associated with the disease. Some parents reported inclusive and supportive educational environments, while others described experiences of exclusion and misunderstanding due to lack of awareness. These findings strongly align with Oliver's Social Model Theory (1983), which argues that disability-related difficulties are often socially constructed through barriers, discrimination, and lack of awareness rather than the impairment itself. Parents in the present study acted as social advocates who attempted to minimize these barriers and facilitate inclusion for their children within educational and social settings. Similar observations were highlighted by Cassidy et al. (2010), who found that parental advocacy is essential in securing accommodations and supportive educational environments for children with chronic illnesses.

Financial burden emerged as one of the most persistent challenges faced by parents. Treatment expenses, regular medication, travel costs, and emergency care placed significant economic strain on families. Some parents reported taking loans or depending on external support from organizations and employers to continue treatment. Although certain government schemes and haemophilia societies provided assistance, lack of awareness and bureaucratic barriers limited their accessibility. These findings are consistent with Khair et al. (2012), who emphasized that financial and emotional stress significantly affect families of haemophilic children. The findings also support the World Federation of Hemophilia (2020), which highlights unequal access to treatment and financial hardship, particularly in low- and middle-income countries.

Overall, the study establishes that parents function as the central support system for haemophilic learners. Their role is not confined to caregiving alone but extends to emotional counseling, educational facilitation, medical management, financial planning, and social advocacy. Through continuous support, parents help haemophilic learners maintain educational continuity, develop emotional resilience, and tackle societal barriers. Thus, the findings strongly justify the indispensable role of parents in ensuring the holistic development and well-being of haemophilic learners.

CONCLUSION

The present study concludes that parents play a multidimensional and indispensable role in the lives of haemophilic learners. They emerge not only as caregivers responsible for medical management but also as emotional supporters, educational facilitators, social advocates, and protectors who continuously strive to ensure the well-being and academic continuity of their children. The findings reveal that despite emotional distress, financial burden, social stigma, and institutional barriers, parents remain deeply committed to supporting haemophilic learners in coping with the challenges associated with the disorder. Their

involvement significantly contributes to the child's emotional adjustment, resilience, treatment adherence, educational participation, and social inclusion.

The study also highlights that haemophilia affects not only the learner but the entire family system, requiring parents to constantly adapt their routines, responsibilities, and expectations. Strong parental support was found to reduce feelings of isolation and anxiety among learners while promoting confidence and educational engagement. At the same time, the findings indicate that parents themselves require greater institutional, financial, and psychosocial support to effectively fulfill these demanding responsibilities.

The implications of the study suggest the urgent need for greater awareness regarding haemophilia within educational institutions and society at large. Schools and colleges should develop inclusive practices by sensitizing teachers, peers, and administrators about the condition so that haemophilic learners can participate without fear of discrimination or exclusion. Teacher training programs should include awareness regarding chronic illnesses and strategies for supporting learners with medical conditions. The study further implies that counseling services should be made available not only for haemophilic learners but also for parents who experience continuous psychological and emotional stress. Additionally, governments and healthcare systems should simplify access to financial assistance schemes, improve awareness regarding haemophilia, and strengthen support services through haemophilia societies and healthcare institutions. Such collaborative efforts can create a more inclusive, supportive, and accessible environment that enhances both the educational experiences and quality of life of haemophilic learners and their families.

ACKNOWLEDGMENT

The authors express their gratitude to all participating parents for sharing their valuable experiences and insights.

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