



Navas Shareef P. P.

Junior Research Fellow

Dept of Education,
University of Calicut,

navaspoonthodan9@gmail.com



Dr. Reesha Karally

Assistant Professor,

Dept of Education,
University of Calicut

drreesha@uoc.ac.in

Persons with Haemophilia in Inclusive Education: Problems and Prospects

Navas shareef P P

Reesha Karally

Abstract:

This qualitative research explores the multiple types of challenges faced by persons suffering from haemophilia in their school life focusing on physical, mental health, emotional & economic social academic and government aids. Through conducting semi-structured interviews with participants who aged 25 years or above. This study enables deeper reflection on their experiences as students. Thematic analysis was conducted to extract common themes and unique ideas about the impact of haemophilia on education and development of a person. Early results show significant hurdles to physical engagement and reach related to educational institutions as they are compounded by social stigma and lack of institutional support. Themes of emotional distress as well as financial hardship emerged, particularly in families with fewer resources. The study finds gaps for government and policy efforts to make sure inclusiveness in education for students with hemophilia. The results of previous studies in this area highlight the importance of tailored actions to combat the problems faced and provide impetus for researchers, clinicians, policymakers and educators alike. Longitudinal studies to assess the needs of individuals living with hemophilia at different life stages should be a priority for future research. Integration of AI in teaching learning process to reduce the challenges also should be a prime concern to overcome the challenges.

Keywords: Hemophilia, Barriers, Inclusive Education

1. Introduction:

Haemophilia is a chronic bleeding illness characterised by improper blood clotting. Lack of a single blood-clotting protein in the blood is the reason. Depending on the blood's clotting factor level, haemophilia can be mild, moderate, or severe (Kids Health Info: Hemophilia Information for Schools, n.d.)¹. Hemophilia presents significant challenges for individuals across various aspects of life. Physical issues include difficulty controlling bleeding, joint deterioration, and pain (duTreil, 2014)². Despite treatment advances, many still experience regular bleeds and

¹ Kids health info: Haemophilia information for schools. (n.d.). Retrieved 21 January 2025, from https://www.rch.org.au/kidsinfo/fact_sheets/Haemophilia_information_for_schools/

² duTreil, S. (2014). Physical and psychosocial challenges in adult hemophilia patients with inhibitors. *Journal of Blood Medicine*, 115. <https://doi.org/10.2147/JBM.S63265>



restrictions in daily activities (Hughes et al., 2020)³. Psychosocial challenges encompass emotional turmoil, social issues, and financial strain (duTreil, 2014; Ramos-Petersen et al., 2023). The disease impacts work, family, leisure, and personal environments (Ramos-Petersen et al., 2023)⁴. Community-dwelling adults with hemophilia face additional concerns, including treatment costs and employment challenges (Okide et al., 2019)⁵. These multifaceted issues highlight the need for comprehensive, multidisciplinary assessments and personalized treatment approaches (duTreil, 2014; Hughes et al., 2020). Patient organizations and healthcare institutions play crucial roles in supporting individuals with hemophilia (Ramos-Petersen et al., 2023). Sustainable efforts in leadership, education, and healthcare provision are necessary to improve the quality of life for those living with hemophilia (Okide et al., 2019). By focusing on the individual needs of these students and leveraging the strengths of inclusive education, it is possible to create an environment where persons with hemophilia can thrive academically and socially (Green & Roberts, 2016)⁶. This paper will further discuss the barriers to inclusive education for persons with hemophilia and explore practical strategies for addressing these challenges (Martin & Thompson, 2011; Wilson & Marks, 2017)⁷, with the goal of advancing the prospects for inclusive education for all students, regardless of their health status.

2. Research Questions:

How do hemophilia-related physical, mental, and health challenges impact the inclusion of students in educational settings, and what support systems are necessary to address these barriers?

3. Objectives

- i) To investigate the specific physical, mental, and health challenges experienced by students with hemophilia in educational environments.

³ Hughes, T., Brok-Kristensen, M., Gargeya, Y., Worsøe Lottrup, A. M., Bo Larsen, A., Torres-Ortuño, A., Mackett, N., & Stevens, J. (2020). "What more can we ask for?": An ethnographic study of challenges and possibilities for people living with haemophilia. *The Journal of Haemophilia Practice*, 7(1), 25–36. <https://doi.org/10.17225/jhp00151>

⁴ Ramos-Petersen, L., Rodríguez-Sánchez, J. A., Cortés-Martín, J., Reinoso-Cobo, A., Sánchez-García, J. C., Rodríguez-Blanco, R., & Coca, J. R. (2023). A Qualitative Study Exploring the Experiences and Perceptions of Patients with Hemophilia Regarding Their Health-Related Well-Being, in Salamanca. *Journal of Clinical Medicine*, 12(16), 5417. <https://doi.org/10.3390/jcm12165417>

⁵ Okide, C. C., Eseadi, C., Koledoye, U. L., Mbagwu, F., Ekwealor, N. E., Okeke, N. M., Osilike, C., & Okeke, P. M. (2019). Challenges facing community-dwelling adults with hemophilia: Implications for community-based adult education and nursing. *Journal of International Medical Research*, 48(1). <https://doi.org/10.1177/0300060519862101>

⁶ Green, D., & Roberts, M. (2016). Social integration of students with hemophilia in schools. *Hemophilia*, 22(1), e47-e51.

⁷ Martin, G., & Thompson, R. (2011). Hemophilia and schooling: The importance of teacher support. *Child: Care, Health and Development*, 37(4), 504-511.



- ii) To assess how these challenges influence their inclusion and engagement in school activities.
- iii) To identify and propose necessary support systems to enhance their participation and overall educational experience.

3. Rationale of the Study:

Inclusive education aims to provide equal learning opportunities for all students, regardless of their physical, intellectual, or emotional challenges. However, students with specific medical conditions, such as hemophilia, face unique difficulties that may not be fully addressed within typical inclusive education frameworks. Hemophilia is a genetic bleeding disorder that impairs the blood's ability to clot, causing the affected individuals to experience frequent bleeding episodes, in joints.

4. Methodology:

The methodology of the study was planned to gain a deep understanding of the educational experiences of individuals with hemophilia. A qualitative approach was chosen, focusing on semi-structured interviews to allow for flexibility and in-depth exploration of participants' experiences. The study followed a qualitative research design, specifically a phenomenological approach. This design was chosen to understand and interpret the lived experiences of individuals with haemophilia in the context of their educational journey.

Table-1: Population of the study

Demographic Characteristic	Details
Age	Above 25
Gender	Male
Year of High School Completion	By 2015

- i) **Sample:** All participants were diagnosed with hemophilia.
- ii) **Sample size:** 20 participants
- iii) **Research Tools:** A tool of Hemophilia Educational Experience Interview Schedule (HEEIS) (Navas Shareef & Reesha Karally,2024).

5. Study Conducted:

This study adopted a qualitative research design to explore the challenges faced by students with hemophilia in inclusive educational settings. To address the research question, in-depth semi-structured interviews were conducted with 20 participants, allowing for a detailed exploration of their lived experiences. The interviews focused on three key themes: physical challenges, mental challenges, and health challenges, with open-ended questions designed to elicit detailed



responses. The qualitative methodology enabled a deeper understanding of the barriers and support systems relevant to the educational experiences of students with hemophilia.

Table 2. Research overview: Sub-questions, study phases, data types, and collection methods.

Research Question (RQ)	Data Type	Data collection method
RQ	Qualitative	Interview

6. Findings and discussion:

Thematic Analysis of Semi-Structured Interviews: Chronic Pain and Mobility Challenges, Exclusion from Physical Activities, Fatigue and Energy Management, and Risk Avoidance Behavior— are shown in the table as physical challenges of hemophilia, along with their respective frequency and percentage.

Table No. 2: Common Physical Challenges Among Participants

Challenge	Description	Frequency	Percentage
Chronic Pain and Mobility Challenges	Persistent pain in knee and elbow joints; limits movement and school engagement.	18	90%
Exclusion from Physical Activities	Avoidance of sports and physical activities; leads to social isolation.	15	75%
Fatigue and Energy Management	Fatigue due to chronic pain; reduces stamina for academic and extracurricular tasks.	12	60%
Risk Avoidance Behaviour	Avoidance of situations that might risk injury; limits participation in activities.	16	80%

The data reveals significant challenges linked to chronic pain, with 90% experiencing mobility issues that limit school engagement. Social isolation affects 75% due to exclusion from physical activities, while 60% report fatigue reducing academic and extracurricular participation. Additionally, 80% exhibit risk-avoidance behaviour, further restricting involvement. These findings underscore the need for holistic interventions, including medical support, inclusive activities, flexible schedules, and confidence-building strategies to address the physical, social, and emotional impacts effectively.

Table No. 3: Mental Challenges Among Participants

Challenge	Description	Frequency	Percentage
Emotional Impact of Sadness	Sadness disrupted focus, motivation, and academic performance, leading to disengagement and loneliness.	14	70%
Isolation and Loneliness	Feelings of being misunderstood or excluded due to their condition intensified emotional distress.	12	60%
Lack of Professional Support or Counselling	Inadequate access to mental health resources; stigma discouraged seeking help.	16	80%



The data highlights the emotional challenges faced, with 80% identifying a lack of professional support or counselling as a key issue, compounded by stigma surrounding mental health. Emotional impact due to sadness, affecting 70%, disrupts focus, motivation, and academic performance, leading to disengagement and loneliness. Additionally, 60% experience isolation and loneliness, often feeling misunderstood or excluded, which intensifies emotional distress. These findings underscore the urgent need for accessible mental health resources, awareness programs to reduce stigma, and supportive environments to address emotional well-being effectively.

Table No. 4: Health Challenges Among Participants

Challenge	Description	Frequency	Percentage
Absence of Health Resources	Schools lack infrastructure, nurses, or first-aid kits specific to hemophilia management.	18	90%
Ineffective Emergency Management	Poor preparation and lack of plans for handling bleeding episodes or injuries.	16	80%
Limited Awareness Among Staff	Teachers aware of the condition lacked actionable training or preparedness.	14	70%

The data highlights critical gaps in health resource management for hemophilia. The absence of essential health infrastructure, such as nurses or first-aid kits tailored to hemophilia, affects 90%, posing significant risks to student safety. Ineffective emergency management impacts 80%, reflecting inadequate preparation for handling bleeding episodes or injuries. Additionally, 70% of teachers, despite being aware of the condition, lack practical training or preparedness. These findings underscore the need for schools to prioritize specialized health resources, implement comprehensive emergency plans, and provide targeted training for staff to ensure the safety and well-being of affected students.

7. Conclusion:

The study highlights the complex challenges faced by students with haemophilia in inclusive educational settings, focusing on physical, emotional, and health-related barriers that impact their participation and overall school experience. Physically, joint pain, particularly in the knees and elbows, restricts their involvement in regular classroom and physical activities, depriving them of opportunities for social interaction and personal growth. This limitation also negatively affects their physical well-being, which is integral to their holistic development. Mentally, students with haemophilia often deal with feelings of isolation, sadness, and emotional distress stemming from their condition. The absence of professional mental health support and counselling in schools further exacerbates these challenges, leaving students feeling unsupported and overwhelmed by the emotional toll of managing a chronic condition. Health-related barriers, including insufficient haemophilia-specific resources and inadequate emergency



protocols, compound these struggles. The lack of preparedness and resources in schools often leads to absenteeism and diminished trust in the school's ability to meet their needs. To address these barriers, schools must implement a holistic approach, including tailored physical accommodations, comprehensive mental health services, and effective health resource management. By fostering an inclusive and supportive environment, schools can ensure that students with haemophilia thrive academically, socially, and emotionally, achieving their full potential.

Suggestions:

- i) To address the government regarding support for students with hemophilia, and to facilitate appropriate assistance for their educational and medical needs.
- ii) Initiate School Management to Provide a Supportive School Environment for Hemophilia Students.

References:

- duTreil, S. (2014). Physical and psychosocial challenges in adult hemophilia patients with inhibitors. *Journal of Blood Medicine*, 115. <https://doi.org/10.2147/JBM.S63265>
- Green, D., & Roberts, M. (2016). Social integration of students with hemophilia in schools. *Hemophilia*, 22(1), e47-e51.
- Hughes, T., Brok-Kristensen, M., Gargeya, Y., Worsøe Lottrup, A. M., Bo Larsen, A., Torres-Ortuño, A., Mackett, N., & Stevens, J. (2020). "What more can we ask for?": An ethnographic study of challenges and possibilities for people living with haemophilia. *The Journal of Haemophilia Practice*, 7(1), 25–36. <https://doi.org/10.17225/jhp00151>
- Kids health info: Haemophilia information for schools. (n.d.). Retrieved 21 January 2025, from https://www.rch.org.au/kidsinfo/fact_sheets/Haemophilia_information_for_schools/
- Martin, G., & Thompson, R. (2011). Hemophilia and schooling: The importance of teacher support. *Child: Care, Health and Development*, 37(4), 504-511.
- Okide, C. C., Eseadi, C., Koledoye, U. L., Mbagwu, F., Ekwealor, N. E., Okeke, N. M., Osilike, C., & Okeke, P. M. D. (2020). Challenges facing community-dwelling adults with hemophilia: Implications for community-based adult education and nursing. *Journal of International Medical Research*, 48(1), 0300060519862101. <https://doi.org/10.1177/0300060519862101>
- Ramos-Petersen, L., Rodríguez-Sánchez, J. A., Cortés-Martín, J., Reinoso-Cobo, A., Sánchez-García, J. C., Rodríguez-Blaque, R., & Coca, J. R. (2023). A qualitative study exploring the experiences and perceptions of patients with hemophilia regarding their health-related well-being, in salamanca. *Journal of Clinical Medicine*, 12(16), 5417. <https://doi.org/10.3390/jcm12165417>
- Wilson, A., & Marks, R. (2017). Strategies for teaching students with hemophilia: A comprehensive approach. *Physical Education and Sport Pedagogy*, 22(5), 508-522.