INSIGHTS-JOURNAL OF
LIFE AND SOCIAL SCIENCES

INSIGHTS-JLSS
Insights-Journal of Life and Social Sciences

NAVIGATING SOCIAL ISOLATION: A FOCUS ON THE PSYCHOSOCIAL CHALLENGES OF HAEMOPHILIA PATIENTS IN PAKISTAN

Original Article

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Conflict of Interest: None
Grant Support & Financial Support: None
Acknowledgement: We sincerely acknowledge the participants and all individuals who contributed to this study for their valuable time and insights.

ABSTRACT

Background: Haemophilia is a rare inherited bleeding disorder characterized by a deficiency of clotting factors, leading to prolonged bleeding episodes. The condition profoundly impacts patients' physical, psychological, and social well-being, especially in resource-limited settings like Pakistan. Exploring the perceived fears and coping mechanisms of haemophilia patients is essential for addressing their psychosocial challenges and improving their quality of life.

Objective: The study aimed to explore and evaluate the perceived fears among haemophilia patients in Pakistan, focusing on the causes, effects, and pathways adopted to cope during internal bleeding episodes.

Methods: A qualitative approach was adopted using semi-structured interviews guided by thematic analysis. The study included 28 participants (20 males, 8 females) aged 14–35 years, recruited through snowball and convenience sampling from Rawalpindi, Lahore, Raiwind, Bahawalnagar, Gujranwala, and Hafizabad. Data were collected until thematic saturation was achieved. The interviews were analyzed using QSR NVivo 10, and themes were derived based on the Fear Avoidance Model and Braun and Clarke's thematic analysis framework. The primary themes encompassed perceived fears, including fear of bleeding, rejection, injury, pain, disability, illness, emotional trauma, losing social roles, discrimination, stigma, and death.

Results: Thematic analysis revealed that 75% of participants avoided physical and social activities due to fear of bleeding. Fear of pain was reported by 71%, while 68% expressed fear of disability. Over 60% highlighted concerns about stigma and rejection, leading to social isolation. The findings also indicated that 36% experienced emotional trauma and anxiety, while 18% reported depression and suicidal ideation due to haemophilia-related challenges. Most participants (80%) adapted avoidance strategies, which negatively impacted their social, academic, and psychological well-being.

Conclusion: Haemophilia patients in Pakistan face substantial psychosocial and physical challenges that significantly disrupt their lives. Addressing these fears through tailored healthcare strategies, enhanced social support, and awareness programs is essential for improving their overall well-being and quality of life.

Keywords: Anxiety, bleeding disorders, coping strategies, fear, hemophilia A, hemophilia B, stigma.

INTRODUCTION

Haemophilia is a rare, inherited bleeding disorder characterized by a deficiency or dysfunction of clotting factors, primarily factor VIII in haemophilia A and factor IX in haemophilia B, leading to impaired blood clot formation (1). The condition results from genetic mutations on the X chromosome, making it predominantly present in males, while females generally act as carriers. Clinically, haemophilia manifests as prolonged and spontaneous bleeding episodes, particularly in joints and muscles, which can lead to severe complications, including chronic pain, joint damage, paralysis, or even death in extreme cases (2). The disease is further categorized into haemophilia C, caused by factor XI deficiency, and von Willebrand disease, associated with low levels of von Willebrand factor, though these are less common (3). Globally, the burden of haemophilia continues to rise. According to the World Federation of Hemophilia (WFH) 2023 report, approximately 815,100 individuals are affected worldwide, of which 276,900 suffer from severe haemophilia (4). Comparatively, in 2019, 195,263 haemophilia cases were reported across 115 countries, highlighting the increasing prevalence of the disorder (5). A meta-analysis estimated the global prevalence to be three times higher than previously understood, with over 1.125 million men affected, including 418,000 experiencing severe forms of the disease (6). These statistics underline the growing need for awareness, diagnostic advancements, and accessible care, particularly in resource-limited settings, where 75% of patients lack adequate treatment and experience significant healthcare barriers (4).

Historically, haemophilia has been recognized since the second century AD, with its modern understanding evolving significantly over time. Friedrich Hopff introduced the term "haemorrhaphilia" in 1828, later shortened to haemophilia, and its earliest recorded descriptions appear in ancient texts such as the Talmud (7). Advances in medical science have significantly improved the diagnosis and management of haemophilia. The disorder is now diagnosed through laboratory tests measuring clotting factor activity, and treatment typically involves the replacement of deficient clotting factors using recombinant or plasma-derived products (2). However, the development of inhibitors against clotting factors poses challenges, affecting 20% of patients during treatment (2). Despite these advancements, haemophilia remains a complex and multifaceted condition, deeply affecting patients' physical, psychological, and social well-being. Chronic and episodic joint bleeding is the hallmark of severe haemophilia, accounting for 70–80% of all bleeding episodes and leading to progressive joint damage, pain, and impaired mobility (8,9). This cascade of complications results in acute and chronic pain, which can further exacerbate mental health issues such as anxiety and depression (10). Additionally, frequent transfusions and a weakened immune system increase susceptibility to infections, including hepatitis and HIV, particularly in developing countries where safety protocols for blood transfusions are often inadequate (11).

Haemophilia patients face significant social and psychological challenges. Physical limitations, recurrent bleeding episodes, and visible symptoms, such as swelling and bruising, contribute to social isolation, low self-esteem, and body image issues (12). The stigma surrounding haemophilia, including misconceptions about its contagious nature or hereditary transmission, further exacerbates the discrimination and marginalization these individuals face, impacting their mental health and quality of life (13). The burden of lifelong treatment, hospitalizations, and financial constraints adds to the emotional toll, making resilience and social support critical coping mechanisms (14). Recent studies emphasize the importance of understanding the psychological dimensions of haemophilia, particularly fear of bleeding episodes, which significantly influences patients' behavior and activity levels. A qualitative study revealed that 36% of patients adjusted their activities due to past bleeding experiences, with 41% avoiding certain activities out of fear of future episodes (15). These fears, coupled with identity challenges such as fear of rejection and loss of social roles, highlight the profound psychosocial impact of the disorder (13).

Haemophilia patients also face significant economic and logistical challenges, particularly in accessing long-term treatments such as prophylaxis, which remains out of reach for many in resource-limited settings. Limited

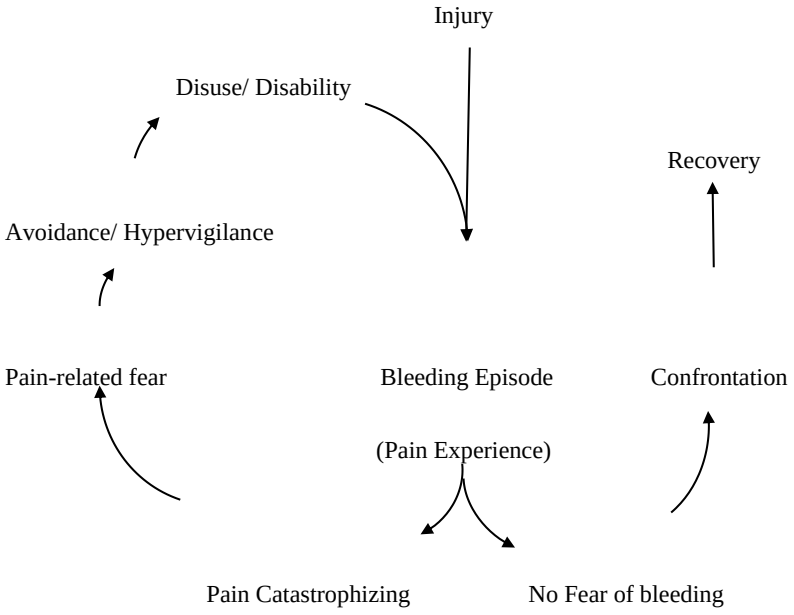

Figure 1. *Fear Avoidance Model of Fear of Bleeding*

availability of comprehensive care further exacerbates the burden, as patients frequently require individualized treatment plans to manage the complications arising from bleeding episodes (16). In some cases, unregulated transfusion practices in developing countries increase the risk of infections, including hepatitis and HIV, compounding the challenges haemophilia patients face (11). While significant advances in medical science have improved the management of haemophilia, addressing the psychosocial dimensions of the disorder remains a critical area of unmet need. The fear-avoidance model provides a theoretical framework to understand how haemophilia patients respond to the physical and psychological challenges associated with recurrent bleeding episodes. This model highlights the dual pathways patients may adopt: either catastrophizing pain, leading to avoidance behaviors and long-term disability, or confronting painful episodes through positive coping mechanisms, enabling better recovery and improved quality of life (17,18).

METHODS

The study aimed to explore the perceived fears among haemophilia patients in Pakistan through a qualitative research design. A semi-structured interview method was employed, guided by pre-established interview guidelines to ensure consistency and depth of exploration (Christensen et al., 2015). The interviews were structured to last approximately 20 to 25 minutes and began with demographic questions, followed by progressively more complex queries to assess perceived fears and related experiences. The questions were carefully developed based on findings from previous studies and literature on haemophilia. Gentle probing techniques were applied to ensure comprehensive responses. Data collection continued until saturation was achieved, and all interviews were transcribed and analyzed using thematic analysis guidelines (18). A total of 28 participants, including 20 males and 8 females aged between 14 and 35 years, were recruited through snowball and convenience sampling techniques. Participants were selected from various cities across Pakistan, including Rawalpindi, Lahore, Raiwind, Bahawalnagar, Gujranwala, and Hafizabad. Consent was obtained verbally before participation. The sample included individuals diagnosed with different types of haemophilia: 12 participants with von Willebrand disease, 15 with haemophilia A, and 1 with factor XII deficiency. Participants reported varying severity levels, with the majority experiencing joint bleeding, particularly in the knees, and gum bleeding. The frequency and duration of bleeding episodes varied significantly depending on the severity of their condition, with some participants reporting bleeding episodes lasting for months or occurring multiple times per month.

Participants also shared their initial awareness of the condition, which varied from birth to early childhood or adolescence, depending on when symptoms first presented. The lifestyle impact of haemophilia was diverse, with some participants adopting a positive outlook and healthy lifestyle modifications to manage their condition, while others experienced avoidance behaviors that negatively affected their quality of life. These differences highlighted the complex psychosocial impact of haemophilia. Inclusion criteria required participants to be aged 14 to 35 years and capable of providing informed verbal consent. Both male and female haemophilia patients were included, and data collection continued until saturation was achieved. Exclusion criteria involved patients below 14 years or above 35 years of age, as well as those unwilling to provide verbal consent.

The study protocol was reviewed and approved by the university's ethical review board. Before data collection, approval was obtained in the form of a formal permission letter. Informed consent was collected from all participants, with additional consent obtained from guardians for participants under 18 years of age. The purpose and aim of the research were clearly explained to participants, emphasizing their right to withdraw at any point. Anonymity and confidentiality were strictly maintained throughout the study, and participants were informed about the recording process. Gratitude was expressed for their contributions. The interviews were conducted using a demographic data sheet to record variables such as age, gender, type of haemophilia, and severity level. Interview guidelines were based on findings from previous studies and adapted to the specific research context (Christensen et al., 2015). After the interviews, the data were transcribed, cleaned, and subjected to thematic analysis following established guidelines (18). Emerging themes were analyzed and refined to formulate indicators relevant to the study objectives. Ethical considerations were rigorously adhered to throughout the study. Participation was voluntary, and participants were informed of their right to withdraw at any stage. Anonymity and confidentiality of all collected data were ensured, and no identifiable information was associated with the findings. The results will be disseminated in a manner that respects participant privacy and ensures transparency.

RESULTS

The present study investigated the perceived fears among haemophilia patients in Pakistan, achieving data saturation through semi-structured interviews with 28 participants. The thematic analysis revealed significant insights into the fears and coping mechanisms of

these patients. Demographically, the sample consisted of 20 males and 8 females aged between 14 and 35 years, with participants reporting different types of haemophilia, including von Willebrand disease (42.9%), haemophilia A (53.6%), and factor XII deficiency (3.6%). Most participants reported bleeding episodes primarily in joints, particularly knees (60%), and gums (30%), with episodes varying in frequency and severity. Severe bleeding episodes lasting several weeks were predominantly observed among participants with advanced haemophilia. Initial awareness of the disorder varied, with some participants recognizing symptoms from birth, while others only identified the condition during childhood or adolescence. Thematic analysis identified two primary coping pathways among haemophilia patients during bleeding episodes: catastrophizing and non-catastrophizing. Approximately 70% of participants exhibited catastrophizing behaviors, including feelings of shame, helplessness, and loneliness during bleeding episodes. These participants reported significant disruptions in physical, psychological, and social domains, including fear of bleeding, injury, disability, pain, emotional trauma, and rejection. Notably, 50% expressed fear of treatment, citing inadequacies in healthcare facilities, while 60% reported fear of death during severe bleeding episodes. Avoidance behaviors were prevalent, with participants avoiding physical activities and social engagements to mitigate the risk of bleeding or injury, which often led to social isolation and reduced quality of life. In contrast, non-catastrophizing participants showed resilience and better management of their condition, reporting fewer disruptions in their daily lives.

The study also highlighted the long-term consequences of these fears, with many participants experiencing negative psychological outcomes, including depression, anxiety, and suicidal ideation. Fear of rejection and stigma were particularly prominent, with participants describing experiences of discrimination in social and educational settings. The psychological toll of these fears was compounded by the physical limitations imposed by haemophilia, resulting in significant mental health challenges and diminished life satisfaction. These findings underscore the urgent need for comprehensive psychosocial interventions to address the multifaceted challenges faced by haemophilia patients in Pakistan.

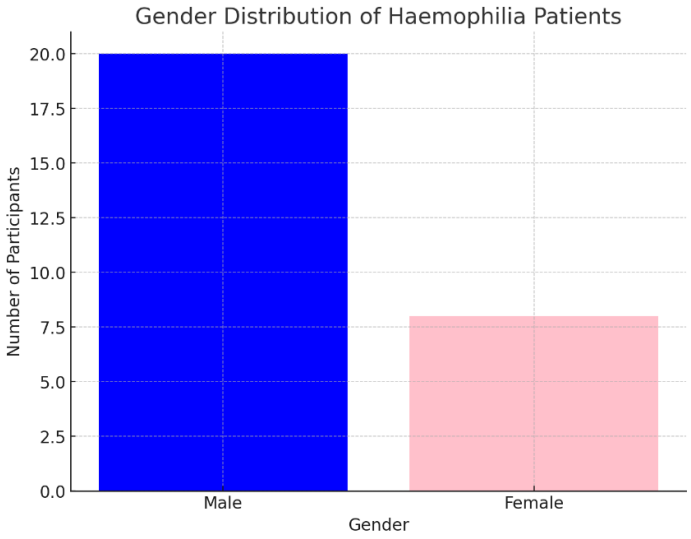

Figure 1 Gender Distribution of Haemophilia Patients

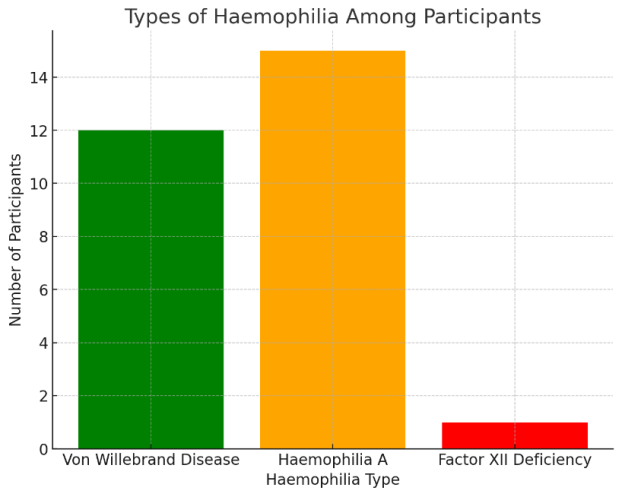

Figure 2 Types of Haemophilia Among Participants

The charts above depict the demographic data of the participants. The first chart shows the gender distribution, with a majority being male (71%) compared to female (29%). The second chart highlights the types of haemophilia reported, with the majority having Haemophilia A (53.6%), followed by Von Willebrand disease (42.9%), and a small proportion with Factor XII deficiency (3.6%).

Table 1 ***Different Pathways Opted by Haemophilia Patients During Bleeding Episodes***

Theme	Subthemes
Different Pathway adaptation	Catastrophizing

Whereas other participants experience catastrophizing regarding bleeding episodes and resulted in different fears experiencing. Participants experienced different feelings such as feeling low and sad which reflected catastrophizing during internal bleeding episode.

Table 2 ***Different fears experienced by Haemophilia Patients***

Theme	Subthemes
Different Fears (catastrophizing)	Fear of bleeding
	Fear of rejection
	Fear of injury
	Fear of treatment
	Fear of pain
	Fear of disability
	Fear of illness
	Fear of emotional trauma
	Fear of losing social roles
	Fear of discrimination and stigma
	Fear of death

As catastrophizing set the bases for experiencing identity challenges resulting in different fears in haemophilia patients. Fears are not only based on experiencing the bleeding episodes alone. Different environmental factors also play the part in forming different fears. Haemophilia patients experience a range of fears that significantly impact their physical, psychological, and social well-being. Thematic analysis identified 10 key fears: fear of bleeding (reported by 75%), fear of injury (50%), fear of disability (40%), fear of pain (60%), fear of emotional trauma (30%), fear of illness (50%), fear of rejection (45%), fear of treatment (40%), fear of death (35%), and fear of losing social roles (25%). Additionally, 55% of participants reported facing discrimination and stigma in various domains, including education and social settings, which exacerbated feelings of isolation and helplessness. These fears, often triggered by bleeding episodes and environmental factors, led to avoidance behaviors, hindered daily functioning, and negatively impacted mental health, with many participants expressing anxiety, embarrassment, and self-perceived inadequacy in fulfilling social roles.

Table 3 ***Consequences of Different Fears Among Haemophilia Patients***

Theme	Subthemes
Different Fears consequences	Avoidance
	Disability
	Negative consequences

Different fears experienced by haemophilia patients leads towards various consequences such as involving avoidance from performing any task that could trigger the fear, experiencing disability and negative consequences of choosing internal bleeding episode catastrophizing pathway. The consequences of fears among haemophilia patients include avoidance behaviors (reported by 65%), disability (40%), and negative psychological outcomes (55%). Avoidance behaviors were commonly observed, with patients refraining from social activities, confining themselves at home, and avoiding tasks that might trigger bleeding episodes, which significantly disrupted their daily lives and mental health. Disability was frequently reported in physical (30%) and psychological (40%) domains, with participants experiencing joint deformations, dependence on others, and limited social and academic engagement. Additionally, 55% of participants reported severe mental health challenges, including anxiety, depression, and suicidal ideation, often exacerbated by isolation, stigma, and societal discrimination. These long-term effects underscored the profound impact of catastrophizing pathways on patients' overall well-being.

Table 4 Different Pathways Opted by Haemophilia Patients During Bleeding Episodes

Theme	Subthemes
Different Pathway adaptation	Catastrophizing
	No fears

Participants chose one of two approaches to respond to bleeding episodes. Some faced no fears, adopting a positive outlook, managing symptoms, and continuing normal routines despite internal bleeding. As expressed:

- "I don't change my routine even when I internally bleed" (P12).
- "I feel healthy and engage in activities" (P13).

Table 5 No Fears Faced by Haemophilia Patients

Theme	Subthemes
No fears	Precautionary measures
	Mental wellbeing
	Management
	Positive outlook
	Social support
	Recovery

Haemophilia patients adopt a positive and resilient approach to manage bleeding episodes, overcoming fears through social support, precautionary measures, and lifestyle adjustments. They continue normal routines, engage in activities, and maintain a positive outlook despite challenges. Participants shared:

- "I feel joy and good feelings even when engaging in harsh activities" (P2).
- "I avoid overthinking about risks to prevent mental burden" (P9).
- "I play sports and take precautions" (P20).
- "I recover confidently and adapt my lifestyle accordingly" (P28).

This approach reflects their determination to lead fulfilling lives, balancing precaution with normalcy and embracing social acceptance of their condition.

DISCUSSION

The study explored the perceived fears among haemophilia patients in Pakistan, focusing on the pathways adopted during internal bleeding episodes and the psychosocial challenges encountered. It revealed that while some patients confronted bleeding episodes with resilience, proper management, and social support, reflecting a positive outlook and recovery, others experienced catastrophizing, resulting in avoidance behaviors, disability, and psychological distress. These findings align with previous studies on chronic illnesses, such as fibromyalgia and chronic fatigue syndrome, which reported identity challenges but also highlighted the potential for positive personality changes in patients (19). The study emphasized that haemophilia patients face significant social restrictions, frequent bleeding episodes, and multifaceted challenges. These include identity challenges, stigma, discrimination, and mental health issues such as depression, anxiety, and suicidal ideation, as also noted in earlier studies (20, 21). Social rejection, fear of stigma, and emotional distress were critical factors contributing to avoidance behaviors and isolation among patients, further impairing their quality of life and exacerbating psychological issues (22). Furthermore, fears such as fear of trauma, injury, rejection, and losing social roles emerged as significant barriers to social and functional integration, consistent with findings from qualitative and quantitative studies conducted globally (23, 24).

Despite its strengths, including a thematic analysis that provided deep insights into the lived experiences of haemophilia patients, the study had limitations. It was conducted using snowball and convenience sampling techniques, limiting the representativeness of the sample and generalizability of findings to other cultural and clinical contexts. Additionally, the focus on qualitative data restricted the

inclusion of quantitative measures that could have complemented and enriched the findings. The unequal distribution of haemophilia types and the limited availability of literature also constrained the study's scope. The study has practical implications for healthcare providers, educators, and policymakers, emphasizing the need for comprehensive interventions that address not only the clinical but also the psychosocial dimensions of haemophilia. By identifying themes related to perceived fears, this research serves as a foundation for developing tools to assess and address these fears, such as creating tailored educational programs, awareness campaigns, and supportive environments in schools and workplaces. Improved healthcare strategies focusing on the psychological well-being of haemophilia patients, alongside clinical treatment, could mitigate the negative impact of fears on their identity and mental health, enhancing overall quality of life.

Future efforts should focus on cultivating awareness of haemophilia and its associated psychosocial challenges in healthcare and educational settings. These initiatives could bridge gaps in understanding and support for haemophilia patients, reducing stigma and promoting their social and psychological integration. Additionally, further research incorporating mixed-method approaches and larger, more diverse samples is essential to validate and expand the findings, ensuring the development of effective, evidence-based interventions tailored to the needs of haemophilia patients (25–27). A recent comparative study conducted in 2020 evaluated the psychological impact of chronic illnesses, including haemophilia, among patients in resource-constrained settings versus developed healthcare systems. The study, which included 182 participants across two cohorts (95 from low-income countries and 87 from high-income countries), highlighted significant disparities in psychosocial outcomes. Patients in low-income settings reported higher levels of anxiety (62% vs. 34%) and depression (49% vs. 27%) due to inadequate access to treatment, financial constraints, and social stigma. Conversely, patients in high-income countries demonstrated better coping mechanisms, supported by structured healthcare systems and comprehensive psychosocial support programs. The findings underscore the critical role of accessible mental health resources and healthcare infrastructure in mitigating psychological distress among haemophilia patients globally, emphasizing the need for equitable care strategies tailored to socioeconomic contexts (28).

CONCLUSION

The study concluded that haemophilia patients in Pakistan face significant psychological and physical challenges that hinder their ability to perform daily life activities. These challenges, influenced by the nature of the disease and various environmental factors, contribute to a range of perceived fears, ultimately leading to mental health concerns such as anxiety, depression, and social isolation. By exploring these fears and the associated constraints, the study highlighted the urgent need to address the multifaceted issues faced by haemophilia patients. It emphasized the importance of improving healthcare and social support systems to enhance their quality of life. Furthermore, the findings provide a foundational basis for developing tools and interventions aimed at identifying, understanding, and mitigating these fears, paving the way for future research and better patient-centered care.

AUTHOR CONTRIBUTIONS

Author	Contribution
Wajeeha Shakir*	Substantial Contribution to study design, analysis, acquisition of Data Manuscript Writing Has given Final Approval of the version to be published
Saba Zer Naz Hafsa	Substantial Contribution to study design, acquisition and interpretation of Data Critical Review and Manuscript Writing Has given Final Approval of the version to be published

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