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Living with Hemophilia: Exploring the Mental and Emotional Health of Patients

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Abstract

India has the highest number of diagnosed hemophilia patients globally, yet many cases remain undiagnosed due to inadequate medical infrastructure and economic challenges. Compounding this issue is a lack of awareness among the general population and healthcare professionals, leading to suboptimal care and a diminished quality of life for those with hemophilia. Despite receiving recognition in the RPWD act, it remains fairly unknown. This study investigates the psychological and emotional health of hemophilia patients in India through a mixed-methods approach, utilizing the WHO Quality of Life (WHO-QOL100) questionnaire and semi-structured interviews on 30 patients to provide a comprehensive understanding of their lived experiences as despite several studies being done prior on this topic but none which shed light on the diverse Indian context.

Quantitative findings reveal that participants report poor physical health (mean score: 33.54, SD: 4.18) and moderate psychological well-being (mean score: 49.58, SD: 9.42), with significant struggles in independence (mean score: 39.16, SD: 6.13) and social relationships (mean score: 18.75, SD: 7.15). Financial difficulties are further highlighted in the Environment domain (mean score: 42.08, SD: 16.16). Qualitative insights enrich these findings, with pain emerging as a dominant theme, alongside high frequencies of anxiety, stigma and the critical need for effective communication between patients and healthcare providers. the overall quality of life is profoundly affected by their condition. Through these results and overall, this study sheds light on the emotional and mental health challenges faced by hemophilia patients in Delhi, India, and advocates for a comprehensive, integrative approach to their care, combining medical, psychological, and social support to enhance their quality of life.

Keywords: *Quality of Life, Mental and Emotional Health, Hemophilia, India*

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Introduction

Hemophilia is a genetic bleeding disorder characterized by improper blood clotting, leading to both spontaneous and post-injury bleeding. It mainly presents as Haemophilia A and B, caused by low levels of clotting factors VIII and IX, respectively, though rarer types exist, such as Factor VII deficiency. The severity of hemophilia is determined by the factor levels in the blood; patients with less than 1% of the clotting factor are at higher risk for severe health consequences. This disorder can result in joint bleeding, chronic joint disease, head and brain bleeding, seizures, paralysis, and, if uncontrolled, even death.

Hemophilia stems from genetic mutations on the X chromosome, affecting mostly males (who have only one X chromosome). Females, who have two X chromosomes, are typically carriers and less often exhibit symptoms. As an "invisible disorder," hemophilia does not outwardly show symptoms unless there is active bleeding, making it difficult for patients to convey their pain and limitations to others. This invisibility contributes to significant emotional and mental health challenges, such as feelings of helplessness, isolation, and abandonment.

The chronic nature of hemophilia requires lifelong medical care, impacting not only the patients but also their families. Many patients feel like a burden to caregivers, face social and academic setbacks due to frequent absences, and struggle with the perception of being misunderstood or dismissed by healthcare professionals. For those with chronic conditions, the psychological impact often becomes a more significant challenge than the physical symptoms, as they cope with ongoing health anxiety, social isolation, and the difficulty of managing an invisible illness that few around them fully understand.

Relevance of the Study and Literature:

India has the highest population of diagnosed hemophilia patients, but there has been very little to study about the various issues that surround such invisible disorders. It is not just about studying one specific disorder but rather opening a gateway to explore how these patients go through so much trouble due to a lack of understanding among people. The individuals suffering

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from such disorders suffer from a multitude of other factors like psychological distress, social stigma, and other glaring issues that impact daily functioning and the quality of life they lead.

The literature on hemophilia highlights a profound impact on quality of life for both individuals with the condition and their families, encompassing physical, psychological, and social domains. Studies on children and adults with hemophilia, such as those by Zourikian et al. (2016) and Gringeri et al. (2015), show increased emotional distress, anxiety, and lower quality of life compared to healthy peers, with calls for mental health support in routine care. Caregivers, as noted by Thornburg et al. (2019), face significant stress and mental health strain, and women with bleeding disorders also experience overlooked anxiety and depression (Soucie et al., 2014). Research into coping strategies (e.g., Côté et al., 2015) indicates that social support and reframing are vital, while stress, identified as a major challenge (Kadir et al., 2018), often exacerbates health risks and decreases treatment adherence. Additionally, Indian studies (Singh et al., 2013; Das et al., 2020) reveal lower quality of life scores for hemophilia patients, with impairments in physical, psychological, and environmental health domains. Overall, the literature suggests that targeted psychosocial interventions and increased access to support systems are essential for improving quality of life among individuals with hemophilia and their families.

Methodology

Research Design:

A mixed research design was employed in this study. This study aims to find out about the quality of life of individuals suffering from Hemophilia. For this, initially Quality of Life questionnaire (QOL-100) (WHO, 1995) was used to understand how people fared on the various domains of quality of life (quantitative method). Next, a semi-structured interview was conducted to understand the challenges faced by individuals on a deeper level as well as gain insight. (qualitative method).

Participants:

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To understand the challenges, the hemophiliacs face as well as get a understanding of the quality of life of patients with hemophilia, 30 people were taken from hemophilia care facilities, namely AIIMS, Delhi and LNJP Hospital, Delhi between the ages of 18-30 years. The sample consists of only males as at least in India, majority of the patients diagnosed are males.

Tools Used

The present study used the Quality-of-Life Questionnaire (QOL-100; WHO,1995) developed by the World Health Organization to measure the participants on 4 major domains, and its 24 subdomains, the main goal being understanding the quality-of-life hemophilia patients lead. It consists of 100 items assessing domains such as psychological health, activities of daily living, pain and discomfort, self-esteem, social support, etc., and was created to gain a holistic understanding of the quality of life of individuals. On a 5-point Likert scale, participants assess their agreement with the statements (1 being strongly disagree, and 5 being strongly agreeing). A total score was calculated from the 100 items and may vary from 0 to 100.

Results

The study assessed the quality of life of individuals with hemophilia using the WHOQOL-100 questionnaire and semi-structured interviews. Results, depicted in Figure 1, show mean scores across six primary domains: Physical Health, Psychological Health, Level of Independence, Social Relationships, Environment, and Spirituality. Quantitative analysis through mean scores and standard deviations revealed varied experiences across these domains, reflecting both strengths and challenges.

Key Findings by Domain

Physical Health: The mean score was 33.54 (SD = 4.18), with notable subdomain scores reflecting moderate energy and fatigue (M = 5.1, out of 10), high pain and discomfort (M = 8.03), and moderate sleep/rest (M = 4.23). These findings suggest that pain is a primary challenge, impacting daily functioning and overall well-being, consistent with studies indicating pain, fatigue,

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and sleep disturbances as major issues in hemophilia populations (Kannan et al., 2017; Khair et al., 2018).

Psychological Health*:* Scoring the highest among the domains, the mean score was 49.58 (SD = 9.42). Subdomain scores included moderate body image concerns (M = 4.76) and negative feelings (M = 5.93), suggesting participants experienced some anxiety, fear, and sadness related to hemophilia. Positive feelings (M = 5.43) and self-esteem (M = 5.73) scores were moderate, indicating resilience despite challenges. Spirituality scored 5.76, highlighting its potential role in coping.

Level of Independence: The mean score was 39.17 (SD = 6.13). Participants reported challenges with Activities of Daily Living (M = 5.7), dependence on medical aids (M = 7.73), and mobility (M = 5), aligning with literature on joint pain and mobility limitations. Work Capacity, with a mean of 4.43, reflects employment and activity restrictions, consistent with findings on decreased work productivity in hemophilia (Amalokwu et al., 2017).

Social Relationships: The lowest scoring domain, with a mean score of 18.75 (SD = 7.15), emphasized difficulties in maintaining personal relationships (M = 5.83) and moderate social support (M = 4.6), suggesting isolation and limited engagement in social activities. Sexual Activity scored 4.56, mirroring research on limitations due to pain and concerns about bleeding during sexual activity.

Environmental: Participants reported low satisfaction with financial resources (M = 3.73) and participation opportunities (M = 3.93), impacting overall satisfaction with life. However, they reported moderate satisfaction with health and social care (M = 5.83) and a high satisfaction level for their physical environment (M = 6.83). Transport satisfaction (M = 4.6) was moderate, pointing to accessibility challenges that may limit independence and social interaction.

Spirituality: Participants scored moderately on meaning and purpose in life (M = 5.06) and personal beliefs (M = 5.13), indicating a generally positive outlook. Religious satisfaction (M = 5.3) suggested that spirituality may offer a source of strength and resilience in coping with chronic illness.

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Qualitative Insights

Semi-structured interviews of 10 participants provided in-depth qualitative data analyzed through content analysis. Responses were organized into five categories: Emotional Well-being, Social Support, Quality of Life, Coping Strategies, and Healthcare Experiences (Table 3). Emotional well-being was influenced by health challenges, highlighting feelings of isolation and anxiety. Social Support responses echoed the quantitative findings, indicating moderate support networks but limited assistance for day-to-day activities.

Quality of life, as reported in interviews, reflected the quantitative scores, with themes of physical pain, limited mobility, and reliance on medical aids. Coping strategies included spiritual beliefs and self-care techniques, while healthcare experiences pointed to the need for improved accessibility and consistency in treatment.

The combined quantitative and qualitative findings reveal a complex picture of life with hemophilia, marked by significant physical, psychological, and social challenges. The Physical and Psychological Health domains show moderate satisfaction levels, indicating resilience and adaptation. However, Social Relationships and Environmental domains scored lower, emphasizing the impact of financial strain, limited social support, and mobility challenges. Spirituality plays a vital role, offering emotional support for some individuals. This study underscores the importance of holistic support systems, integrating medical, social, and emotional support to enhance the quality of life for people with hemophilia.

Discussion

The study integrates quantitative scores from the WHOQOL-100 and qualitative themes from interviews, providing a comprehensive view of the multifaceted challenges faced by individuals with hemophilia in Delhi, India. Low mean scores in domains such as Physical Health (33.54) and Social Relationships (18.75) underscore the profound physical limitations and social isolation that significantly impact quality of life. These scores reflect common issues such as

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dependency on medical aids and difficulty maintaining social connections, often compounded by the persistent pain and fatigue that characterize the condition.

Moderate scores in the Psychological Health (49.58) and Environment (42.08) domains suggest that, while individuals with hemophilia demonstrate resilience, mental health challenges and financial burdens remain prominent. The Environment score, especially low in the subdomain of financial resources, highlights the economic strain often experienced due to the high cost of medical treatments and limited employment opportunities.

Qualitative insights enhance the understanding of these challenges, with 100% of participants reporting pain as a significant and continuous issue, and high frequencies of anxiety (70%) and stigma (80%) further contextualizing the emotional and social toll. Positive coping mechanisms such as resilience (60%) and communication with healthcare providers (80%) were notable, yet these strategies often proved inadequate against the chronic challenges of hemophilia. The discussion, therefore, highlights the urgent need for enhanced healthcare access, increased social support, and comprehensive interventions to address both the physical and psychosocial dimensions of living with hemophilia in this population.

Conclusion

This study highlights the significant emotional and mental health burden experienced by individuals with hemophilia in Delhi, India. Despite social support, anxiety and fear of bleeding episodes negatively impacted their quality of life.

To address these challenges, healthcare providers should integrate psychological assessments into routine care, while patient support groups can offer valuable peer support. Policymakers must prioritize affordable and comprehensive healthcare access for this vulnerable population.

Future research should employ larger sample sizes and longitudinal designs to delve deeper into the long-term mental health implications of hemophilia. A holistic approach, encompassing

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psychological, social, and medical support, is crucial for improving the overall well-being of individuals with hemophilia.

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Appendix A

Table 1 Sociodemographic details of participants

Variables	n
Age	
18-24	20
25-30	10
Education	
High School degree	12
Undergraduate	15
Drop outs	3
Type of hemophilia	
A	24
B	6
Severity of hemophilia	
Mild	8
Moderate	18
Severe	4
Socio-economic status	
Low	11
Medium	16
High	3

Note: n= number of participants

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Table 2 Mean and Standard Deviation of participant responses on seven domains

Domain	Mean	Standard Deviation
Physical Health Domain	33.54	4.18
Psychological Health Domain	49.58	9.42
Level of Independence domain	39.17	6.13
Social Relationships Domain	18.75	7.15
Environment Domain	42.08	16.16
Spirituality/Religion/Personal Beliefs Domain	21.88	8.80
Overall Quality of Life Domain	31.25	6.57

Table 3 Results of content analysis of interviews conducted on 10 participants

Emotional well-being	depression stress pain anxiousness	"I feel depressed because I can't do the things I used to enjoy" “I cannot go out and play freely like everyone else” “Most of my days are spent in pain” “I often feel anxious if my bleeds will limit me during crucial times and derail my life”

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Social support	emotional support practical support family friends healthcare providers stigmatization denial of opportunities	"My family is very supportive and helps me manage my condition," "I don't have anyone to talk to about my hemophilia" "People do not understand much about hemophilia" "Even normal doctors and nurses do not understand the impact of hemophilia fully" "People think I am different" "I have been denied opportunities assuming I cannot perform"
Quality of life	daily activities work school leisure activities sports	"I have to miss school often because of bleeds," "I can't play sports because of my condition" "I can't do strenuous work" "I am judged due to my absence most of the times" "I am looked upon by my peers and mostly people are not empathetic"
Coping strategies	positivity resilience overwhelming conditions experiences	"I try to stay positive and focus on the things I can do" "I talk to my doctor when I feel overwhelmed" "I try to research and connect with other hemophiliacs and their experiences"
Healthcare	healthcare providers access to care	"It's difficult to find a doctor who understands

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experiences	quality of care communication with providers understanding of needs assistance handling of episodes	hemophilia," "My doctor is very helpful and answers all my questions" “It becomes difficult to explain my condition to different doctors, especially if I were to travel”

Table 4 Frequency distribution of content analysis

Codes	Frequency	Percentage
Pain	10/10	100%
Anxiety	7/10	70%
Support	9/10	90%
Positivity	7/10	70%
Resilience	6/10	60%
Communication	8/10	80%
Care	9/10	90%
Stigma	8/10	80%

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Appendix B

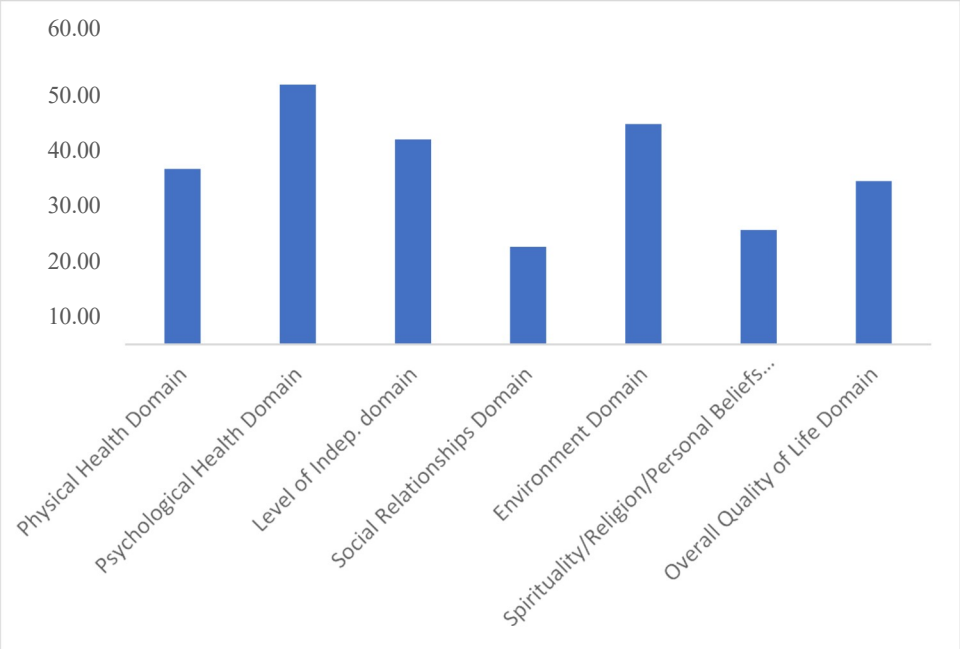

Figure 1: showing mean scores of the domains

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