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Chronic Illness and Mental Health: A Comprehensive Analysis of Hemophilia across the Lifespan

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Abstract
Hemophilia is a rare X-linked bleeding disorder associated with significant psychological, social, financial, and developmental challenges across the lifespan. This paper presents a narrative literature review that synthesises current evidence to examine the complex mental health burden experienced by people with hemophilia (PwH) within a biopsychosocial framework. A structured non-systematic search of databases, including PubMed, PsycINFO, and Google Scholar, was conducted using keywords related to hemophilia, mental health, chronic pain, trauma, quality of life, and psychosocial development. Peer-reviewed sources published primarily between 2000 and 2026 were included based on relevance to psychosocial outcomes, with priority given to empirical and clinical studies. Findings indicate that PwH experience higher rates of depression, anxiety, and health-related post-traumatic stress, driven by the interaction of chronic pain, fear of bleeding, intensive treatment demands, social isolation, stigma, and financial burden. The review highlights significant global disparities, with individuals in low- and middle-income countries facing greater barriers to treatment access and mental health care. Clinical implications highlight the importance of trauma-informed, multidisciplinary care models that include mental health professionals in hemophilia treatment teams. Evidence supports the use of cognitive-behavioural interventions and family systems approaches to address unhealthy coping styles and enhance psychosocial functioning. However, the prevalence of cross-sectional and qualitative studies limits the ability to determine causality, emphasising the need for longitudinal and intervention-focused research. This review advances clinical practice by promoting holistic, developmentally informed, and trauma-sensitive care by guiding counselling through the identification of key psychological patterns and evidence-based interventions.

Key terms: Biopsychosocial model, chronic illness, hemophilia, mental health, trauma-informed care.

INTRODUCTION

Hemophilia is an uncommon inherited hemorrhagic disorder associated with the X chromosome. It is characterised by impaired blood coagulation resulting from a deficiency or absence of clotting factors VIII (hemophilia A) or IX (hemophilia B). The disorder affects approximately 1 in every 5,000 to 10,000 male births globally and varies in severity from mild to severe. Affected individuals may encounter spontaneous bleeding episodes or experience prolonged bleeding following injuries or trauma. Such episodes can lead to complications involving the joints, muscles, and internal organs (Perolla & Kalaja, 2024).

Although significant advancements in treatment, especially the use of prophylactic therapy, have improved life expectancy and reduced the frequency of acute bleeding episodes, hemophilia remains a lifelong condition requiring ongoing medical management. Importantly, the burden of hemophilia extends beyond its physical effects. Individuals living with the condition often face a complex combination of psychological stress, social limitations, financial strain, and challenges related to identity and overall quality of life, highlighting that the impact of hemophilia is both physiological and psychosocial in nature (Perolla & Kalaja, 2024).

Over the last few years, mental health in this population has been increasingly studied; the findings from a meta-analysis demonstrated that PwH are at significantly higher risk of depression, anxiety, and attention deficit disorders than the general population (Raheja et al., 2024). This paper aims to critically reflect on these multi-dimensional mental health issues from a biopsychosocial perspective using developmental, trauma, and cognitive-behavioural approaches to clinical practice. This paper suggests that mental health issues are not a secondary concern to hemophilia treatment but a primary one, and that counsellors and clinicians need to be trained to respond to all aspects of psychological burden throughout the lifespan.

LITERATURE REVIEW

Medical and Physical Challenges

The physical consequences of hemophilia are significant and are linked to psychological stress. Repeated episodes of joint bleeding (recurrent hemarthrosis) lead to progressive joint damage and hemophilic arthropathy, a painful and disabling form of joint degeneration (Schmitt et al., 2026). Chronic pain related to arthropathy is one of the key factors associated with poor mental health in people with hemophilia (PwH). Steen Carlsson et al. (2022) demonstrated that there is a dose-response relationship between the severity of hemophilia and the prevalence of pain, with higher severity correlating with increased levels of depression and anxiety. Ucero-Lozano et al. (2022) also found that kinesiophobia (irrational fear of movement due to anticipated pain or injury) is closely associated with perceived pain levels in individuals with hemophilic arthropathy. This adds psychosocial burden, as fear-driven avoidance behaviours exacerbate suffering, compounding the physical challenges of the disease.

Treatment regimens increase physical stress. Managing the condition is complicated by the frequent use of clotting factor concentrates, the placement of ports in children, and the risk of developing inhibitors (anti-clotting factors) (Brod et al., 2023). The formation of inhibitors significantly hampers treatment success and is linked to higher anxiety, increased hospitalisation risk, and decreased quality of life. Moreover, PwH must constantly assess the risk of spontaneous bleeds during routine activities such as walking, cooking, and exercising, which can restrict daily life. This hypervigilance is tightly connected to a chronic stress response and may lead to somatic anxiety; in some cases, it can cause learned helplessness (Schmitt et al., 2026).

Psychological and Emotional Challenges

Hemophilia significantly impacts mental health, with depression and anxiety being the most common issues. Schmidt et al. (2025) conducted a cross-site observational study showing that arthropathy-related factors, such as pain and joint deterioration, are key predictors of depressive and anxious symptoms. Jimenez-Cebrian et al. (2022) also observed that patients with hemophilia tend to have a notably poorer psychological profile compared to healthy controls, emphasising the disease-specific nature of these mental health challenges. Similarly, Steen Carlsson et al. (2022) found that 28 per cent of adults with hemophilia in their multinational survey reported experiencing anxiety or depression, with higher rates

linked to increased disease severity. Nonetheless, Raheja et al. (2024) noted that many affected individuals had not received formal diagnoses, suggesting under-diagnosis.

A crucial yet often overlooked source of psychological trauma in the hemophilia community is the contaminated blood crisis from the 1970s to the early 1990s. During this era, clotting factor concentrates made from pooled human plasma were commonly used to treat individuals with hemophilia (PwH). Unfortunately, before effective viral inactivation and screening were in place, these products were contaminated with blood-borne pathogens, including HIV and hepatitis C (Institute of Medicine [IOM], 1995). Consequently, many people with hemophilia worldwide contracted serious infections through their medical treatments.

In the United States, it is estimated that about 50 per cent to 90 per cent of people with severe hemophilia contracted HIV during the early years of the epidemic, and most were also exposed to hepatitis C (IOM, 1995; Evatt, 2006). Similar trends emerged internationally due to the global reliance on pooled plasma products. In the UK, official reports show that tens of thousands of individuals contracted hepatitis C and several thousand contracted HIV, with over 3,000 deaths linked to contaminated blood products (UK Infected Blood Inquiry, 2023; Department of Health and Social Care, UK, 2022). These numbers highlight the severity of the crisis, marking it as one of the most serious iatrogenic public health disasters of the late twentieth century.

The contaminated blood crisis is both a significant historical medical event and a striking example of iatrogenic harm, where essential treatments caused widespread illness and death. In addition to physical health effects, it deeply affected mental well-being, leading to feelings of betrayal by the medical system, collective grief among patient groups, and lasting damage to trust in healthcare institutions (IOM, 1995; Evatt, 2006).

This crisis has been widely recognised as a form of iatrogenic harm caused unintentionally by medical treatment, resulting in long-term physical and psychosocial consequences (IOM, 1995; McHenry & Khoshnood, 2014). Many affected individuals experienced profound betrayal by the medical system, as treatments intended to prolong life instead caused life-threatening illnesses, leading to enduring distrust in healthcare institutions (IOM, 1995). In addition to the physiological burden of dual diagnoses, people with HIV (PwH) and their families often faced widespread bereavement within tightly connected patient communities, along with stigma associated with HIV and hepatitis C infections (Obeagu & Ngomo, 2024). These experiences contribute to increased risks of psychological distress, including symptoms consistent with post-traumatic stress, as well as social and identity disruptions.

Importantly, this historical trauma continues to influence how individuals with hemophilia interact with healthcare systems today. While recent studies, such as Ramos-Petersen et al. (2023), highlight ongoing concerns about well-being and quality of life, the legacy of the contaminated blood crisis remains a crucial context for understanding these findings. Therefore, the experiences of PwH should be viewed through a trauma-informed lens, acknowledging both the historical reality of iatrogenic harm and its persistent psychological and social effects across generations.

These cognitive-behavioural models offer insights into how a distorted threat assessment, catastrophising, and avoidance behaviours contribute to the development of chronic pain and unpredictable bleeding. Other aspects related to children's and adolescents' anxiety responses that align with attachment theory include repeated medical procedures, parental worry, and disrupted normal development. A cycle of emotional regulation difficulties has been well documented. It involves feedback between parents and children, in which children's emotional regulation worsens due to parents' emotional regulation, thereby negatively affecting the family's emotional climate. Paley and Hajal (2022) mention that when caregivers are highly dysregulated, whether because of the child's distress or other stressors, they are less likely to use parenting skills that could help the child manage negative emotions, and this may be a two-way process. An extremely dysregulated child can destabilise caregivers and impact the entire family system.

Social and Relational Challenges

High interpersonal costs are associated with hemophilia. Physical barriers to participating in group activities and the emotional toll of managing a stigmatised, invisible illness create social isolation. In a 2023 Italian survey of over 2,700 participants, 51 per cent of PwH reported hiding their symptoms at least once a week, and 68 per cent worried about being treated differently by friends if they disclosed their condition (Fornari et al., 2024). This concealment reflects the disclosure dilemma faced by those living with hemophilia. Stigmatisation also emerged as a key theme in qualitative interviews with PwH by Ramos-Petersen et al. (2023), who found that hiding from peers was driven by fear of judgment and shifts in social dynamics.

Parental and caregiver overprotection, though understandable, can be very harmful to the autonomy and development of children with hemophilia from a family systems perspective. Königs et al. (2024) note that adolescents with hemophilia may be torn between feeling a sense of belonging with peers and the need to follow their treatment, leading them to neglect it as a way to assert their identity intentionally. The social psychology of difference also adds complexity: being labelled as fragile or exceptional within a peer group has developmental significance, affecting adult relationship formation and professional identity.

Practical and Financial Stressors

Hemophilia is among the most costly chronic conditions to manage, particularly in high-income countries where advanced therapies are available. In the United States, annual healthcare costs for individuals with hemophilia B can exceed $200,000 per patient—more than 25 times the cost for demographically matched controls (Buckner et al., 2021). These figures underscore the substantial economic burden associated with the condition, including expenses related to clotting factor replacement, ongoing monitoring, and complication management. However, while such data provide strong quantitative evidence of financial strain, most cost analyses are derived from insurance-based or healthcare utilisation datasets in high-income settings, limiting their generalizability to lower-resource environments where costs may manifest differently (e.g., through lack of access rather than high expenditure).

For individuals and families, this financial burden is experienced not only as a healthcare cost but as a persistent stressor that intersects with daily functioning. Prior authorisation requirements, insurance coverage gaps, and income loss from missed work or complex treatment regimens contribute to chronic financial instability. Emerging research suggests that this economic strain has important psychological implications, including increased anxiety, emotional exhaustion, and potential disruptions in treatment adherence. However, much of this evidence is drawn from cross-sectional studies, which can identify associations but cannot establish causal pathways between financial stress and mental health outcomes. As such, while the relationship is well-supported descriptively, it remains an area requiring longitudinal investigation.

Functional challenges further compound this burden. This is because work and school accommodations often require individuals with hemophilia to make complex decisions about disclosure, weighing the risk of stigma or discrimination against the need for support. Daily activities, such as travel, may also be restricted due to the need to transport temperature-sensitive medications and maintain access to specialised care. Although these challenges are widely acknowledged, most current evidence is qualitative, offering detailed insights into lived experiences but with limited generalizability.

These challenges become even more severe in low- and middle-income countries (LMICs), where structural inequalities shape the experience of hemophilia in fundamentally different ways. In these settings, limited healthcare infrastructure, inconsistent access to clotting factor therapies, and a shortage of specialised treatment centres create barriers beyond individual coping abilities. Perolla and Kalaja (2024) highlight that people in resource-limited environments often face interrupted treatment access and very limited mental health services. While this work offers an important global perspective, it is crucial to recognise that most research on LMIC populations remains limited and often descriptive, underscoring

the need for more thorough and methodologically sound studies.

Systemic barriers frequently exacerbate the psychological burden in these situations. Restricted access to mental health services, combined with cultural stigma and underfunded systems, results in untreated conditions such as anxiety, depression, and chronic stress. Additionally, financial stress is heightened, particularly in systems where healthcare expenses are paid out of pocket, and employment opportunities are limited. These factors tend to perpetuate a cycle in which poor access to care leads to deteriorating health outcomes, thereby restricting social and economic participation. Although this cyclical model is logical in theory, there is limited empirical evidence examining these interactions over time.

Overall, these findings highlight both the significance and the boundaries of existing evidence. While there is strong descriptive evidence of the financial and structural challenges associated with hemophilia, as well as their impact on psychosocial development, the reliance on mostly cross-sectional and qualitative studies limits causal inference and reduces the generalizability of the results. Additionally, the overrepresentation of research from high-income countries creates notable gaps in understanding the worldwide experience of hemophilia.

Recognising these limitations is crucial for progress in both research and practice. To better understand how financial and structural factors affect psychological outcomes, a stronger evidence base is necessary. This should include more longitudinal studies, intervention trials, and greater input from LMIC settings. Simultaneously, existing evidence underscores the importance of system-level strategies, including expanding access to treatment, integrating mental health services, and implementing policies to reduce structural inequities. Viewing hemophilia through this inclusive, equity-focused perspective provides a deeper insight into its effects and helps create care models that are both effective and globally applicable.

Identity and Developmental Considerations

Erikson's psychosocial theory is a robust developmental model for understanding identity issues across the life course for PwH. The industry versus inferiority stage is relevant in childhood. Low levels of participation in physical play and physical activity, compared to typical developmental tasks, are associated with lower self-perception in children with hemophilia, including lower overall self-worth and social acceptance (Chiu et al., 2021). Notably, Chiu et al. (2021) demonstrated that, for boys with hemophilia who received unrestricted access to comprehensive, lifelong prophylactic care, few restrictions on participation were observed. The boys' self-perception was found to be similar to that of healthy peers, suggesting that effective disease management and adequate social support protect against this developmental risk. Königs et al. (2024) highlight the role of treatment non-adherence and risk-taking behaviour that often occur as adolescents strive to fit in with peers who are not hemophilia patients, leading adolescents to reject a medical identity imposed on them by others.

For adults with hemophilia, career challenges, dating, and family planning are unique concerns. Hakimi et al. (2024) developed a conceptual model that captured the burden of hemophilia A from a humanistic perspective across ages, noting that each age group had unique emotional burdens associated with the disease's changing nature. Chronic pain and the progressive physical limitations that can occur can impact body image and self-concept in ways that continue as a person grows older, and as hemophilic arthropathy and other comorbid conditions of older age add to the psychological vulnerability.

Table 1 below provides an overview of the five interrelated domains examined in this review, summarising representative stressors, associated mental health outcomes, and key supporting sources for each.

Table 1. Biopsychosocial Domains of Hemophilia and Associated Mental Health Outcomes

Domain	Key Stressors	Mental Health Impact	Key Sources
Medical and Physical	Recurrent hemarthrosis, joint damage, intensive infusion regimens, inhibitor risk, fear of spontaneous bleeding	Chronic stress response, somatic anxiety, learned helplessness, kinesiophobia	Schmitt et al. (2026); Steen Carlsson et al. (2022); Ucero-Lozano et al. (2022)
Psychological and Emotional	Chronic pain, repeated medical procedures, contaminated blood crisis trauma	Depression, anxiety, health related PTSD, and emotional dysregulation	Schmidt et al. (2025); Jiménez-Cebrián et al. (2022); Ramos-Petersen et al. (2023)
Social and Relational	Symptom concealment, stigma, caregiver overprotection	Social isolation, identity conflict, reduced autonomy	Fornari et al. (2024); Königs et al. (2024)
Practical and Financial	High treatment costs, insurance barriers, and work or school accommodations	Anxiety, burnout, and reduced treatment adherence	Buckner et al. (2021); Perolla and Kalaja (2024)
Identity and Developmental	Restricted physical participation, adolescent nonadherence, body image changes	Lower self-worth, identity disruption, risk-taking behavior	Chiu et al. (2021); Hakimi et al. (2024)

Integrated Analysis

A comprehensive understanding of hemophilia requires an integrated framework that considers the interaction of biological, psychological, and social factors. The biopsychosocial model, first introduced by Engel (1977), emphasises that health and illness cannot be understood solely through biological processes; they must also be understood through cognitive, emotional, and social influences. Instead of viewing psychological distress as a direct result of physical pathology, this model highlights how individual perceptions, social environments, and life experiences influence the overall illness experience.

Within this framework, the physical realities of hemophilia, such as joint damage, chronic pain, and ongoing treatment, interact with psychological processes, including cognitive appraisal, coping strategies, and emotional responses. These factors are further influenced by social context, including family support, cultural attitudes, and access to healthcare resources. Together, they create a complex and dynamic picture of well-being that cannot be reduced to any single domain, as Engel (1977) proposed. Effective understanding and care require attention to the whole person, not merely the disease.

Empirical research supports this integrated perspective. For example, Schmitt et al. (2026) demonstrate that the severity of hemophilia is linked not only to physical outcomes but also to mental health and quality-of-life measures, indicating that biological factors have cascading psychological and social effects. Similarly, Steen Carlsson et al. (2022) highlight that untreated or poorly managed pain is both a physical and psychological burden, often contributing to broader challenges in social participation, employment, and interpersonal functioning. Pain, in this sense, becomes not only a symptom but a multi-dimensional experience with far-reaching consequences.

Overall, these findings highlight the importance of the biopsychosocial model as a framework for understanding hemophilia. By acknowledging the interconnected physical, psychological, and social factors, this approach offers a more comprehensive

and clinically relevant understanding of the condition, thereby better guiding holistic, patient-centred care. The interrelationships between these domains are two-way and reinforcing. Depression makes it harder to take the medications, and the less people take them, the more likely they are to bleed more, which makes the joints more damaged and painful, and the more painful the joints, the more depressed people will feel. Kinesiophobia increases anxiety about getting hurt, which decreases physical activity, which leads to a faster deterioration of the joints. Social isolation reduces access to peer support; limited support increases psychological distress, and increased distress decreases access to health care systems. Understanding these feedback loops is critical for clinical intervention, as intervening in a single domain alone is not enough to break the cycle.

Table 2 brings together several quantitative findings discussed throughout this review, and Figure 1 illustrates a subset of these findings expressed as percentages.

Table 2. Selected Quantitative Findings from Reviewed Studies

Finding	Sample or Context	Source
Annual U.S. healthcare costs exceed $200,000 per patient, more than 25 times those of matched controls.	Adults with hemophilia B (United States)	Buckner et al. (2021)
51% reported hiding symptoms at least weekly; 68% worried about being treated differently if disclosed	International survey of more than 2,700 participants	Fornari et al. (2024)
28% reported experiencing anxiety or depression, with higher rates at greater disease severity	Adults with hemophilia in Sweden, Finland, and Denmark (MIND study)	Steen Carlsson et al. (2022)
Moderate and severe depression categories appeared only in the hemophilia group, but not in healthy controls.	Adults with hemophilia compared with matched controls (Spain)	Jiménez-Cebrián et al. (2022)

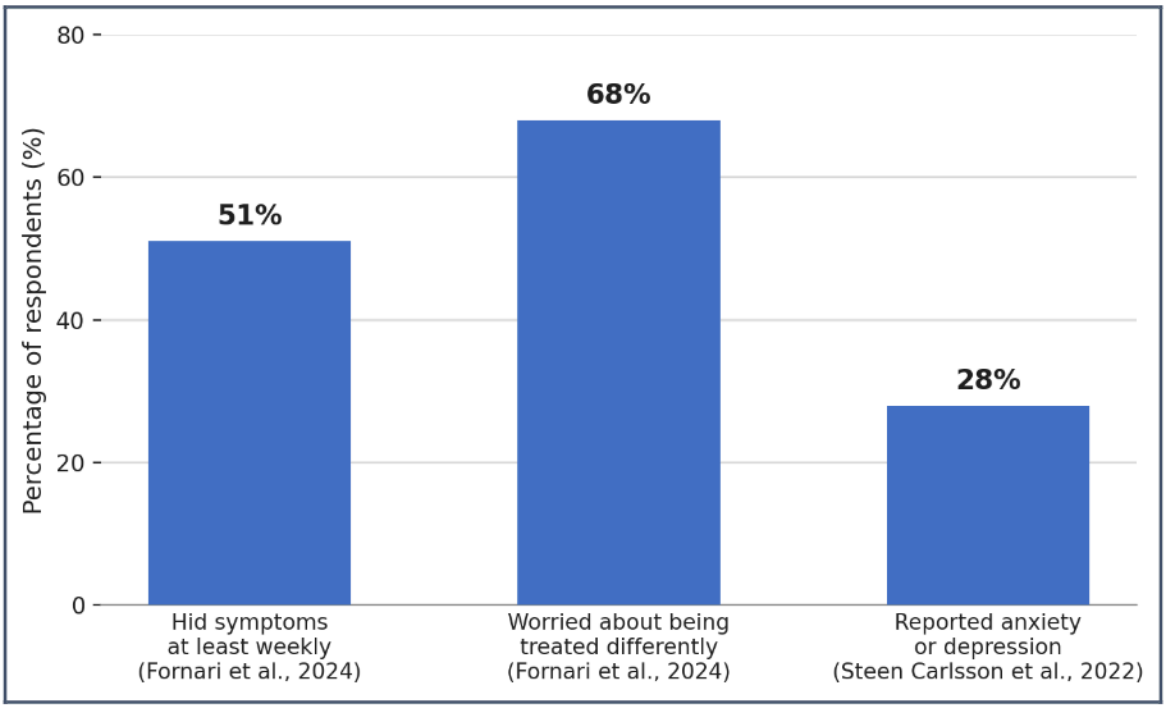


Figure 1. Selected Percentage-Based Findings from Reviewed Studies

Clinical Implications

This analysis emphasises the significant clinical implications, stressing the importance of trauma-informed care as a key aspect of services for people with hemophilia (PwH). It is particularly vital for those affected by the contaminated blood crisis, where medical treatment posed risks of harm. Therefore, trauma-informed approaches should be deliberately integrated into clinical practice to create safe, trustworthy, and respectful care environments.

Berring et al. (2024), in their scoping review on trauma-informed care, highlight a biopsychosocial framework that emphasises safety, patient choice, empowerment, and healing relationships, especially in situations involving medical trauma. For PwH, this means adopting clinical practices that actively prevent retraumatisation, recognise institutional betrayal and iatrogenic harm as valid sources of trauma, and build therapeutic relationships based on trust and transparency. Counsellors and healthcare providers must remain aware of the historical and relational aspects of trauma, acknowledging that interaction with medical systems may itself cause distress in this group.

At the same time, it is crucial to evaluate the nature and strength of the evidence supporting these clinical recommendations. The current literature on hemophilia and psychosocial outcomes includes a range of study designs, including cross-sectional surveys, qualitative studies, case-control studies, scoping reviews, and psychometric validation research. While this variety offers valuable insights, it also presents significant limitations. Notably, much of the research is cross-sectional, limiting the ability to determine causal relationships among physical illness, psychological distress, and social outcomes. Findings from qualitative studies, although rich and contextually meaningful, may not apply to broader populations. Similarly, post-hoc analyses and scoping reviews provide important syntheses but depend on the quality and scope of the existing studies.

Therefore, although there is consistent evidence supporting the importance of trauma-informed and biopsychosocial approaches, the field would benefit from more long-term and intervention-focused research to better establish causality and strengthen evidence-based practice. Recognising these methodological limitations does not diminish the value of current findings; rather, it situates them appropriately within the broader landscape of evidence.

Considering the clinical requirements of people with HIV (PwH) and the current body of evidence, a trauma-informed, biopsychosocial approach remains indispensable. Nevertheless, clinicians and researchers are obligated to continue critically appraising and advancing the existing literature to ensure that care practices are not only compassionate and comprehensive but also grounded in progressively more rigorous evidence.

Cognitive-behavioural therapy (CBT) is a proven, evidence-based method for addressing psychological issues like catastrophising, avoidance, anxiety, and depression common among people with hemophilia (PwH). Unlike purely descriptive or qualitative research, an increasing number of clinical and systematic studies confirm that CBT effectively manages distress related to chronic illnesses, pain perception, and maladaptive coping mechanisms. For example, systematic reviews have shown that CBT can significantly reduce fear of pain, improve coping skills, and enhance emotional health in those with chronic conditions, particularly when persistent pain and functional impairments are involved (Ehde et al., 2014; Hofmann et al., 2012).

Within the context of hemophilia, these findings are particularly relevant, as the condition often involves chronic pain, repeated injuries, and anticipatory anxiety related to bleeding episodes. Ramos-Petersen et al. (2023) highlight the lived experiences of PwH, noting patterns of fear, avoidance, and emotional burden. However, as a qualitative study, it mainly provides descriptive insights rather than evidence of treatment effectiveness. When considered alongside broader clinical evidence, CBT appears to be a strong therapeutic option for addressing these psychological patterns.

In addition to psychotherapy, integrated, non-pharmacological interventions, such as combining Cognitive Behavioural Therapy (CBT) with physiotherapy, have demonstrated significant efficacy

in alleviating pain and kinesiophobia (fear of movement), while concurrently enhancing overall functioning and quality of life (Ehde et al., 2014). These methodologies address both the physical and psychological aspects of chronic conditions, thereby aligning effectively with a biopsychosocial model of care.

A central component of cognitive-behavioural therapy (CBT) for hemophilia is psychoeducation, particularly regarding the pain–fear–avoidance cycle. Patients experiencing pain may begin to avoid movement due to fear, potentially resulting in deconditioning, greater disability, and heightened anxiety. Educating patients about this cycle and providing them with effective coping strategies can disrupt this pattern, thereby encouraging more active participation in daily activities.

Given this evidence, mental health care should not be seen as just an optional addition; instead, it is a crucial part of hemophilia treatment. Hemophilia treatment centres should regularly include mental health professionals in multidisciplinary teams to make sure psychological care is smoothly combined with medical and rehabilitative services. This method not only helps manage symptoms but also enhances long-term quality of life and functional results.

Caregiver and family support are also essential. Brod et al. (2023) report that most caregivers of children with hemophilia experience at least mild depression and anxiety, and that there is a psychological, social, financial, and occupational burden for caregivers. Caregivers need clinician-led interventions, such as support groups, psychoeducation, and respite. Motivational interviewing and developmentally sensitive counselling that validate identity needs and support treatment engagement are best practices with adolescents. Peer support programs and community advocacy groups also serve a protective role by minimising isolation and promoting community resilience.

CONCLUSION

Conclusion: Hemophilia is not just a bleeding disorder. It is a condition that changes one's identity, compromises relationships, puts a strain on families, and creates psychological suffering that is frequently unrecognised. The literature synthesis in this paper has shown that mental health problems are widespread, serious, and complex, and that mental health is closely linked with physical and social problems of hemophilia. The biopsychosocial model, developmental theory, trauma frameworks, and cognitive-behavioural approaches all offer a solid clinical basis for addressing these challenges. Future studies should focus on longitudinal studies of mental health outcomes throughout the life span of PwH and the effects of new gene therapies and longer-lasting treatments on mental health over time. Increased investment in routine mental health screening at HMCs, education on trauma-informed communication for hematology staff, and culturally appropriate psychosocial interventions for PwH in low- and middle-income countries are all urgent priorities. Most importantly, the field should realise that caring for a person with hemophilia is caring for the whole person, body, mind, spirit, and community.

REFERENCES

Aledort, L. M. (2007). HIV and hemophilia. Journal of Thrombosis and Hemostasis.

Berring, L. L., Holm, T., Hansen, J. P., Delcomyn, C. L., Søndergaard, R., & Hvidhjelm, J. (2024, April). Implementing trauma-informed care—settings, definitions, interventions, measures, and implementation across settings: a scoping review. In Healthcare (Vol. 12, No. 9, p. 908). MDPI. https://doi.org/10.3390/healthcare12090908

Brod, M., Bushnell, D. M., Neergaard, J. S., Waldman, L. T., & Busk, A. K. (2023). Understanding treatment burden in hemophilia: development and validation of the Hemophilia Treatment Experience Measure (Hemo-TEM). Journal of Patient-Reported Outcomes, 7(1), 17. https://doi.org/10.1186/s41687-023-00550-6

Buckner, T. W., Bocharova, I., Hagan, K., Bensimon, A. G., Yang, H., Wu, E. Q., ... & Li, N. (2021). Health care resource utilisation and cost burden of hemophilia B in the United States. Blood Advances, 5(7), 1954–1962. https://doi.org/10.1182/bloodadvances.2020003424

Chiu, A. S., Blanchette, V. S., Barrera, M., Hilliard, P., Young, N. L., Abad, A., & Feldman, B. M. (2021). Social participation and hemophilia: Self-perception, social support, and their influence on boys in Canada. Research and Practice in Thrombosis and Haemostasis, 5(8), e12627. https://doi.org/10.1002/rth2.12627

Department of Health and Social Care (UK). (2022). Infected blood compensation framework.

Ehde, D. M., Dillworth, T. M., & Turner, J. A. (2014). Cognitive-behavioural therapy for individuals with chronic pain: Efficacy, innovations, and directions for research. American Psychologist, 69(2), 153–166. https://doi.org/10.1037/a0035747

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. Science, 196(4286), 129–136.

Erikson, E. H. (1963). Childhood and society (2nd ed.). New York, NY: Norton. (Original work published 1950)

Erikson, E. H. (1968). Identity: Youth and crisis. New York, NY: Norton.

Evatt, B. L. (2006). The tragic history of AIDS in the hemophilia population, 1982–1984. Journal of Thrombosis and Haemostasis, 4(11), 2295–2301. https://doi.org/10.1111/j.1538-7836.2006.02213.x

Fornari, A., Antonazzo, I. C., Rocino, A., Preti, D., Fragomeno, A., Cucuzza, F., & Mantovani, L. G. (2024). The psychosocial impact of hemophilia from patients' and caregivers' point of view: The results of an Italian survey. Hemophilia, 30(2), 449–462. https://doi.org/10.1111/hae.14926

Hakimi, Z., Ghelani, R., Bystrická, L., Kragh, N., Marquis, P., Nazir, J., & McGale, N. (2024). Patient experience of living with haemophilia A: a conceptual model of humanistic and symptomatic experience in adolescents, adults, and children. Journal of Health Economics and Outcomes Research, 11(2), 95. https://doi.org/10.36469/001c.123374

Hofmann, S. G., Asnaani, A., Vonk, I. J., Sawyer, A. T., & Fang, A. (2012). The efficacy of cognitive behavioural therapy: A review of meta-analyses. Cognitive Therapy and Research, 36(5), 427–440. https://doi.org/10.1007/s10608-012-9476-1

Institute of Medicine (US). (1995). HIV and the blood supply: An analysis of crisis decision making. National Academies Press.

Jiménez-Cebrián, A. M., Palomo-López, P., Becerro-de-Bengoa Vallejo, R., Losa-Iglesias, M. E., Navarro-Flores, E., San-Antolín, M., & López-López, D. (2022). Impact of depression on patients with hemophilia: a retrospective case-control research. Frontiers in Psychiatry, 13, 892321. https://doi.org/10.3389/fpsyt.2022.892321

Königs, C., Motwani, J., Jiménez-Yuste, V., & Blatný, J. (2024). Teenagers and adolescents with hemophilia–need for a specific approach. Journal of Clinical Medicine, 13(17), 5121. https://doi.org/10.3390/jcm13175121

McHenry, L., & Khoshnood, M. (2014). Blood money: Bayer's inventory of HIV-contaminated blood products and third world hemophiliacs.

Obeagu, E. I., & Ngomo, S. S. I. (2024). Impact of HIV on hemophilia patients: A review.

Paley, B., & Hajal, N. J. (2022). Conceptualising emotion regulation and coregulation as family-level phenomena. Clinical Child and Family Psychology Review, 25(1), 19–43. https://doi.org/10.1007/s10567-022-00378-4

Perolla, A., & Kalaja, B. (2024). Improving hemophilia care in low- and middle-income countries: Addressing challenges and enhancing quality of life. Cureus, 16(6), e62817. https://doi.org/10.7759/cureus.62817

Raheja, P., Kragh, N., Bystrická, L., Eriksson, D., Aroui, K., Mezghani, M., & Linari, S. (2024). Long-term efmoroctocog alfa prophylaxis improves perceived pain, mental, and physical health in patients with hemophilia A: post hoc analysis of phase III trials using patient-reported outcomes. Therapeutic Advances in Hematology, 15, 20406207241257917. https://doi.org/10.1177/20406207241257917

Ramos-Petersen, L., Rodríguez-Sánchez, J. A., Cortés-Martín, J., Reinoso-Cobo, A., Sánchez-García, J. C., Rodríguez-Blanque, 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

Schmidt, A., Tomschi, F., Möllers, P., Brühl, M., Richter, H., Oldenburg, J., & Hilberg, T. (2025). Factors Influencing Symptoms of Depression, Anxiety and Stress in Patients With Haemophilia. Haemophilia, 31(5), 884–892. https://doi.org/10.1111/hae.70079

Schmitt, F., Maier, L., Lerch, S., Albisetti, M., Trinchero, A., Graf, L., & Kartal-Kaess, M. (2026). Hemophilia Severity and Its Association With Mental Health and Health-Related Quality of Life—Results From a Cross-Sectional Multicenter Study. Haemophilia. https://doi.org/10.1111/hae.70219

Steen Carlsson, K., Winding, B., Astermark, J., Baghaei, F., Brodin, E., Funding, E., & Lethagen, S. (2022). Pain, depression and anxiety in people with haemophilia from three Nordic countries: cross-sectional survey data from the MIND study. Haemophilia, 28(4), 557–567. https://doi.org/10.1111/hae.14571

Ucero-Lozano, R., López-Pina, J. A., Ortiz-Pérez, A., & Cuesta-Barriuso, R. (2022). The relationship between chronic pain and psychosocial aspects in patients with haemophilic arthropathy. A cross-sectional study. Haemophilia, 28(1), 176–182. https://doi.org/10.1111/hae.14469

UK Infected Blood Inquiry. (2023). Final report.