

# Navigating Life with Hemophilia: A Qualitative Exploration of Patient's Lived Experiences

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## Index Terms:

Hemophilia, lived experiences, qualitative Research, resilience, nursing care, Negros Oriental

**Abstract.** This qualitative phenomenological study explored the lived experiences of nine individuals diagnosed with hemophilia A or B in Negros Oriental, Philippines. Using Sister Callista Roy's Adaptation Model as a theoretical framework, the researchers conducted in-depth, semi structured interviews and applied Colaizzi's descriptive phenomenological method to identify six emergent themes: fragility, turmoil, stigma, disruption, anchors, and breakthrough. Findings revealed that participants experience multifaceted challenges including chronic joint pain, restricted mobility, treatment burdens, financial constraints, emotional distress, and social stigma. However, resilience emerged as a central finding, with family support, faith, companionship, self-acceptance, and hope serving as key adaptive resources. These findings underscore the need for holistic, empathetic, person-centered nursing care that integrates physical, emotional, social, and spiritual dimensions of care for individuals living with hemophilia.

## Introduction

Hemophilia is a rare hereditary bleeding disorder caused by a deficiency of clotting factors VIII (hemophilia A) or IX (Hemophilia B) and is characterized by prolonged bleeding episodes, spontaneous joint bleeding, and potentially life-threatening hemorrhages (World Federation of Hemophilia, 2021). The Centers for Disease Control and Prevention stated that unique challenges extend beyond the physical manifestations of this condition. Significant advances have been made in treatments, such as recombinant clotting factors and gene therapy, which have greatly improved the life expectancy and quality of life of people with hemophilia; however, the condition still has a deep impact on many aspects of their lives (Srivastava et al., 2020). For example, chronic pain and joint damage can take a toll on mental health (Pinto et al., 2021), while societal perceptions and the challenges of managing a lifelong condition can affect relationships and career opportunities (Forsyth et al., 2019).

Globally, hemophilia faces challenges, including disparities in healthcare access, high treatment costs, and limited specialized care in low- and middle-income countries (Srivastava et al., 2020). Over 75% of people with bleeding disorders are believed to remain undiagnosed or untreated worldwide, highlighting persistent inequities in healthcare delivery (World Federation of Hemophilia, 2023). In high-income countries, access to advanced therapies, such as recombinant clotting factors and gene therapy, has improved the quality of life of many patients. However, these treatments are often inaccessible in low- and middle-income countries (LMICs), where healthcare facilities are underdeveloped, and reliance on less effective options, such as plasma-derived products, prevails (Srivastava et al., 2020). Additionally, the economic burden

of managing hemophilia extends beyond direct medical costs, encompassing loss of income, reduced productivity, and strain on families, which are disproportionately felt in resource-limited settings (Poon et al., 2021).

While advancements in the medical field have improved hemophilia management globally, Filipinos still face challenges due to resource limitations in the country's health-care system. According to the World Federation of Hemophilia, there are 1,644 registered cases in the country, which accounts for only 14.2% of the expected number of cases based on population estimates (World Federation of Hemophilia 2023). This discrepancy highlights a critical issue: the lack of awareness and understanding of the disease. Limited awareness of hemophilia is a primary issue among both the public and healthcare providers, contributing to delayed diagnosis and leaving many individuals undiagnosed due to a lack of understanding of the condition and its symptoms (WFH of Hemophilia, 2023).

While there are studies on the experiences of individuals with hemophilia in the Philippines (Srivastava et al., 2020), no research has focused on the Negros Oriental province. Most research has been quantitative, looking at clinical or statistical data, but a qualitative approach can provide an opportunity to uncover meaningful insights into the resilience, experiences, and coping strategies of individuals with hemophilia. Additionally, many studies have been conducted in urban areas, making it difficult to apply their findings to Negros Oriental, which has unique healthcare challenges and economic conditions. Thus, the present study aims to explore the lived experiences of patients with hemophilia in the province, focusing on their coping strategies, ways of drawing on support systems, and aspirations for improved health services. This study is expected to provide valuable insights into patient-centered approaches and localized interventions tailored to their unique needs.

#### *Research Questions*

To explore the phenomenon in depth, the study addressed the grand-tour question: "What is the lived experience of people living with hemophilia?"

## **Methodology**

This qualitative phenomenological study employed a purposive and convenience sampling approach to recruit participants based on their accessibility, proximity to the researchers, and demonstrated willingness to participate in the research (Polit, D. F., & Beck, C. T. 2022). Nine participants were ultimately included in the study, as recruitment and data collection proceeded iteratively until theoretical saturation was attained, at which point no new themes emerged from additional interviews.

Data were collected through face-to-face, semi-structured interviews utilizing open-ended questions, with all participants providing informed written consent and explicit permission for audio recording (Polit, D. F., & Beck, C. T. 2022). Following transcription by the researchers, interview recordings were assigned codes and aliases rather than participant names to ensure anonymity, and all audio files were systematically destroyed after transcription to protect participant confidentiality. Data analysis adhered to Colaizzi's descriptive phenomenological method, which involved repeated, careful reading of all transcripts, identification of significant statements relevant to the phenomenon, formulation of meanings from these statements, systematic clustering into thematic categories, development of an exhaustive integrated description of the phenomenon, and member checking through participant validation of the final findings to ensure accuracy and fidelity to participants lived experiences (Kumar, P., & Grace, T. D. 2023). To enhance the rigor and trustworthiness of the study, the researchers employed several quality assurance strategies throughout the research process. These included bracketing personal assumptions to minimize researcher bias, intentionally establishing rapport with participants, practicing active listening, and carefully observing nonverbal cues during the interviews. The researchers also ensured the accuracy of the data through audio recording and verification of interview transcripts. In addition, a comprehensive audit trail was maintained to document methodological and analytical decisions throughout the study. Ongoing consultation with the faculty adviser further supported the consistency, credibility, and integrity of the research process. (Kakar, P. 2023).

Ethical integrity was anchored in foundational principles of beneficence, nonmaleficence, justice, and autonomy with explicit assurances that participation was entirely voluntary, withdrawal was permitted without consequence at any point, and robust confidentiality safeguards were implemented and maintained throughout all phases of the study.

## **Results and Discussion**

The analysis of interviews revealed six emergent themes that collectively portray hemophilia as a multidimensional experience shaped by bodily vulnerability, emotional and social challenges, disruption of life opportunities, support systems, and personal transformation. The findings demonstrate that living with hemophilia extends far beyond clinical

management of physical symptoms; it profoundly influence's emotional stability, psychological resilience, social relationships, and spiritual outlook.

#### Theme 1: Fragility

Participants described their lived experience through the lens of bodily fragility and vulnerability. Chronic joint pain, deformities, activity restrictions, self-managed care, and treatment challenges characterized their daily lives. Participants articulated the unpredictability of bleeding episodes and the constant vigilance required in managing their condition. The physical vulnerability was compounded by the demands of self-care management and the burdensome nature of treatment regimens, which were essential yet exhausting aspects of their existence.

#### Theme 2: Turmoil

The emotional landscape of hemophilia was marked by significant psychological turmoil. Participants reported experiencing denial, fear, sadness, anger, and isolation as they grappled with their diagnosis and its implications. However, the narrative was not one of unrelenting despair; participants also described a gradual trajectory toward acceptance and resilience, suggesting that emotional turmoil represented a dynamic process of adaptation rather than a static emotional state.

#### Theme 3: Stigma

Beyond the physical and emotional dimensions, participants confronted systematic social misunderstanding. Discrimination, myths, cultural misconceptions, and public misunderstanding of hemophilia emerged as significant barriers to social integration. Stigma functioned as an invisible yet pervasive force that complicated social relationships and reinforced a sense of otherness, adding a social burden to an already medically challenging condition.

#### Theme 4: Disruption

Bleeding episodes, hospital visits, and pain were inextricably associated with interrupted schooling, limited career opportunities, and social exclusion. These disruptions were not temporary setbacks but represented a pervasive alteration of life trajectories, affecting educational attainment, vocational possibilities, and full participation in peer and community activities.

#### Theme 5: Anchors

Despite the multifaceted challenges, participants identified crucial sources of sustenance and support. Family support, faith, and companionship provided both practical and emotional support, fostering a sense of belonging and encouragement. These anchors served as stabilizing forces that enabled adaptation and resilience in the face of ongoing adversity.

#### Theme 6: Breakthrough

The final emergent theme reflected participants capacity for transformation. Self-acceptance, empowerment, hope, positive transformation, and reflection supported adaptation and a renewed sense of purpose. Many participants described a reorientation toward their condition, moving from viewing hemophilia as purely limiting toward recognizing opportunities for personal growth and meaning making.

The findings underscore that hemophilia is not solely a medical condition but a complex, multidimensional experience requiring holistic and person-centered approaches in nursing care. Despite enduring pain, financial difficulties, and social stigma, participants demonstrated strong resilience, faith, and acceptance, highlighting the importance of empathy, active listening, and advocacy in nursing practice.

These results emphasize the necessity of moving beyond symptom management to address the emotional, social, and spiritual dimensions of the hemophilia experience. Healthcare providers must recognize hemophilia as affecting every aspect of a person's life and provide interventions that support not only medical compliance but also psychological well-being, social integration, and spiritual meaning-making.

The identification of anchors with family support, faith, and community provides actionable insights for nursing interventions that strengthen existing support systems and foster resilience. Family-centered approaches, psychosocial assessment, and spiritual care emerge as essential components of comprehensive hemophilia care that honor the lived realities of patients navigating this chronic condition.

## Conclusion and Recommendations

This study sought to gain an in-depth understanding of the lived experiences of individuals with hemophilia, emphasizing how they interpret, adapt to, and find meaning in their condition within the context of everyday life. Through qualitative exploration and in-depth interviews conducted across Negros Oriental, the research revealed comprehensive insights into the multidimensional nature of hemophilia as a chronic condition.

The study revealed that living with hemophilia extends beyond the clinical management of physical symptoms. It profoundly influences one's emotional stability, psychological resilience, social relationships, and spiritual outlook. These findings highlight that hemophilia is not solely a medical condition but a complex, multidimensional experience that requires holistic and person-centered approaches in nursing care. Despite enduring pain, financial difficulties, and social stigma, the participants showed strong resilience, faith, and acceptance. These experiences underscore the importance of empathy, active listening, and advocacy in nursing practice.

This study demonstrated that hemophilia is more than a clinical diagnosis, it affects every aspect of a person's life and deserves just as much attention as any other chronic illness.

### *Healthcare Providers and Policymakers*

The findings have critical implications for healthcare delivery and policy development. Healthcare providers and policymakers should prioritize improving access to treatment, especially prophylaxis and Factor VIII, by building stronger partnerships with the local government and international organizations. Many participants reported that obtaining needed medications is difficult because of high cost and limited supply, necessitating collaborative efforts with organizations like the World Federation of Hemophilia and government offices to make treatments more available and affordable. Institutionalizing routine psychological screening and counseling for hemophilia patients is essential to address mental health needs. Several participants reported emotional struggles, including frustration, sadness, and hopelessness. Regular mental health assessments, along with counseling services, can help patients better cope with chronic illness and prevent the onset of depression or anxiety. Additionally, advocacy for the passage and implementation of the Hemophilia Care Act is crucial to guarantee free or subsidized medication and support services. Legislation that provides a legal framework for funding, treatment access, and nationwide patient registries are essential to institutionalize long-term care for hemophilia and integrate services into the public health system.

### *Family and Caregivers*

The identification of family support, faith, and companionship as critical anchors in participants' experiences underscores the importance of engaging families as partners in care. Consistent emotional support and involving patients in decision-making about their care are vital strategies that leverage the strength of familial relationships to enhance resilience and adaptation.

### *Schools and Workplaces*

The disruption of educational and vocational pathways identified in this study necessitates systemic interventions in schools and workplaces. Inclusive policies, disability accommodations, and awareness programs are required to enable hemophilia patients to participate fully in educational and professional opportunities without discrimination or exclusion.

### *Community and Advocacy*

The pervasive stigma and public misunderstanding surrounding hemophilia identified in this research indicate a pressing need for community education and awareness initiatives. Public health campaigns and peer support networks can help combat myths, reduce discrimination, and foster social acceptance of individuals living with hemophilia.

### *Future Research*

This study opens pathways for future researchers to deepen understanding of hemophilia as a lived experience. Further research exploring culturally adapted interventions, longitudinal outcomes of psychosocial support, and family-centered care models would strengthen the evidence base for holistic hemophilia management.

### *Overall Significance*

By sharing the voices of hemophilia patients through this research, individuals living with this condition can receive the support, understanding, and resources they truly need. This study calls for a paradigm shift in hemophilia care from disease-centered management toward patient-centered, holistic approaches that address the emotional, social, spiritual, and practical dimensions of the lived experience. Only through such comprehensive, multidisciplinary engagement can healthcare systems genuinely support the wellbeing and life aspirations of individuals living with hemophilia.

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The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this article.

## Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analyzed in this study; all data used were obtained from previously published sources as cited in the reference list.

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## Appendices

No appendices are attached to this study.