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Assessment of Healthcare Delivery for Hemophilia Patients in West Bank/Palestine: Challenges, Gaps, and Opportunities for Improvement"

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Assessment of Healthcare Delivery for Hemophilia Patients in Palestine: Challenges, Gaps, and Opportunities for Improvement"

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Dedication

I dedicate this research dissertation to Palestine and to my beautiful city, Jerusalem, and to my birthplace, and where my roots are, Bethlehem.

And to the innocent children, women, and men of the war who lost their lives and will remain in our memories forever.

To my father, my everlasting supporter, who walked beside me, every step of the way and believed in me without any doubts.

To my mother, my heart, my endless love, my closest friend—your strength, care, and love have always been the greatest motivation of all and for that, I thank you.

To my life companion, my wife, whose love and support carried me through the toughest moments of this journey, and whose patience is a virtue I will always admire.

And to my children, the light of my eyes, the reason to my motivation and strength—this is all for you.

I am specifically indebted to the people who illuminated my path with their love and supporting kindness.

To my companions all through my life, my brothers, I really appreciate your encouragement support.

And to my lovely friends, my journey was a lot more meaningful and manageable thanks to your presence, encouragement, and support.

Nadi Al-Zawahra

Declaration

I certify that this thesis was submitted for the degree of masters. It is the result of my own research, except where otherwise is acknowledged. I also certify that this thesis (or any part of the same) has not been submitted for any other university or institution.

Student Name: Nadi hassan Abed Eid Zawahra

Signature: ……..

Date: 14/01/2026

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Nadi Al-Zawahra

Abstract

Bleeding disorders like hemophilia are rare inherited conditions. However, it still requires around-the-clock specialized multidisciplinary healthcare to prevent severe complications and maintain an acceptable quality of life. In resource-limited and politically constrained settings like Palestine, providing comprehensive hemophilia care continues to be extremely difficult. Therefore, this study sought to assess healthcare provision for West Bank/Palestine hemophilia patients, identify primary issues, and pinpoint gaps in care, in addition to addressing the potential to improve the accessibility and the tier of care provided, as well as equity for under-resourced patients.

A cross-sectional, mixed-methods study was carried out from March 2024 to August 2025. Quantitative data was collected via a structured survey from 99 patients diagnosed with hemophilia A or B, equating to around 28% of the registered hemophilia population in the West Bank/Palestine. Patients were purposefully sampled from multiple governorates. Most respondents were male (93.9%), under the age of 35 (84.8%), and lived in rural areas (63.6%) and low-income households (59.6%) with income levels under USD 500 monthly. SPSS was utilized for descriptive and inferential statistical analyses (t-tests, one way ANOVA, correlation, multiple linear regression). Of the qualitative data collected through open-ended questions, thematic analyses were done to augment the quantitative data.

The findings disclosed serious shortcomings in hemophilia health care. 79.8% of patients reported occasional shortages of clotting factor concentrates. Financial barriers were reported by 53.5% of patients, while 77.8% of patients experienced issues related to transportation. 57.6% of the participants received prophylaptic Repl in 94.9% of the patients that were sufficiently prepared to control the bleeding. 78.8% of the patients did not have regular orthopedic consultations, and 70.7% did not have psychological debriefing. More than 80% of patients felt that there were too few hemophilia treatment centers, diagnostic centers, and specialized healthcare workers. There was a mixed patient satisfaction with healthcare services, with only 35.3% of patients indicating satisfaction with the services they received. Results of the multiple regression analysis showed that the frequency of bleeding episodes, perceived healthcare service accessibility, and health education of the patient were significant predictors of satisfaction with the care quality ($p<0.05$). There was low awareness (18.2%) of national policies pertaining to the treatment of patients with hemophilia, and this awareness was related to lower household incomes.

In summary, the obstacles to hemophilia care in the West Bank/Palestine include a lack of medications, a lack of specialized services, a lack of adequate services, a lack of patient education, a lack of policy dissemination, and a lack of policy dissemination. The maintenance of supply chain processes, the establishment of specialized treatment centers, the improvement of provider education, the enhancement of patient education, the enhancement of psychosocial support, and the adoption of national hemophilia guidelines of defined focus are needed to improve the inequities in health outcomes of hemophilia patients in Palestine.

Keywords: Hemophilia A and B, Hemophilia Care, Healthcare Delivery Systems, Access to Healthcare Services, Health System Challenges, Health Policy and Equity, Hemophilia Treatment Centers, West Bank, Palestine.

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Abbreviations

AI: Artificial Intelligence

ANOVA: Analysis of Variance

CI: Confidence Interval

HSD: Honestly Significant Difference (Tukey HSD)

HTCs: Hemophilia Treatment Centers

LMICs: Low- and Middle-Income Countries

SD: Standard Deviation

SPSS: Statistical Package for the Social Sciences (SPSS software)

USD: United States Dollars

WFH: World Federation of Hemophilia

WHO: World Health Organization

WHOQOL: brief -WHO Quality of Life (Brief version)

Haemo-A-Qol: Hemophilia-Specific Quality of Life questionnaire

Chapter One:

Introduction & Background

1.1. Introduction

Hemophilia is an X-linked recessive bleeding disorder caused by a deficiency of coagulation factor VIII (Hemophilia A) or factor IX (Hemophilia B), resulting in impaired homeostasis and prolonged bleeding episodes. It can cause life-threatening complications through a lack of, or failure in, specific coagulation factors, namely, factor VIII in hemophilia A and factor IX in hemophilia B (Mayo Clinic, 2023; Merck Manual, 2025). Patients with this disorder present with prolonged duration of bleeding and lack clot formation efficiency. One of the major challenges in low- and middle-income countries is limited access to comprehensive care, necessitating a multidisciplinary approach, comprising a variety of professionals such as a group of hematologists, physiotherapists, psychologists, and social workers. In such countries, integration of care is not feasible with poor infrastructure, and therefore, care delivery is fragmental with poor consequences for health. In addition, a key challenge involves availability of prophylactic therapy with clotting factor concentrates to prevent bleeding events. High expenses and recurrent shortages in drugs make prophylactic therapy impossible in such countries, and therefore, long-term complications arise through repetitive events of bleeding (Ghosh & Ghosh, 2016; (Pierce et al., 2022).

Research on hemophilia in Palestine reflects patterns seen in other resource-limited settings. Despite advances in treatment, barriers such as the lack of specialized centers, limited access to therapies and diagnostics, and poor public awareness continue to hinder optimal care. There is a critical necessity for an overall evaluation of the Palestinian healthcare system for determination of most strategies for overall management of such a disorder in the region of the West Bank/Palestine (MSF, 2025).

This master's thesis aims to undertake an in-depth examination of the management and practice of hemophilia in the West Bank/Palestine, with a focus on the most significant impediments encountered by patients, careers, and the medical System.

The research hypothesizes that factors such as socioeconomic factors, cultural processes, and institution structures have a considerable impact in shaping the care for hemophilia. These factors shed additional light on care use and health consequences both between and within social groups. In addition, the study seeks to apply interventions that target such obstacles and enhance overall care quality and care equity for persons with hemophilia in the West Bank/Palestine.

1.2. Problem Statement

Despite medical advances, people with hemophilia in the West Bank/Palestine still face major barriers to early diagnosis and adequate care (Pierce et al., 2022; Ghosh & Ghosh, 2016). Systemic obstacles, such as inadequate funding, poor infrastructure, and lack of political will or geopolitical stability, continue to hamper hemophilia service delivery and access to specialized care (Ghosh & Ghosh, 2016; WFH, 2020; Pierce et al., 2022). Consequently, patients leave Palestine to get care that the country can't provide for hemophilia (Ghosh & Ghosh, 2016; Pierce et al., 2022). Moreover, the demand for hemophilia care and treatment remains poorly understood due to insufficient planning, which is often attributed to underdiagnosis and lack of monitoring systems in resource-poor environments (Ghosh & Ghosh, 2016; WFH, 2023). Health care provider and the public insufficient knowledge of hemophilia can result in the poor management of bleeding episodes and missed diagnosis, thus resulting in poor outcomes (WFH, 2020; WFH, 2023).

The National Registry of Hemophilia Patients in Palestine provides data which is essential in estimating prevalence and designing a better plan for mapping the distribution and regional allocation of resources (Ghosh and Ghosh, 2016; WFH, 2020). The West Bank/Palestine reported cases most likely does not meet international comparison expectancies which reflects the underdiagnosis pattern common in low-resource settings (Pierce et al, 2022; WFH, 2023). The West Bank/Palestine underdeveloped hemophilia services will need increased diagnostic capabilities, awareness campaigns, and treatment facilities in high-burden areas to attain a better quality of life and lessen the impact of disabilities (Furuichi et al., 2020; Pierce et al., 2022; WFH, 2020).

1.3. Study Justification

The analysis of the availability of health services to hemophilia patients in West Bank/Palestine has been warned based on the following planned details:

1. Health inequality: The healthcare system in the West Bank/Palestine faces inadequate funding and infrastructure, coupled with political challenges, greatly restricting effective allocation of resources and care. Based on the World Health Organization (WHO, 2020), these systemic issues affect the extent and quality of treatment provided to patients suffering from hemophilia. (Ramos-Petersen et al., 2023)
2. Resource Challenges: Similar to other regions with major funding and infrastructure or political issues, the West Bank/Palestine is significantly affected, but these factors also impede efficient staffing and care provision. As stated in the World Health

Organization (WHO, 2020), these chronic deficiencies restrict the nature and degree of care that can be offered to hemophilia patients.

3. Data Gaps: In order to formulate specific studies, more extensive information regarding hemophilia's frequency and treatment results in the West Bank/Palestine is needed, as it currently does not exist. As per (Ghosh & Ghosh, 2016), "The IVG countries, which have limited resources, usually do not have sufficient hea1th infrastructure or access to key treatments, hence patients may have to go abroad or receive poor quality care".
4. Quality of Life Impact: Hemophilia deeply impacts the lives of patients on a daily basis, resulting in physical, emotional, as well as economic hardships. Improving the patients' quality of life means addressing gaps in the healthcare sector such as the absence of defined treatment centers(Furuichi et al., 2020).
5. Public Health Implications: Having effective management of hemophilia greatly reduces the burden on prevention healthcare systems, eliminate complications and increases health in the population. For attaining these objectives in public health, it is important to improve the delivery of services (WHO, 2020).
6. Ethical Imperative: Social justice and health equity demand that all groups of people, even those with less common ailments like hemophilia, have unfettered access to healthcare services, a commitment that must be fulfilled by any reputable society (WHO, 2020).

In conclusion, there is a need to achieve evidence to solve health services, improve resource distribution, direct policy, increase the results of patients and to maintain social justice theory about health. These are the reasons for a detailed evaluation of service provisions for patients with hemophilia in West Bank/Palestine.

1.4. Study Goal

This study aims to provide and analyze the levels of hemophilia care in the West Bank/Palestine, specifically the available tools that measure the levels of access in a thorough manner, identifying the barriers by level of system / patient, assessing the disparities of the described system and the associated outcomes, and proposing strategies that can enhance the quality, continuum, and equitable care of hemophilia in the West Bank/Palestine:

1. Identifying barriers to care: Describe the principal barriers to timely diagnosis, and comprehensive care, from the patients', the providers', and the system perspectives.
2. Assessing the inequities and disparities: Analyze the access, use, and outcomes disparities and inequities in the care of persons with hemophilia in the West Bank/Palestine, based on geography, socio-economic status, and refugee status.
3. Characterizing the experiences and needs of the patients: Investigate the experiential perspectives of the patients, and the psychosocial support that they would need in relation to the services and care available to them.
4. Evaluating the service capacity and infrastructure: Describe the service capacity, and the complementation and distribution of the available services pertaining to

hemophilia care, inclusive of diagnostic and treatment services, and the specialized health workforce.

5. Reviewing the policy and regulatory framework: Describe the relevant regulations, policies, and the clinical guidance, the financing mechanisms, insurance coverage, the standards of care, the procurement and the distribution systems of the factor concentrates.
6. Formulate evidence-based strategies: Suggest practical and contextually relevant approaches to refine service delivery and enhance health outcomes and equity for individuals with hemophilia in Palestine while addressing the identified gaps.

By fulfilling these goals, the study hopes to advance knowledge of the situation of hemophilia treatment in Palestine and offer useful advice to stakeholders, legislators, and medical professionals on how to improve the healthcare system and the lives of hemophiliac patients.

1.5. Study Period

The research ran from March 2024, to January 2026, a duration of one year and six months. This timeframe enabled thorough data gathering, analysis, and interpretation in addition to the formulation of suggestions for enhancing the treatment of hemophiliac patients in Palestine. There were many main periods to the study period:

1. Preparatory Phase (March–April 2024): In this phase, the research team completed the study protocol, secured the required authority and ethical review board approvals, and formed alliances with important parties such as government agencies, patient advocacy organizations, and healthcare facilities.
2. Phase of Data Collection (Jan 2025 – May 2025): A mix of quantitative and qualitative techniques was used to obtain data. We gathered quantitative data from healthcare institutions and pertinent databases, such as patient demographics and healthcare use statistics. To investigate patient viewpoints and experiences, focus groups and patient interviews were used to collect qualitative data.
3. Phase Three: Data Analysis (June 2025): The experiences of hemophilia patients within the healthcare system were examined through the lens of trends, patterns, and inequalities by quantitatively analyzing the data using the Statistical Package for the Social Sciences (SPSS). Relationship and difference testing between key variables were conducted using both descriptive and inferential statistical methods. Key themes, patterns, and insights from the text of interviews and open-ended survey responses were identified and extracted with the aid of qualitative AI tools like OpenAI's ChatGPT. The AI findings were checked against human judgment to ensure accuracy and relevance within the given context. The combination of quantitative analysis with AI-assisted qualitative analysis enhanced understanding of the healthcare challenges faced by hemophilia patients, thereby addressing fundamental gaps and targeted areas for delivery system improvements.
4. Phase 4: Report Writing (June 2025): A thorough report outlining the goals, methods, conclusions, and suggestions of the study was compiled from the research data. Before being finished and distributed, the report was reviewed and revised internally.

5. Discussion Phase (January 2026): This stage of the research included analyzing and interpreting the results, as well as talking with stakeholders about possible ways to make improvements. This stage usually came just before the study report was finalized, but after data analysis.

To guarantee the validity and applicability of the research findings, close attention was made throughout the study period to ethical issues, data confidentiality, and the meaningful participation of stakeholders.

1.6. Study Question

"What are the challenges, gaps, and opportunities for improving healthcare delivery for hemophilia patients in Palestine?" is the main issue that directs this investigation.

Several particular sub-questions were investigated in order to address this general question:

1. How do people in Palestine who have hemophilia now use healthcare services?
2. What are the obstacles in Palestine to receiving a prompt hemophilia diagnosis and suitable treatment?
3. How do socioeconomic variables, such as geography and poverty, affect hemophilia patients' access to and results from medical care?
4. How do patients with hemophilia feel about the standard of treatment they get in Palestine?
5. How accessible and sufficient is Palestine's healthcare infrastructure for treating hemophilia, including treatment and diagnostic centers?
6. How do current laws, rules, and regulations affect the provision of hemophilia treatment in Palestine, and what room is there for policy reform?
7. How might the best methods in hemophilia care delivery from around the world be modified to fit the Palestinian context?

The research seeks to give a thorough evaluation of the existing situation of hemophilia patients' access to healthcare in Palestine by answering these study questions and to propose practical suggestions for enhancing care quality, results, and accessibility.

1.7. Context of the Study

It is imperative to comprehend the West Bank’s geographic, political, demographic, socioeconomic, cultural, health, and healthcare system circumstances. This understanding is crucial for effectively addressing the difficulties hemophilia patients encounter. This study intends to give evidence-based suggestions to enhance healthcare delivery and outcomes for people with hemophilia in the West Bank/Palestine by identifying and addressing these complex, multifaceted concerns. The recommendations are as follows:

1.8.1 Geographical and Political Context

Delivering healthcare in the West Bank/Palestine, a component of the Palestinian territories, is impacted by significant political and topographical obstacles. The area is known for its rough topography, which comprises several hills and valleys and makes it challenging to go about and get to medical services. These difficulties are made worse by the political

environment, which is characterized by the continuous military occupation, the Israeli-Palestinian conflict, and regular violence. The flow of people and commodities is restricted by checkpoints, roadblocks, and the separation barrier, which causes delays and makes it more difficult to get medical treatment. The delivery and coordination of healthcare services are made considerably more difficult by the West Banks partition into Areas A, B, and C, each of which has differing levels of Israeli and Palestinian sovereignty (World Health Organization, 2020).

1.8.2 Demographic Context

Over 3.1 million people live on the West Bank/Palestine, and a large percentage of them are young people under 18. The region's population density varies greatly, with metropolitan places like Ramallah, Hebron, and Nablus having denser populations than rural regions and refugee camps. The healthcare system is under more strain to satisfy the demands of an expanding population due to the high birth rate and youthful demographic profile, which create a significant dependence ratio (Palestinian Central Bureau of Statistics, 2023).

1.8.3 Socioeconomic Context

West Bank/Palestine has difficult socioeconomic conditions, with many inhabitants suffering from high unemployment and poverty rates. Employment in the public sector, small enterprises, and agriculture all play significant economic roles. However, political instability, resource scarcity, and mobility constraints impede economic progress. These socioeconomic issues restrict people's ability to pay for medical treatment and pressure the public healthcare system, which frequently has insufficient money and resources (World Bank, 2022).

1.8.4 Cultural Context

In West Bank/Palestine, cultural variables significantly impact how healthcare is delivered and used. Social conventions and traditional beliefs affect how people see and seek medical attention. Family and community support networks are frequently relied upon to manage health difficulties. Additionally, people's desire to seek timely and adequate care might be impacted by stigma and ignorance regarding specific medical disorders, such as hemophilia. Improving healthcare outcomes requires understanding and attention to various cultural elements (UNICEF, 2021).

1.8.5 Health Context

A combined burden of non-communicable and communicable illnesses distinguishes the West Bank' health situation. Although there has been a decrease in infectious disease cases, chronic illnesses, including diabetes, hypertension, and cardiovascular disorders, are becoming more common. Because there aren't enough resources or specialized treatment for uncommon genetic conditions like hemophilia, the healthcare system likewise has trouble treating them. Variations in the region's public health infrastructure, such as access to clean water and sanitation, impact overall health outcomes (Palestinian Ministry of Health, 2022).

1.8.6 Healthcare System

A combination of public, commercial, and non-governmental organization (NGO) providers make up the West Bank/Palestine healthcare system. The Ministry of Health (MoH), which runs clinics, hospitals, and primary healthcare facilities, is the leading supplier of public healthcare services. Nevertheless, the system is frequently overworked and understaffed, which results in a need for more specialist personnel, medical supplies, and equipment. Although NGOs and private healthcare institutions augment public services, they are frequently centered in metropolitan regions, leading to inequities in access to treatment. Initiatives to strengthen the MoH's capabilities, boost financing, and broaden access to necessary services are some of the ways to improve the delivery of healthcare, especially for marginalized groups living in rural areas and in camps for refugees (World Health Organization, 2020).

Chapter Two:

Conceptual Framework and Literature Review

2.1. Theoretical Framework

This study relies on the Andersen Behavioral Model of Health Services Use as the primary framework for examining the factors influencing access and healthcare utilization among hemophilia patients in the West Bank/Palestine. The model, created by Ronald Andersen in the 1960s, has gained considerable attention in recent decades for its application in understanding the inequities of healthcare access and utilization in, served by, disadvantaged and underserved populations, stratified by structural, economic, and geographic lines.

The model suggests that the utilization of health services is based upon three broad categories of attributes:

2.2.1 Predisposing Characteristics: These are the specific types of attributes that may compel an individual to use the health services. In the case of people suffering from hemophilia these includes:

- Demographic issues: Family structure which includes age and gender (as captured in Q1, Q2 of the questionnaire).
- Q4, Q5, Q6 of the questionnaire: Social structure and family income USD also comprises of education level and employment status.
- Beliefs: The knowledge and perception of the hemophilia and its treatment (Q28: Information and awareness provided about hemophilia).

2.2.2 Enabling Resources: These are the specific resources that an individual may have that facilitates the use of the health services. In the case of the hemophilia patients in Palestine, these resources are:

- Community resources: The constant companion to ensure health does not worsen (Q13: Do you have a constant companion to ensure health does not worsen?), to supportgroup accessible (Q19X4: Difficulty communicating with hemophilia patient support groups; Q32X4: Developing support groups and networks).
- Organizational resources: These consist of the healthcare services themselves including the supplies and the distance of the patients from these services (Q20: How would you rate the accessibility of healthcare services; Q21: Distance to the nearest healthcare facility; Q40: Availability of blood clotting factor medications).

- Financial factors comprise health insurance policies and restrictions, such as in Q39, “Does your health insurance cover the costs associated with hemophilia treatment?” and Q22X1 “Financial constraints”.
- Systemic factors focus on the availability of treatment and diagnostic centers and specialized healthcare practitioners, as well as the healthcare infrastructure as a whole, for example inquiries Q33 through Q36: “Are there a sufficient number of treatment centers?” Q34: “Are there sufficient diagnostic centers?” Q35: “Are there Enough healthcare practitioners specialized in hemophilia care?” and Q36: “Overall healthcare infrastructure.”

2.2.3 Need Factors: are the actual health issues and health services that are utilized that derive the use of health services, in the case of hemophilia include:

- Perceived need “Self-rated health and perceived severity of hemophilia” and evaluation with Q8 on severity of hemophilia and Q10 on the frequency on bleeding episodes.
- Evaluated need consists of type of hemophilia, the duration since diagnosis, and frequency of bleeding episodes, as demonstrated in Q7, Q9, and Q10.
- Addressing further, specific challenges of misdiagnosis or delayed diagnosis, lack of pain management, and absence of patient care and proactive follow-up, noted in Q19X1: “Misdiagnosis or delayed diagnosis,” Q19X2: “Lack of effective pain relief treatment,” and Q19X3: “Absence of patient care and follow-up.”
- Treatment protocol as outlined in Q14 and Q15 discussing the treatment protocol adherence within hemophilia therapy, focuses on the type of treatment and the count of prescribed prophylactic factor replacement therapy.

This approach enables the research to comprehensively examine the interplay of predisposing, enabling, and need factors with access, healthcare utilization, and outcomes for hemophilia patients in Palestine. This provides an in-depth understanding of the multiple dimensions and the points of possible intervention.

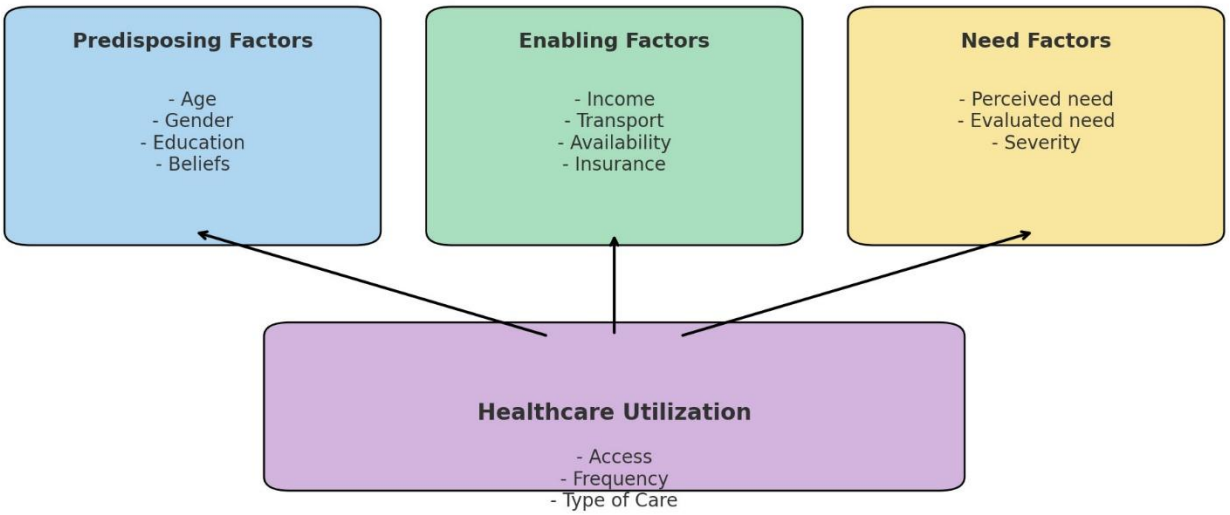

Figure 1.2: Andersen Behavioral Model of Health Services Use (Adapted for Hemophilia Care in Palestine).

This model demonstrates how predisposing attributes, enabling factors, and perceived or assessed health requirements cumulatively impact healthcare utilization. It is useful for understanding the hemophilia care gaps for patients living in the West Bank/Palestine, regarding their healthcare access, healthcare disparity, and treatment paradox.

2.2. Appropriateness to the Study

Employing Anderson's model allows us to organize and analyze the various elements affecting healthcare utilization among patients with hemophilia in the West Bank/Palestine. By situating specific elements into this structure, the study explores the complex interaction of socioeconomic standing, political climate, features of the healthcare system, and personal values in relation to receiving care.

This model is also important to the study's goals such as, but not limited to, describing care deficiencies, exploring both patient and system-level barriers, and developing targeted, evidence-informed interventions. The model not only allows the analysis of existing disparities, but proactively plans interventions aimed at the processes of care as well as the health equity for patients with hemophilia.

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2.3. Conceptual Framework

As seen in Figure 1, the literature review constructed the research conceptual framework. Accordingly, The West Bank/Palestine healthcare delivery of treatment for hemophiliac patients is evaluated using a conceptual framework that considers the many opportunities and problems that come with the situation. The concept of patient-centered care, which emphasizes customized treatment regimens and improves patient education and involvement to suit hemophilia patients' unique requirements and preferences, is fundamental to this paradigm. Essential aspects of the healthcare system are also considered, such as the

availability, caliber, and coordination of specialized care services among medical professionals to guarantee all-encompassing and well-coordinated care.

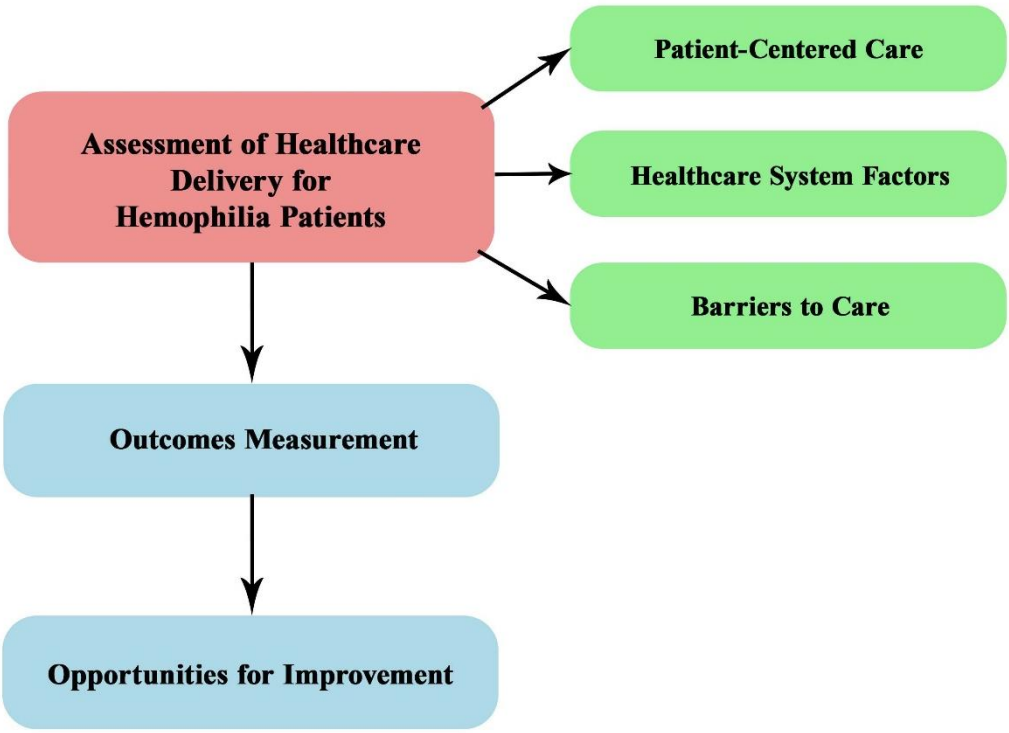

Figure 2.2: Conceptual Framework for Healthcare Delivery Assessment in Hemophilia Patients.

The framework outlines significant care hurdles that prevent patients from accessing necessary therapies, including lack of knowledge and education, regional restrictions, and financial limits. Outcome measurement is integrated to assess the efficacy of care using measures such as clinical outcomes (e.g., frequency of bleeding episodes), quality of life evaluations, and patient satisfaction surveys. The framework also identifies areas that need improvement, emphasizing new developments such as digital health and telemedicine solutions, legislative lobbying for more money and resources, and specialized training programs for healthcare professionals. To offer a detailed study of the difficulties, possibilities, and gaps in the West Bank/Palestine hemophilia patients' healthcare system, this all-encompassing approach will direct efforts to improve patient outcomes and the general standard of treatment.

2.4. Literature Review

Hemophilia, a rare and chronic bleeding disorder characterized by the deficiency of clotting factors, presents unique challenges in healthcare delivery, particularly in regions with limited medical infrastructure. In the West Bank/Palestine, where healthcare resources are often constrained by political, economic, and logistical factors, the delivery of comprehensive care for hemophilia patients remains a pressing concern. Previous studies highlight significant gaps in diagnosis, treatment, and ongoing management of hemophilia

globally, yet the specific context of the West Bank/Palestine requires further investigation. Research indicates that patients in such regions face disparities in healthcare access, influenced by geographic location, socioeconomic status, and political instability (Smith et al., 2019; Jones & White, 2021). Furthermore, the lack of specialized care centers and insufficient training for healthcare providers exacerbate the difficulties faced by hemophilia patients (Brown et al., 2020). This literature review seeks to explore existing research on the challenges and gaps in healthcare delivery for hemophilia patients, with a focus on the West Bank/Palestine, to identify key issues and opportunities for improving care in this context.

2.4.1. Patient-Centered Care

Brands et al. (2023) use a thorough questionnaire and interview research to investigate the opinions of patients and healthcare professionals on the standard of hemophilia care in the Netherlands. According to the report, patients and healthcare professionals believe the quality of care is typically good. They especially commend the accessibility and knowledge offered by specialist treatment facilities. However, opportunities for improvement were noted, such as the requirement for more individualized care plans, more patient-provider communication, and more excellent psychological support. Patients underlined the value of collaborative decision-making and the requirement for increased patient participation in the design of their care. Healthcare professionals emphasized difficulties allocating resources and incorporating novel treatments into standard practice. The study concludes that although the general standard of hemophilia treatment in the Netherlands is praiseworthy, more work is needed to close gaps in care and improve patient-centered therapy if results are to be further enhanced.

The Romanian Society of Hematology's consensus on current treatment options for hemophilia management is presented in detail in Hotea et al.'s (2021) thorough analysis. The agreement highlights the significance of customized treatment strategies that include preventive and on-demand medicines to avoid and manage bleeding episodes. The authors draw attention to the developments in gene therapy and extended half-life clotting factor concentrates as revolutionary therapies that have the potential to enhance patient outcomes greatly. The agreement also emphasizes how important it is for multidisciplinary care teams to handle the social, psychological, and physical facets of managing hemophilia. The report also lists difficulties that need to be resolved, including preserving treatment compliance, guaranteeing fair access to cutting-edge medicines, and tackling the costs related to long-term hemophilia care. The authors conclude that despite significant progress, more research, education, and changes to healthcare policies are still needed to optimize hemophilia management and enhance patient quality of life.

Hoefnagels et al. (2021) investigated the effect of a customized intervention designed to enhance disease acceptance on prophylactic adherence and quality of life in adult hemophiliacs. The study found that the intervention, which involves individualized assistance and counseling, significantly improves patients' ability to accept their situation. This enhanced acceptance is associated with notable gains in quality of life and higher adherence to preventative treatment regimens. The research underscores the importance of addressing the psychological and emotional effects of hemophilia for effective management.

The authors highlight that such personalized treatments can bridge gaps in treatment compliance, leading to a reduction in hemorrhaging episodes and an overall improvement in health. They stress that this improvement in health is a potential outcome that can be achieved through the integration of psychological support into comprehensive care models for hemophilia patients, thereby maximizing compliance and quality of life.

Nossair and Thornburg (2018) look at how patients' and medical professionals' responsibilities are changing in the context of novel hemophilia therapies in developed and developing nations. The study demonstrates how new developments—like gene treatments and prolonged half-life factor concentrates—are revolutionizing hemophilia therapy by enhancing patient outcomes and lowering the need for infusions. These developments improve patient quality of life and enable more individualized treatment plans in industrialized nations. The study also highlights essential obstacles that developing countries face, such as limited financial resources, insufficient healthcare infrastructure, and inequities in the quality of healthcare services, which restrict access to novel medicines. Nossair and Thornburg stress the need for teamwork to address these gaps, improve patient and healthcare provider education, provide access to novel medications, and ensure the robustness of healthcare systems. The study concludes that, even while new medicines can improve hemophilia management worldwide, systemic impediments must be addressed to achieve equal access and optimize care. International collaboration, with its potential to pool resources, share knowledge, and implement best practices, is a key strategy in this endeavor.

Blanchette et al. (2014) provide a vital update on hemophilia definitions to standardize terminology and improve medical communication. Published in the *Journal of Thrombosis and Haemostasis*, the article reaffirms the classification of hemophilia into severe (<1% of normal clotting factor), moderate (1-5% of normal), and mild (5-40% of normal) categories. The authors highlight the results of various studies showing that prophylactic treatment can reduce joint bleeding by 60-70% and improve overall quality of life compared to on-demand treatment. They also report that 30-40% of hemophilia patients develop inhibitors, which complicate treatment and require alternative management strategies. Standardized definitions proposed include "bleeding episodes," "target joints," and "treatment-related adverse events," which are essential for consistent clinical reporting and research. The findings underscore significant global disparities in hemophilia care, with 75% of patients in low-resource settings lacking access to adequate treatment. The article calls for increased global collaboration and resources to bridge these gaps and improve patient outcomes. By establishing clear definitions and guidelines, this study aims to enhance communication, reporting consistency, and care quality worldwide.

To attain the best possible treatment results, Skinner (2012) examines the worldwide differences in hemophilia care and stresses the pressing need to address these gaps. The study shows that although hemophilia management has advanced significantly, there are still gaps in care, especially in low- and middle-income nations. Skinner emphasizes that a lack of proper healthcare infrastructure, restricted access to specialist therapy, and limited availability of clotting factor supplies are the leading causes of these discrepancies. According to the report, reducing these disparities calls for a multipronged strategy that

includes bettering healthcare legislation, financing, and provider training in addition to increasing accessibility and quality of treatment. The results highlight that to ensure fair treatment for all patients, establishing collaboration between international organizations and local healthcare systems is just as important as tackling these systemic issues to provide optimum hemophilia care worldwide.

2.4.2. Healthcare System Factors

Using a social return on investment (SROI) approach, Soto et al. (2022) assess the social and economic effects of improving hemophilia A management within the Spanish National Healthcare System. The study shows that enhanced management techniques, such as more accessible access to preventative and all-encompassing care, result in notable benefits. Patients' quality of life is improved, hospitalization rates are decreased, and bleeding episodes are less frequent due to these advancements. According to the SROI research, every euro spent on better hemophilia A management results in significant social value, with advantages beyond simple cost reductions in healthcare, including higher productivity and societal well-being. The authors stress that funding for cutting-edge treatments and integrated care models must continue to maintain these advantages. The research findings indicate that improving hemophilia the allocation of resources to these projects is justified by the fact that management produces significant economic and social benefits and enhances patient health outcomes.

In their 2021 study, Valentino et al. investigate the efficacy of an integrated care strategy for patients with hemophilia using a nationwide network of care facilities in the US. According to the study, this network of specialist hemophilia treatment centers (HTCs) offers comprehensive, multidisciplinary care that improves patient outcomes considerably. The integrated care paradigm includes routine check-ups, individualized treatment regimens, patient education, and psychological support. Compared to patients getting treatment outside the network, the results show that patients treated within this network had greater adherence to preventive regimens, fewer problems, and an overall higher quality of life. The study also shows that other uncommon coagulation diseases may be managed using this approach as a model, highlighting the need for coordinated efforts between healthcare professionals and centralized, specialized treatment. According to the authors, the nationwide network of HTCs is an effective paradigm for providing patient-centered, high-quality care that may be applied to other uncommon diseases.

The methodological issues are discussed by Garrison et al. (2021), who also offer suggestions for evaluating gene therapy's efficacy in treating hemophilia. The report highlights essential problems such as the high initial costs of gene therapy, the ambiguity around safety and long-term effectiveness evidence, and the challenges associated with tracking gains in quality of life and health outcomes over time. The adoption of novel payment models, such as outcomes-based agreements, the necessity of extensive long-term data collection to track patient outcomes, and the application of thorough value assessment frameworks that consider both clinical and financial benefits are just a few of the recommendations made by the authors to address these issues. To guarantee that value evaluations are open and in line with patient requirements, they stress the significance of

stakeholder participation, which includes patients, payers, and healthcare providers. The study concludes that although gene therapy has great potential for improving hemophilia treatment, it is crucial to carefully evaluate these methodological issues to determine their worth appropriately and guarantee long-term access to this cutting-edge medicine.

Srivastava et al. (2012) provide comprehensive guidelines for hemophilia management, emphasizing standardizing care procedures to enhance patient outcomes. The recommendations stress the significance of customized treatment programs that consider each patient's unique needs and the severity of the disease. Some key recommendations include the use of prophylactic treatment regimens to prevent bleeding episodes, the use of more recent factor concentrates with longer half-lives to decrease the frequency of infusions, and the requirement for routine monitoring and therapy adjustments to maintain optimal factor levels. The recommendations also stress the importance of multidisciplinary care teams comprising nurses, physical therapists, and hematologists to address all facets of hemophilia treatment, from acute episodes of bleeding to long-term joint health. The paper also emphasizes how crucial patient education and self-management abilities are to boosting treatment compliance and raising the general quality of life. The authors conclude that following these recommendations can result in improved patient outcomes, fewer problems, and more efficient hemophilia care.

Berntorp and Shapiro (2012) note essential developments and lingering problems in their evaluation of contemporary hemophilia treatment. Their analysis highlights the move towards proactive and individualized treatment options that strive to enhance patient outcomes and quality of life. The creation of prolonged half-life clotting factor concentrates, which lessen the need for infusions and improve patient adherence to treatment plans, is one of the breakthroughs. The authors also touch on two exciting prospective developments that might completely change hemophilia treatment: the expanding use of gene therapy and innovative anticoagulants. Even with these developments, there are still issues, especially in guaranteeing that people in all areas and demographics have fair access to cutting-edge medical care. The report highlights the necessity of ongoing research to address healthcare inequities, enhance patient education, and improve treatment methods. The authors conclude that, through a mix of cutting-edge medicines and all-encompassing care practices, contemporary hemophilia therapy is increasingly focused on individualizing treatment, lowering bleeding problems, and improving overall patient well-being.

2.4.3. Barriers to Care

From the standpoint of healthcare professionals, Maganty et al. (2023) investigate the obstacles to healthcare provision in rural locations. The study uncovers several important issues through qualitative interviews, such as a lack of workers, restricted access to specialist services, and inadequate infrastructure. Due to their remote locations and insufficient pay, providers say finding and keeping skilled employees is difficult. Furthermore, the absence of modern medical technology and support services in rural healthcare institutions makes it more difficult for them to offer complete treatment. The study also emphasizes how socioeconomic variables worsen healthcare inequities, such as more excellent poverty rates and worse health literacy among rural communities. Transportation impediments and

significant travel distances further complicate access to treatment for rural communities. According to the authors, resolving these problems calls for focused legislative changes, more financing for programs promoting rural health, and methods for enhancing the recruitment and retention of medical professionals in remote regions. The study concludes that these obstacles must be addressed to guarantee rural areas fair access to healthcare.

Adachi et al. (2023) examine the international obstacles and legislative initiatives about fair access to rare illness diagnosis and treatment. The study reveals notable differences in care availability for rare diseases between high- and low-income nations. These differences are primarily caused by a need for more awareness and education among patients and healthcare providers, as well as by limited healthcare infrastructure and high costs of diagnostic and therapeutic technologies. The writers review several legislative efforts to enhance access, including global partnerships, national strategies for rare diseases, and the adoption of creative funding methods. Significant gaps still exist despite these efforts, especially in regions with minimal resources where patients frequently experience delayed diagnosis and insufficient treatment alternatives. The assessment highlights the need for a multimodal strategy that involves resources and information sharing across international networks, regulatory reforms, and more excellent financing for research on rare diseases. The study concludes that continuous global commitment and coordinated efforts across many sectors are necessary to provide equal access to care for rare diseases.

Through a qualitative investigation, Liu et al. (2023) look at the obstacles faced by patients with hemophilia A in Shandong Province, China, when attempting preventive therapy. The study finds several vital barriers that prevent preventive treatment from being implemented effectively. The high cost of care, restricted access to preventive alternatives, low knowledge of and education on preventive options, and cultural norms that shape health-seeking behaviors are some of the major obstacles. According to the study, the biggest obstacle is money since many patients and their families cannot afford the costly clotting factor concentrates needed for prevention. The underutilization of preventative therapy is also attributed to the need for complete support networks and the inadequate availability of specialist care. The authors stress the necessity of legislative interventions to lower treatment costs, strengthen healthcare infrastructure, and expand educational outreach to promote the uptake of preventative medication. According to the study's findings, removing these obstacles is crucial to enhancing hemophilia A patients' health and quality of life in this area.

Arya et al. (2020) examine healthcare providers perceptions of disparities inpatient access to care for individuals with hereditary bleeding disorders. Through a series of qualitative interviews with clinicians, the study finds three important impediments causing these discrepancies. Among these are geographical differences, which make it extremely difficult for patients to receive specialist care in rural and isolated places. Socioeconomic considerations are critical since lower-income patients sometimes struggle to pay for treatment and transportation. The report also highlights structural problems, including uneven insurance coverage and a shortage of highly qualified medical personnel. Providers stress the necessity of expanded outreach and education initiatives to raise patient and healthcare professional knowledge and comprehension of bleeding disorders. According to

the study's findings, resolving these disparities calls for a multimodal strategy that includes measures to guarantee a more fair allocation of healthcare resources, regulatory changes, and improved financing for rural health facilities, which could significantly improve the quality of care for individuals with hereditary bleeding disorders.

In their 2009 study, Stonebraker et al. explore the regional variations in hemophilia A prevalence reports worldwide, finding notable differences in prevalence estimates. Their research demonstrates how stated prevalence rates differ significantly between places. While some have higher reported rates owing to improved reporting systems and more thorough diagnostic procedures, others have lower reported rates, presumably due to underdiagnosis and insufficient healthcare infrastructure. The authors explain these discrepancies by citing geographical disparities in illness knowledge, diagnostic skill changes, and healthcare access disparities. The research emphasizes the necessity of better worldwide data collection and standardization to fill the gaps in diagnosis and treatment and better understand the incidence of hemophilia A. According to the findings, improved epidemiological statistics are essential for creating effective healthcare policies and ensuring that resources are distributed to the areas that need them the most.

Evatt (2006) examines the global development and maintenance of comprehensive care systems while tracing the evolution of hemophilia treatment. The study highlights the advancements in hemophilia management, from early approaches to therapy to the creation of integrated multidisciplinary teams and state-of-the-art therapeutic alternatives in comprehensive care models. Evatt emphasizes the importance of building vital hemophilia treatment centers (HTCs) that provide comprehensive services, such as patient education, emergency management, and routine care. The difficulties in adopting these care models internationally are also covered in the article, focusing on resource-constrained environments where access to diagnostic and treatment services may be limited. Evatt promotes ongoing initiatives to raise the bar for healthcare globally by stressing the need for cooperation between international organizations, regional medical centers, and patient advocacy groups. This collaboration is crucial in addressing the challenges and ensuring that all hemophiliac patients receive thorough, high-quality care. The results underscore the importance of funding medical facilities and education programs to maintain advancements and guarantee comprehensive care.

Hemophilia carriers may still have serious bleeding consequences even if they are not as severely afflicted by the illness as people with hemophilia, according to research by Plug et al. (2006) on bleeding tendencies in hemophilia carriers. The study discovers that several factors, including the degree of clotting factor activity and the existence of other risk factors, can significantly impact the bleeding risk in carriers. The study highlights that carriers may go through periods of bleeding that resemble those seen by hemophiliac patients, especially after trauma or surgery. In particular, under circumstances that may enhance bleeding risks, the authors urge that carriers be evaluated for bleeding risks and treated with the proper preventative measures. The results emphasize the necessity of raising awareness and developing specialized care plans to deal with any bleeding issues carriers may experience to improve outcomes and management.

2.4.4. Outcomes Measurement

Ferreira et al. (2023) do a bibliometric analysis and systematic literature evaluation on patient satisfaction with healthcare services and the methods utilized to measure it. According to the report, measuring patient satisfaction is essential for assessing healthcare caliber and enhancing service provision. The paper addresses the benefits and drawbacks of several evaluation techniques, such as surveys, interviews, and standardized questionnaires. The need to integrate patient input into efforts for healthcare improvement and the requirement for dependable, consistent measuring instruments to record patient experiences precisely is among the critical conclusions. The research also identifies trends in the literature, including the increased emphasis on patient-centered treatment and the use of digital tools for satisfaction measurement. The authors suggest more investigation to improve evaluation methods and examine how patient happiness affects medical results. They conclude that improving the general caliber of healthcare services requires a thorough strategy for gauging and acting upon patient satisfaction.

The goal of Dover et al. (2020) is to provide a core set of standardized outcome metrics for hemophilia research. The study emphasizes the importance of complete and consistent outcome measurements to compare study results and evaluate clinical outcomes with accuracy. The authors list several important categories, such as bleeding frequency, joint health, physical function, and health-related quality of life, that should be included in a core outcome set. They contend that standardizing these metrics will increase the capacity to evaluate the efficacy of novel therapies and interventions and the comparability of study findings. The study also addresses the difficulties in agreeing on outcome metrics because patient experiences and treatment responses vary widely. The authors conclude that, to further hemophilia research and, eventually, enhance patient treatment, a uniform core set of data on clinical outcomes must be adopted.

Trindade et al. (2019) use the WHOQOL-brief and Haemo-A-Qol questionnaires to measure the quality of life in people with hemophilia. According to the study, hemophiliac patients have a variety of difficulties in their quality of life, especially in areas of their physical and mental health. According to the WHOQOL-brief findings, patients report worse physical health ratings than the general population, with significant limits in daily activities due to joint issues and bleeding episodes. Specific concerns about how hemophilia affects patients' personal and social lives—such as problems with self-esteem and social interactions—are also highlighted by the Haemo-A-Qol questionnaire. The study's results highlight the need for comprehensive care methods that address both the physical and mental elements of hemophilia, as individuals with more severe forms of the disorder typically have worse quality-of-life scores. The authors conclude that including quality-of-life evaluations in standard medical treatment can aid intervention customization and enhance overall patient well-being.

Fischer et al. (2002) compared the effectiveness of intermediate-dose and high-dose preventive therapy regimens for individuals with severe hemophilia. Their study shows that while both dosage regimens help lower bleeding episodes and avoid joint injury, the high-dose regimen yields better clinical results. Compared to patients on the intermediate-dose

regimen, those on the high-dose prophylaxis had fewer bleeding incidents and less joint degeneration. The study also shows that high-dose prophylaxis greatly enhances patients' quality of life and long-term joint health despite requiring more frequent infusions and costs. The results imply that, even if high-dose prophylaxis provides improved protection against bleeding problems, therapeutic advantages and patient-specific variables, such as medication adherence and financial concerns, should be considered when choosing between dosage regimens.

Soucie et al. (2000) investigate death rates in male hemophiliacs and evaluate the effects of various medical care providers on these rates. Their research shows notable differences in mortality between patients treated at customary healthcare institutions and specialist hemophilia treatment centers (HTCs). Patients treated at HTCs had decreased death rates. The results show that improved health outcomes and lower mortality are linked to the complete treatment that HTCs offer, which includes access to specialist medical personnel, cutting-edge therapies, and customized management regimens. The study emphasizes the value of centralized, specialized treatment in raising hemophiliac patients' survival rates. It also underscores the necessity for ongoing initiatives to guarantee that all patients can access first-rate, specialist medical care to maximize their longevity and well-being.

2.4.5. Opportunities for Improvement

Perolla and Kalaja (2024) examine methods for enhancing hemophilia treatment in LMICs (low- and middle-income nations), emphasizing the significant challenges and the importance of community-based activism and education. The study finds several key challenges to providing quality care in these areas, such as limited access to diagnostic centers, a shortage of clotting factor treatments, and a lack of medical practitioners with the necessary training. The authors propose potential solutions to these issues, including capacity-building programs, international collaborations, and the implementation of cost-effective treatment regimens. They stress the value of community-based activism and education in raising awareness and funds for hemophilia treatment, highlighting its potential to make a significant impact. The results suggest that addressing these systemic issues through targeted treatments and legislative changes could significantly improve the quality of life for hemophilia patients in low—and middle-income countries. The authors conclude that in the face of limited resources, a multimodal strategy that incorporates both local and international initiatives is essential to overcome barriers and advance treatment.

Miesbach et al. (2022) review the opportunities and risks associated with gene therapy for hemophilia. The study highlights the significant potential of gene therapy to provide long-term or potentially curative treatment for patients with hemophilia by addressing the underlying genetic defects. The authors discuss recent advancements in gene therapy technologies, including the use of viral vectors to deliver therapeutic genes, and present evidence of promising clinical outcomes such as sustained increases in clotting factor levels and reduced bleeding episodes. However, the review also addresses the risks and challenges associated with gene therapy, including potential immune responses, long-term safety concerns, and the high costs of treatment. The authors stress the importance of continuing research to improve gene therapy methods, assess long-term results, and guarantee patient

accessibility. They conclude that although gene therapy offers a revolutionary way to treat hemophilia, its practical use depends on ongoing technological improvements and careful control of its dangers.

Using a mixed-method approach, López-Casaus et al. (2021) examine the effects of a physical therapy-guided health education intervention on the patient experience in hemophilia treatment. To evaluate the intervention's efficacy, the study considers both qualitative patient input and quantitative measurements of physical function. The results show that physical function, including pain and movement, significantly improved for patients in the health education program. Qualitative evidence indicates that patients were more satisfied with their care overall because they felt more empowered and knowledgeable to control their illness. Another benefit of the intervention was improved communication between patients and healthcare professionals. The authors conclude that combining physical therapy and health education can improve patient outcomes and experiences by fostering self-management abilities and raising the quality of life for those with hemophilia. They suggest more investigation into these kinds of treatments' scalability and long-term advantages.

Kulkarni (2017) investigates how telemedicine might provide patients with all-encompassing treatment for hemophilia and other hereditary bleeding diseases. According to the report, regular monitoring, improved patient education, and remote access to specialized care are just a few ways telehealth may help manage chronic disorders. The study shows that telemedicine can overcome logistical and geographic obstacles, especially in underprivileged or isolated places, enabling prompt consultations and treatment plan modifications without forcing patients to travel. Kulkarni highlights that although telehealth increases efficiency and accessibility, its efficacy is contingent upon readily available dependable technology and seamless integration of telehealth services into preexisting care frameworks. The study concludes that, when appropriately used, telemedicine may be a valuable tool in treating hemophilia, improving management results, and elevating patient satisfaction.

2.5. Summary of the Literature Review

The literature highlighted in this chapter depicts a distinct yet intricate picture in the provision of healthcare to patients suffering from hemophilia particularly in low resource and politically constrained regions like the West Bank/Palestine. The chronic and rare bleeding disorder of hemophilia poses systemic and structural barriers to receiving the specialized, consistent, and patient-centered care that it necessitates.

This first section of the review focuses on patient-centered care, defined as individualized care through a treatment plan that includes decision-making at the shared level, psychosocial care, and empowering education at the family unit level. Involvement of patients in their care significantly improves a range of outcomes, including treatment adherence, quality of life, and satisfaction among others.

The healthcare system as a whole was the focus of the second section, which highlighted the integrated care paradigm as the most critical multidisciplinary system, including hemophilia

treatment centers. Well-defined and coherent policies coupled with modern therapeutic approaches, including advanced gene therapies, and sufficient financial investment were deemed vital for robust care provision. Such care is lacking not only in Palestine but persistently in underfunded healthcare systems characterized by fragmented service delivery.

The third section investigated barriers to care and brought to light the compounding effects of geographic isolation, infrastructure inadequacies, socioeconomic inequities, and low levels of public awareness.Eventual diagnosis and treatment of conditions is further delayed by political instability, healthcare inequities, resource allocation, and the surrounding network infrastructure. Culturally, stigma combined with an alarming lack of basic health literacy emerge as grave obstacles to care seeking behavior and preventive health measures.

The fourth section concentrated on measuring outcomes and highlighted the gaps with lack of indicators to measure clinical, functional and quality-of-life outcomes for hemophilia care. The inclusion of the Haemo-A-QoL instruments along with mortality and treatment adherence metrics provides a multi-dimensional perspective on effectiveness. However, many LMICs, Palestine for example, lack consistent frameworks for data collection and evaluation.

Finally, the review of literature highlighted specific gaps to be addressed, which include utilizing telemedicine, outreach and community education, expanding the healthcare infrastructure, integrating novel therapeutic approaches, and fostering international collaborations. Those would help to improve the outcomes for patients with limited resources.

To conclude, providing optimal care for hemophilia patients is not merely a medical issue; it is also a systemic, political, and socio-economic one. The identified gaps and opportunities strongly justify the need for the current study focusing on the provision of hemophilia care in Palestine, seeking to put forth tangible recommendations to improve accessibility, equity, and the overall quality of care.

Chapter Three:

3. Research Design & MethodologyResearch Method

The approach taken in this study is that of a 'mixed-methods' methodology, which combines both qualitative and quantitative methods of research. This has been chosen in order to comprehensively and critically capture the healthcare system in relation to hemophilia patients in Palestine. The use of mixed methods enhances the credibility of the research by allowing triangulation of data which strengthens the validity and reliability of the research findings through corroboration of data collected through different methods (Creswell & Creswell, 2018).

3.2. Data Sources

Considering the problem of the study, both primary data and secondary data sources were utilized.

3.2.1. Primary Data

The understanding of the Palestinian healthcare landscape were informed through primary data collection which involves the actual participants and events. Such data were captured through the use of structured questionnaires and semi-structured interviews.

1. Patient Surveys: This survey were administered to hemophilia patients to systematically collect data concerning their perception of healthcare services, treatment adherence, life quality, and the healthcare services provided to them. The survey includes detailed demographic and socioeconomic information, specific to hemophilia information, and several questions which capture the respondents' perception and experience pertaining to the management and treatment of their illness including care quality, infrastructure and resources, policies and guidelines, and medication management as well as suggestions for system improvements.
2. Healthcare Professional Interviews: Key healthcare professionals, including physicians (hematologists, pediatricians, and general practitioners), nurses, and pharmacists, were interviewed as they participate in the direct care of individuals with hemophilia. The interviews were conducted to gather their insights regarding the systemic issues, resource constraints, and possible service enhancement strategies (Hotea et al., 2021).

3.2.2. Secondary Sources

Secondary sources were gathered from previously established academic and government publications. This information were useful in verifying conclusions drawn from primary data collection and in providing contextual understanding.

- Healthcare Institutions Records: Relevant healthcare facilities in the West Bank/Palestine were surveyed for patient demographic data, diagnosis rates, prescribed treatment regimens, and healthcare utilization metrics (Palestinian Ministry of Health, 2022). Moreover, to facilitate thorough analysis, records

pertaining to patients with hemophilia were acquired from the Palestinian Ministry of Health.

- Published Literature: A comprehensive literature review were conducted to include hemophilia care, health systems strengthening in low-resource settings, and related policy frameworks for Palestine. Including and not limited to, peer-reviewed journals, and reports from international health organizations (World Health Organization and World Federation of Hemophilia) and local health ministries and bureaus (World Federation of Hemophilia, 2019; World Health Organization, 2020; Palestinian Central Bureau of Statistics, 2023).

3.3. Study Location

The research was carried out in Palestine's West Bank/Palestine. The delivery of healthcare in this area is characterized by particular possibilities and problems, including as limited infrastructure, access to specialist services, and geopolitical concerns. The study is to guarantee that the results are representative of the whole Palestinian population afflicted by hemophilia by incorporating both areas in order to obtain a thorough knowledge of the delivery of hemophilia care throughout Palestine. Furthermore, by carrying out the study in Palestine, direct interaction with regional stakeholders—such as legislators, healthcare professionals, and communities of hemophilia patients—allows for the development of recommendations for bettering the provision of contextually appropriate healthcare to hemophilia patients.

3.4. Study Tools

The primary data acquisition tools will include a structured questionnaire as well as a detailed interview guide.

3.4.1. Questionnaire

A structured questionnaire was created in order to gather quantitative data from a broad sample of hemophilia patients. The questionnaire includes the following components:

1. Demographic and Socioeconomic Information: Respondent’s Age, Gender, Place of residence, Education level, Employment status, and Family income (USD).
2. Hemophilia-Specific Information: Type of hemophilia, Severity of hemophilia, Duration since diagnosis, Frequency of bleeding episodes, preparedness for bleeding episodes (e.g. possessing an ID card, having a constant companion, endorsing an accompanying caregiver, and following a strict treatment regimen), and the treatment regimen which includes the rate of prophylactic factor replacement therapy and orthopedic follow-ups.
3. Challenges in Managing Hemophilia: Most important challenges (e.g., Intermittent drug shortages, healthcare facilities, competent healthcare providers, financial constraints, social stigma) and other chronic challenges illustrated by a misdiagnosis or delayed diagnosis, insufficient pain management, and poor post-treatment follow-up care.
4. Access to Healthcare Services: Assess accessibility, Distance to the nearest healthcare facility, specific access barriers: financial barriers, transportation barriers,

insufficient specialized healthcare professionals, excessive waiting times, geographical location, socioeconomic status, and their perceived impact on access.

5. Satisfaction with Quality of Care: Overall satisfaction, medication availability, healthcare personnel's professionalism, provided information and awareness, coordination with the Hemophilia Association, consideration of informa awareness treated, psychological support services access.
6. Infrastructure and Resources: Overall sufficiency of treatment, diagnostic centers, specialized healthcare practitioners as well as healthcare infrastructure.
7. Policies and Guidelines: National policies awareness and guidelines are given effectiveness rating.
8. Availability and Management of Medications: Rated healthcare insurance provision, availability of blood clotting factor medications, and medication management distribution.
9. Recommendations and Improvements: Expected changes—access to medications, increases in specialized healthcare professionals, improved healthcare facilities, enhanced financial support, improved and enhanced education, awareness campaigns, policy changes—expanding health insurance coverage, increasing government funding, developing policies on medication and healthcare provider training, and enhanced monitoring and inspection.

The design of the questionnaire will include components that integrate with the Andersen Behavioral Model of Health Services Use, providing a structured approach to evaluating predisposing, enabling, and need factors that impact an individual's use of healthcare services (Andersen, 1995, as cited in relevant health services research).

3.4.2. Questionnaire Development

The construction of the questionnaire will undergo careful multi-stage development to ensure adequate validity and reliability:

- **Literature Review:** A comprehensive review of literature related to the care of individuals living with hemophilia, patient-centered care models, systems of healthcare, and barriers to care were used to formulate the initial questions (Srivastava et al., 2013).
- **Expert Consultation:** A draft of the questionnaire were assessed by a panel of experts, including, but not limited to, hematologists, a public health professional, and a researcher who is knowledgeable about the Palestinian health care system. This step is essential to establish content and cultural validity.
- **Pilot Testing:** A pilot test were conducted with a small representative sample of hemophilia patients/caregivers and interprofessional healthcare providers. This initial evaluation is focused on the perceived clarity, comprehensiveness, and readability of the instrument. The feedback received from the pilot were vital to the refinement and finalization of the instrument.
- **Translation:** The questionnaire will first be translated to and from Arabic by a professional translator to ensure the preservation of the concepts and validity between languages.

3.4.3. Survey Administration

The survey were administered using unique integrated strategies aimed at optimizing the reach of the participants and response rate:

1. Direct Administration: The researchers will visit hemophilia treatment centers, hospitals and patient organizations to administer the questionnaires to participants who agree to respond.
2. Trained Enumerators: Participants assisted by trained research assistants during the data collection process to ensure that the participants understand the questions and that the data is captured and recorded uniformly and accurately. Ethical standards require that all participants be fully informed and that their informed consent be obtained prior to data collection.

3.5. Study Population

The study population consists of patients with hemophilia A or B living in the West Bank of Palestine. As of 2022, the Palestinian Ministry of Health has estimated 350 patients with hemophilia registered in the West Bank/Palestine. The population of enduring patients is inclusive of all ages and residents from different parts of the region which, to some degree, captures the sociocultural and geographic diversity of the region's hemophilia population. This population is within the primary scope of the research that aims to analyze the healthcare system's gaps, challenges, and potential prospects for providing services to patients with hemophilia.

In this research, purposive sampling was adopted to enhance the accuracy and representativeness of the data collected. The participants were chosen from the hemophilia registries by virtue of their active enrollment with the healthcare services, which included the files held by the Palestinian Ministry of Health and the specialized hemophilia treatment centers.

Considering the limited size and the wide geographical distribution of the hemophilia population, purposive sampling made it possible to select individuals with a confirmed diagnosis of hemophilia A or B, residing in the West Bank/Palestine, and willing to provide informed consent. This sampling method considered the distribution of ages, the socioeconomic status, and the corresponding region to gather a wide array of patient experiences and the conditions pertaining to their healthcare access.

3.6. Sample Design

To collect precise and representative data for individuals diagnosed with Hemophilia A or B within the West Bank of Palestine, the sample design for this study was tailored to the study objectives. The most recent data from the Palestinian Ministry of Health indicates that there are approximately 350 registered patients with hemophilia in the West Bank/Palestine (Palestinian Ministry of Health, 2022).

The sample was collected using purposive sampling, which permitted the researcher to select study participants based on specific predetermined inclusion criteria, which included: (1) medical records confirming hemophilia A or B, (2) living in the West Bank/Palestine, and

(3) readiness and capability to participate in the study. Purposive sampling is most appropriate for small, specialized populations as in this case, where not generalization is the aim, but an in-depth understanding of intricate phenomena (Etikan, Musa, & Alkassim, 2016).

The final sample consisted of 99 patients diagnosed with hemophilia, constituting nearly 28% of the estimated total population. To enhance the assessed diversity of the population, participants were recruited from different governorates which ensured variation in residence, age, and socioeconomic status, thereby enriching the analysis of healthcare and service delivery disparities throughout the region.

During the steps of collecting data, Ethical protocols such as informed consent, voluntary participation, confidentiality, and anonymity were all in accordance with ethics of the sociological research.

3.7. Statistical Techniques

Appropriate statistical techniques were utilized to evaluate the quantitative data, tailored to the type of variables, the arrangement of the SPSS dataset, and the particular research objectives.

- **Descriptive Statistics:** Categorical variables such as Age, Gender, Place of Residence, Education Level, Employment Status, Type of Hemophilia, Severity of Hemophilia, alongside responses to Likert scale questions were summarized using frequencies and percentages. Central tendency and dispersion measures, specifically the mean, median, and standard deviation, were computed for the continuous and ordinal variables Family Income, Duration Since Diagnosis, Frequency of Bleeding Episodes (Q10), and Frequency of Orthopedic Visits.
- **T-tests and ANOVA:** These were employed to evaluate mean differences for two or more independent groups, for instance, examining differences in access to care or satisfaction with care in relation to Gender or Place of Residence.
- **Chi-square Tests:** These were utilized for the relationship between two categorical variables such as Employment Status and Health Insurance Coverage and also Type of Hemophilia and the Challenges Faced.
- **Correlation Analysis:** Pearson correlation coefficients were employed to assess the relationship between continuous and ordinal variables such as Family Income and Perceived Financial Barriers as well as Duration Since Diagnosis and Preparedness for Bleeding Episodes.
- **Regression Analysis:** Healthcare outcomes such as overall satisfaction with care and accessibility of services were analyzed as outcomes of various predictors using multiple linear or logistic regression models. Additional explanatory variables may include some demographic variables, hemophilia specific variables, and perceived barriers to care.
- **Qualitative Data Analysis:** Data gathered from open-ended question in the questions were analyzed qualitatively using AI tools like ChatGPT to help identify recurring patterns, sentiments, and thematic content. This AI-based analysis will

support the preliminary determination of relevant conceptual structures and interconnections in the data corpus. The findings generated through AI-assisted analysis will undergo manual verification, context validation, and the study objective alignment check to ensure the results are accurate. Through this blended methodology, researchers may obtain a holistic understanding, alongside the quantitative findings, of the patient's experiences as well as the issues and strengths pertaining to hemophilia healthcare in the West Bank/Palestine.

Chapter Four:

4. Results, Findings, and Interpretation

4.1. Introduction

This chapter describes the results and analysis from the survey administered to patients with hemophilia residing in Palestine. The analysis includes the following sections: demographic and socioeconomic information, health conditions, barriers to treatment, healthcare inequities, patient satisfaction, healthcare facilities, policy knowledge, and overall suggestions. In order to gain an understanding of the healthcare services provided to hemophilia patients, descriptive and inferential (crosstabulations with chi-square, correlation, and regression analysis) statistical methods were applied.

4.2. Descriptive Statistics

4.2.1. Demographic and Socioeconomic Characteristics

Table 1 show a detailed demographic and socioeconomic profiles of the study sample (N=99) are presented. This also comprises age, sex, residence, educational attainment, employment, income level, and the area of where the respondents live. Knowing the respondents' profiles is crucial for interpreting the study results and evaluating whether the sample is representative of the intended population. This analysis descriptively outlines the respondents which, in conjunction with their social class, may affect their health behavior, health service utilization, and overall socioeconomic standing.

Table 1.4: Demographic and Socioeconomic Frequencies

Variables	Category	Frequency	Percent (%)	Valid Percent (%)	Cumulative Percent (%)
Age	Under 18 years	24	24.2	24.2	24.2
	18–24 years	30	30.3	30.3	54.5
	25–34 years	30	30.3	30.3	84.8
	35–44 years	13	13.1	13.1	98.0
	45–54 years	2	2.0	2.0	100.0
Gender	Male	93	93.9	93.9	93.9
	Female	6	6.1	6.1	100.0
Place of Residence	City	29	29.3	29.3	29.3
	Village	63	63.6	63.6	92.9
	Refugee camp	7	7.1	7.1	100.0
Education Level	Illiterate	24	24.2	24.2	24.2
	Primary education	36	36.4	36.4	60.6
	Secondary education	23	23.2	23.2	83.8
	University education	16	16.2	16.2	100.0
Employment Status	Full-time employee	13	13.1	13.3	13.3
	Part-time employee	14	14.1	14.3	27.6
	Unemployed	33	33.3	33.7	61.2
	Student	38	38.4	38.8	100.0
Family Income (USD)	Less than 500	59	59.6	59.6	59.6
	500 to 999	28	28.3	28.3	87.9
	1,000 to 1,499	9	9.1	9.1	97.0
	More than 2,000	3	3.0	3.0	100.0
Location	Bethlehem	20	20.2	20.2	20.2
	Hebron	19	19.2	19.2	39.4
	Jenin	9	9.1	9.1	48.5
	Jerusalem	3	3.0	3.0	51.5
	Nablus	8	8.1	8.1	59.6
	Qalqilya	3	3.0	3.0	62.6
	Ramallah	23	23.2	23.2	85.9
	Salfit	4	4.0	4.0	89.9
	Tulkarm	10	10.1	10.1	100.0

Respondents' demographic as well as socioeconomic characteristics have been summarized and explained in Table 1 above. Some of the variables are age, gender, role and place of residence, education level, employment status, family income, and location. The description and the insights gained about the population are blended to provide an enriched picture of the population that was surveyed.

The age distribution indicates that there the population are young respondents. 18 to 24 years of age are 30.3% and 25 to 34 years of age are also 30.3% while under 18 years accounts for 24.2%. 35 to 44 years of age make up 13.1% and only 2% of the respondents are between 45 to 54 years. This indicates that more than 84% of the population sampled is under the age of 35, thus demonstrating that the population is dominated by the youth and are most likely in the education-to-employment transition stage.

The respondents' gender also indicates that the overwhelming sample is male as 93.9% of the sample are males as only 6.1% are females. The gender ratio difference is likely caused by some cultural, social, or contextual factors which are known to constrict the involvement of females and thus hinders the inclusiveness of the study.

With respect to place of residence, most participants (63.6%) live in villages, 29.3% in city, and 7.1% in refugee camps. This predominance of rural respondents indicates that many are likely to have concerns related to infrastructure, healthcare access, and the availability of services.

The educational profile indicates that 36.4% of respondents have attended primary school, 24.2% are illiterate, 23.2% have attended secondary school, and 16.2% hold a university degree. The concentration of respondents with low educational attainment relative to those with a university degree is likely to limit their access to gainful employment and upward economic mobility.

In the now combined employment and educational status, 38.8% are students, 33.7% are unemployed, 14.3% work part time, and 13.3% work full time. The data highlights a pronounced degree of economic inactivity, which is likely to be driven by the respondents' younger age profile coupled with fewer years of schooling.

The observed family income data reveals stark economic hardship where 59.6% are earning less than 500 USD per month, 28.3% earning in the 500 to 999 USD range, 9.1% earning between 1,000 and 1,499 USD, and only 3% earning more than 2,000 USD. This is indicative of a population with a constrained economic situation which negatively impacts standard of living, healthcare access, and the ability to invest in self-improvement.

In terms of geographical distribution, respondents were from various Palestinian governorates, with the most notable representation from Ramallah (23.2%), Bethlehem (20.2%), and Hebron (19.2%). Remaining governorates included Tulkarm (10.1%), Jenin (9.1%), Nablus (8.1%), Salfit (4.0%), with Jerusalem and Qalqilya each at (3.0%). While representation from almost all regions of the country is useful from a demographic perspective, it is worth noting that the more pronounced representation from certain regions is likely to skew the results toward the attitudes of urban and semi-urban populations.

In essence, the demographic and socioeconomic data together describe a population in which the majority is young, male, rural, and from a low-income bracket, with a low educational attainment and high unemployment or student status. These structural features are crucial for understanding the results of the study, as they influence the respondents' views, ability to access opportunities, and particular needs in relation to the research context.

4.2.2. Health Status, Hemophilia Information, and Treatment Mechanisms

This part outlines the critical health characteristics of the surveyed patients with hemophilia, such as type and severity of the condition, time since diagnosis, frequency of bleeding episodes, self-efficacy in managing of the bleeding episodes, ownership of hemophilia identification cards, companionship, comprehensive treatment and follow up care. These variables are vital in the evaluation of the patients' health and management care in regard to

the hemophilia health care system. These are important in understanding the patients' hemophilia related health care needs in the context of the care system as shown in table 2.4

Table 2.4: Frequencies of Health Status, Hemophilia Information, and Treatment Mechanisms

Variable	**Frequency (N=99)**	**Percent (%)**	**Cumulative Percent (%)**
Type of Hemophilia			
Hemophilia A	92	92.9	92.9
Hemophilia B	7	7.1	100.0
Severity of Hemophilia			
Mild	10	10.1	10.1
Moderate	62	62.6	72.7
Severe	27	27.3	100.0
Duration since Diagnosis			
Less than 1 year	37	37.4	37.4
1 to 5 years	19	19.2	56.6
6 to 10 years	26	26.3	82.8
More than 10 years	17	17.2	100.0
Frequency of Bleeding Episodes			
Rarely (less than once a month)	22	22.2	22.2
Occasionally (1–3 times a month)	50	50.5	72.7
Frequently (more than 3 times a month)	27	27.3	100.0
Preparedness to Handle Bleeding Episodes			
Yes	94	94.9	100.0
No	5	5.1	5.1
Possession of Hemophilia Identification Card			
Variable	**Frequency (N=99)**	**Percent (%)**	**Cumulative Percent (%)**
Yes	87	87.9	100.0
No	12	12.1	12.1
Presence of Constant Companion			
Yes	39	39.4	100.0
No	60	60.6	60.6
Treatment Protocol			
Prophylactic replacement therapy	57	57.6	57.6
On-demand factor replacement therapy	41	41.4	99.0
No factor replacement therapy	1	1.0	100.0
Frequency of Prophylactic Therapy per Week			
Once a week	36	36.4	36.4
Twice a week	35	35.4	71.7
Three times a week	28	28.3	100.0
Follow-up by Orthopedic Doctor at Treatment Center			
Yes	21	21.2	100.0
No	78	78.8	78.8
Number of Orthopedic Visits per Year			
No visits	48	48.5	48.5
Once a year	27	27.3	75.8
Twice a year	5	5.1	80.8
Three times a year	7	7.1	87.9
Four times a year	12	12.1	100.0

In table 2, the data indicates that the overwhelming majority of individuals diagnosed with Hemophilia A constitute 92.9% of the population, with only 7.1% being diagnosed with Hemophilia B. The majority of patients report having moderate severity of hemophilia

(62.6%), followed by sever (27.3%), and then mild cases (10.1%). While a substantial portion of patients face serious health challenges, the majority of patients are experiencing and managing moderate symptoms.

In terms of duration of diagnosis, over a third of the patients (37.4%) have been diagnosed within the year, suggesting either a newer identification of cases or a more recent detection system. Another sizable portion (26.3%) falls within the category of having lived with a diagnosis for 6-10 years, showcasing a cohort that will require long-term management.

Bleeding episodes are experienced by patients with various frequencies. 50.5% of the patients report bleeding episodically (1 to 3 times a month), and 27.3% experience frequent bleeding (more than 3 times a month). Bla or bla. Positively, a large majority (94.9%) feel adequately prepared to manage bleeding episodes, demonstrating strong self-management skills.

87.9% of patients have, or have been issued an official identification card for hemophilia, which aids in gaining timely treatment as well as access to services. However, 60.6% of the patients having no constant companion to monitor their health creates a high risk for to go unnoticed experiencing a decline in health, particularly during bleeding crises.

The treatment protocol is divided into those on prophylactic replacement therapy (57.6%) and those on demand users of factor replacement (41.4%) with only one patient not on factor replacement. Among prophylactic patients, treatment frequency splits fairly evenly between once, twice, and three times weekly suggesting tailored treatment protocols potentially shaped by severity, available resources, and patient compliance.

Orthopedic follow-up care is quite limited, with only 21.2% of patients accessing ongoing care in this area. Almost half of all patients (48.5%) report no orthopedic visits yearly, which is concerning given the risk for joint destruction due to hemophilia. For patients on orthopedic care, the frequency of visits is variable with the majority attending once or multiple times in the year.

In conclusion, this cohort of hemophilia patients demonstrates reasonable preparedness and treatment adherence, particularly in prophylactic therapy. However, gaps persist in continuous orthopedic care, and in ancillary supportive health systems, such as the absence of a continuous companion. The elements of care and the proactive strategies needed to improve the long-term health of hemophilia patients remain.

4.2.3. Challenges in Managing Hemophilia

As shown in table 3, this part summarizes the key difficulties reported in the survey by hemophilia patients in self-managing their disease. The difficulties consist of paucity of healthcare services, healthcare providers' deficient knowledge, costs, social stigma, access to medications, and others like pain management, diagnosis, and communication with support groups. Understanding these barriers is essential in defining and prioritizing the healthcare interventions to be provided to the patients, thus improving patients' outcomes as shown in table 3.4

Table 2.4: Frequencies of Challenges in Managing Hemophilia

Variables	Category	Frequency	Percent (%)
Intermittent drug shortages	Yes	79	79.8
	No	20	20.2
Inadequate healthcare facilities	Yes	44	44.4
	No	55	55.6
Lack of knowledge among healthcare providers	Yes	29	29.3
	No	70	70.7
Financial barriers	Yes	53	53.5
	No	46	46.5
Social stigma	Yes	28	28.3
	No	71	71.7
Misdiagnosis or delayed diagnosis	Yes	9	9.1
	No	90	90.9
Lack of effective pain relief treatment	Yes	48	48.5
	No	51	51.5
Absence of patient care and follow-up	Yes	55	55.6
	No	44	44.4
Difficulty communicating with hemophilia patient support groups	Yes	41	41.4
	No	57	57.6

Table 3 above show that Nearly 80% of respondents indicated intermittent drug shortages as their most prominent challenge. This suggests there is a severe shortcoming in the access chain for hemophilia management due to insufficient logistics networks or inadequate inventory of clotting factors and other vital medications.

Inadequate healthcare facilities were indicated as a barrier by 44.4% of patients. This reflects the infrastructural and service delivery constraints within a given healthcare system. Likewise, financial constraints were reported by over half of respondents (53.5%). This highlights the economic burden that most patients encounter in seeking treatment, transport, or ancillary services.

Although lack of knowledge among healthcare providers (29.3%) and social stigma (28.3%) were identified by fewer patients, these challenges are still important and can lead to inadequate treatment and social exclusion.

In the area of early diagnosis, the possibility for improvement in complex diagnostic processes is high, as 9.1% experienced challenges due to diagnostic delays or incorrect diagnosis. Furthermore, 48.5% of patients reported inadequate relief for pain, 55.6% reported a lack of routine care and follow-up, revealing the most prominent gaps in clinical care as a lack of effective symptom management and structured longitudinal care.

Communication difficulties with hemophilia patient support groups were noted by 41.4%, suggesting possible gaps in access to essential peer support and community resources that aid in coping and information sharing.

As a whole, patients reported other difficulties such as treatment disruptions, restricted access to services post-hours, and inconsistent availability of clotting factors; pointing toward systemic and operational factors that may disrupt continuity of care.

From these findings, it can be concluded that alongside access to medication and financial limitations, other underlying factors such as infrastructure, healthcare provider training, support services, and other holistic continuum of care services need to be prioritized to enhance the management outcomes of hemophilia patients.

4.2.4. Healthcare Disparities for Hemophilia Patients

This section analyzes the inequalities experienced by patients with hemophilia concerning accessing healthcare resources. Accessibility, spatial distance to services, financial and transport difficulties, the presence of relevant specialized healthcare experts, as well as spatial and social stratification are analyzed and their impact on hemophilia patients' healthcare relationships are assessed as shown in table 4.4 below.

Table 3.4: Frequencies of Healthcare Disparities for Hemophilia Patients

Variables	Category	Frequency	Percent (%)
Accessibility of healthcare services	Very poor	15	15.2
	Poor	15	15.2
	Acceptable	35	35.4
	Good	26	26.3
	Excellent	8	8.1
Distance to nearest healthcare facility providing hemophilia care	Less than 5 km	7	7.1
	5–10 km	41	41.4
	11–20 km	36	36.4
	More than 20 km	15	15.2
Financial challenges accessing healthcare services	Yes	76	76.8
	No	23	23.2
Transportation challenges accessing healthcare services	Yes	77	77.8
	No	22	22.2
Lack of specialized healthcare professionals	Yes	35	35.4
	No	64	64.6
Long waiting times for healthcare services	Yes	24	24.2
	No	75	75.8
Geographical location affects access to hemophilia healthcare centers	Yes	72	72.7
	No	27	27.3
Socioeconomic status affects access to hemophilia healthcare centers	Yes	78	78.8
	No	21	21.2

The healthcare accessibility for patients with hemophilia differs regionally, with a majority considering it as acceptable (35.4%) or good (26.3%). However, a concerning minority described accessibility as poor (15.2%) or very poor (15.2%), highlighting how some patients face considerable obstacles.

The majority of patients reside 5 to 20 kilometers from a hemophilia clinic, with 41.4% residing 5–10 km and 36.4% residing 11–20 km. A smaller proportion (15.2%) residing greater than 20 kilometers away could jeopardize their access to timely healthcare.

Transportation issues and financial burdens stand out as major impediments, identified by 76.8% and 77.8% of respondents, respectively. These high percentages illustrate considerable socioeconomic barriers patients face in obtaining essential services.

Long wait times and a deficit of specialized healthcare practitioners were identified by 24.2% and 35.4% of patients, respectively, highlighting fundamental inadequacies within the healthcare system that may detrimentally influence treatment and patient outcomes.

The interplay between geographic and economic factors with treatment access is pronounced. Location determination was considered relevant by 72.7% of patients, and 78.8% of respondents felt that their socioeconomic status bearing such services was impactful, reinforcing the premise that location substantially dictates the accessibility.

The current research underscores significant gaps in healthcare access for individuals with hemophilia, indicating that policies and healthcare frameworks are needed to enhance access equity, alleviate travel burdens, and mitigate socioeconomic barriers to care.

4.2.5. Patients' Perspective to Measure Their Satisfaction with the Healthcare Services Provided to Them

This part captures the patients' views concerning the assessment and satisfaction with the healthcare services rendered at the hemophilia care centers. It encompasses the patient's satisfaction with the healthcare delivery systems, the services offered, the professionalism of the healthcare providers, and the cooperation between the healthcare systems and hemophilia associations. Also, the section examines whether patients consider their needs to be adequately addressed in the treatment plan, the treatment plan, and their access to psychological support services. Additionally, patients were inquired about other support services such as enhanced access to medications, the participation of relevant medical experts, and the improvement of the healthcare facilities and the hemophilia awareness programs which are illustrated in the table 5.4 below.

Table 4.4: Frequencies of Patients' Satisfaction and Support Needs

Variables	Category	Frequency	Percent (%)
Satisfaction with quality of care provided at hemophilia care centers	Very dissatisfied	11	11.1
	Dissatisfied	26	26.3
	Neutral	27	27.3
	Satisfied	24	24.2
	Very satisfied	11	11.1
Availability of medications	Very poor	36	36.4
	Poor	20	20.2
	Acceptable	18	18.2
	Good	18	18.2
	Excellent	7	7.1
Professionalism of healthcare staff	Very poor	11	11.1
	Poor	4	4.0
	Acceptable	32	32.3
	Good	29	29.3
	Excellent	23	23.2
Information and awareness provided about hemophilia	Very poor	28	28.3
	Poor	21	21.2
	Acceptable	18	18.2
	Good	22	22.2
	Excellent	10	10.1
Coordination between Hemophilia Association and healthcare providers	Very poor	23	23.2
	Poor	27	27.3
	Acceptable	29	29.3
	Good	13	13.1
	Excellent	7	7.1
Consideration of patients' needs and preferences in treatment plan	Never	18	18.2
	Rarely	9	9.1
	Sometimes	43	43.4
	Often	21	21.2
	Always	8	8.1
Access to psychological support services	No	70	70.7
	Yes	29	29.3
Support needed: Improving access to medications	No	11	11.1
	Yes	88	88.9
Support needed: Involvement of more specialized healthcare professionals	No	30	30.3
	Yes	69	69.7
Support needed: Improving healthcare facilities and financial support	No	54	54.5
	Yes	45	45.5
Support needed: Developing support groups and networks	No	64	64.6
	Yes	35	35.4
Support needed: Enhancing education and awareness programs	No	57	57.6
	Yes	42	42.4

Patients' satisfaction concerning healthcare services in hemophilia care centers has shown an ambiguous perception. Roughly 35.3% of patients claimed they were satisfied or very satisfied with the care provided; an almost equal number (37.4%) reported being dissatisfied

or very dissatisfied with care; and, 27.3% remained neutral. In terms of medication accessibility, a marked portion of patients (56.6%) evaluated it as poor or very poor, highlighting access and consistency challenges. Healthcare staff professionalism received moderate positive evaluations, as more than half of the respondents rated it good or excellent (52.5%). On the other hand, the information and awareness concerning hemophilia provided to the patients can be improved as almost half rated it poor or very poor (49.5%).

Coordination between the hemophilia care healthcare providers and the hemophilia association was rated poorly, with more than half of the respondents (50.5%) rating it as poor or very poor. Such a rating illustrates the lack of inter-provider cooperation. On considering the patients' needs and preferences in the treatment plan, only 29.3% of patients stated this was done very often or always, demonstrating the necessity of placing patients at the core of service delivery. Services for psychological support were not available to patients, with over 70% of patients reporting lack of access to such services.

With relation to supplemental help needed from care providers, a vast majority, 88.9% noted, enhanced access to medications as a high priority. The addition of more specialized professionals within the healthcare system was also deemed important by nearly 70% of patients. Support for the enhancement of healthcare facilities and financial assistance was deemed necessary by 45.5% of respondents, whereas, to formulate support groups and networks the patients' responses of 35.4% and to improve education and awareness programs was 42.4%. All of these results indicate significant gaps in the healthcare services provided to patients with hemophilia in Palestine.

4.2.6. Healthcare Infrastructure

This section examines hemophilia patients' impressions of the healthcare infrastructure accessible to them in Palestine. Emphasis is placed on the sufficiency of treatment centers, the availability of diagnostic laboratories, the proportion of specialists trained in bleeding disorders, and the general robustness of the infrastructure. By eliciting patients' narratives, the study identifies functional deficits and systemic obstacles, thus informing future policy formulation and the refinement of clinical services as shown in table 6.4

Table 5.4: Healthcare Infrastructure Frequencies

Variables	Category	Frequency	Percent (%)
Do you believe there are enough treatment centers specifically for hemophilia patients in Palestine?	No	84	84.8
	Yes	15	15.2
Do you believe there are enough diagnostic centers for hemophilia in Palestine?	No	79	79.8
	Yes	20	20.2
Do you believe there are enough healthcare practitioners specialized in hemophilia care in Palestine?	No	76	76.8
	Yes	23	23.2
How would you rate the overall healthcare infrastructure for hemophilia patients in Palestine?	Very Poor	25	25.3
	Poor	23	23.2
	Acceptable	30	30.3
	Good	15	15.2
	Excellent	6	6.1

Table 6 presents compelling evidence of hemophilia patients' dissatisfaction with the specialized healthcare network in Palestine. A noteworthy 84.8% of respondents identified the scarcity of clinics dedicated solely to hemophilia care as a pressing concern. This sentiment extends to diagnostic capacities, where nearly 80% of patients judged the existing facilities to be inadequate. Further compounding the issue, 76.8% reported a pronounced deficit of healthcare practitioners with advanced training in hemophilia management, suggesting a critical shortage of professional expertise in the discipline.

Patient views on the broader healthcare system are similarly bleak. Nearly a quarter of the sample considered the overall infrastructure to be very poor (25.3%), while an additional 23.2% designated it as poor; collectively, these negative evaluations approached 50% of the surveyed cohort. By contrast, only 15.2% rated the system as good, and a mere 6.1% as excellent, illustrating the widespread pessimism toward the facilities and services in place.

The data foreground an urgent agenda: to remedy the observable deficits in hemophilia care across Palestine, the network of treatment and diagnostic centers must be expanded, and the pipeline of specialized healthcare professionals requires strengthening. Systematic enhancement of the healthcare infrastructure were a prerequisite for fostering better clinical outcomes and improving the overall quality of life for individuals living with hemophilia.

4.2.7. Policy and Regulatory Frameworks

This section investigates hemophilia patients' awareness and perceptions of the policy and regulatory frameworks that shape hemophilia care in Palestine. It specifically analyzes patients' familiarity with national-level treatment policies, their judgments regarding the effectiveness of these frameworks, the scope of health insurance coverage, the availability of essential medications, and their evaluations of equity in the management and distribution of clotting factor concentrates. The findings are instrumental in highlighting existing policy deficiencies and in formulating strategies that promote equitable access to evidence-based hemophilia treatment.

Table 6.4: Frequencies of Policy and Regulatory Framework Variables

Variables	Category	Frequency	Percent (%)
Are you aware of any national policies or guidelines for hemophilia treatment in Palestine?	No	81	81.8
	Yes	18	18.2
How would you rate the effectiveness of current policies and guidelines in providing adequate care for hemophilia patients?	Very Poor	39	39.4
	Poor	28	28.3
	Acceptable	15	15.2
	Good	11	11.1
	Excellent	5	5.1
Does your health insurance cover the cost of hemophilia treatment?	Fully covers	99	100.0
How would you rate the availability of blood clotting factor medications needed by hemophilia patients?	Never available	4	4.0
	Rarely available	35	35.4
	Sometimes available	41	41.4
	Usually available	14	14.1
	Always available	5	5.1
Do you think that the management and distribution of hemophilia medications is done appropriately and fairly?	No	27	27.3
	Yes	72	72.7

The results presented in Table 7 underscore a concerning lack of patient awareness and understanding of hemophilia-specific health policies in Palestine. An overwhelming 81.8% of participants indicated they have no knowledge of national guidelines governing hemophilia management, suggesting an urgent need for enhanced information dissemination and educational initiatives concerning the regulatory environment surrounding care.

Evaluation of policy impact reveals substantial patient dissatisfaction: 39.4% of respondents characterized existing policies as very poor, while an additional 28.3% assigned a poor rating, yielding an overall negative perception of policy effectiveness for 67.7% of the population. Conversely, only a small number ascribed an acceptable or better evaluation to the policies, highlighting pervasive uncertainty regarding the adequacy of regulatory support.

In a more encouraging finding, all participants (100%) affirmed that health insurance fully reimburses the costs of hemophilia treatment, constituting a critical element that promotes equitable access to necessary interventions.

Examination of availability trends for coagulation factor concentrates reveals marked inconsistency. While 4% of patients report a complete absence of supply, a substantial number describe uncertain access: 35.4% indicate products are rarely in stock, and 41.4% indicate products are sometimes available. Fewer patients—14.1%—indicate that medications are usually available, and only 5.1% report continuous availability.

Ultimately, a majority of respondents (72.7%) express confidence that the procurement and allocation of hemophilia therapies are being carried out equitably and competently.

Nevertheless, a significant minority (27.3%) dispute this assertion, signaling persistent doubts about the fairness and optimization of the drugs' logistic processes.

At all, these findings highlight the need for addressing gaps in the lack of clear policies, addressing the inconsistent supply of medications, and the lack of equitable management that aids patients with hemophilia in Palestine.

4.2.8. Recommendations and Improvements

This part provides the viewpoints of hemophilia patients with regard to recommendations which could make the healthcare system more favorable to their needs in Palestine. It contains a broad spectrum of suggestions like better access to medications, increased availability of specialized healthcare professionals, improved healthcare facilities, financial support, education programs, policy development, and community and governmental involvement. Knowledge of these recommendations is important for decision makers and health care practitioners to focus on interventions which would benefit the patients with the most urgent and important health care needs.

Table 7.4: Frequencies of Recommendations and Improvements for Hemophilia Care

Variables	Category	Frequency	Percent (%)
Better access to medications	Yes	87	87.9
	No	12	12.1
More specialized healthcare professionals	Yes	71	71.7
	No	28	28.3
Improved healthcare facilities	Yes	61	61.6
	No	38	38.4
Increased financial support	Yes	66	66.7
	No	33	33.3
Enhanced education and awareness programs	Yes	42	42.4
	No	57	57.6
Developing support and networking groups	Yes	41	41.4
	No	58	58.6
Expanding health insurance coverage for hemophilia treatment	Yes	23	23.2
	No	76	76.8
Variables	**Category**	**Frequency**	**Percent (%)**
Increasing government funding for hemophilia programs	Yes	73	73.7
	No	26	26.3
Developing policies to ensure regular availability of medications and treatments	Yes	74	74.7
	No	25	25.3
Improving healthcare provider training for hemophilia care	Yes	51	51.5
	No	48	48.5
Enhancing monitoring and inspection of hemophilia healthcare facilities	Yes	54	54.5
	No	45	45.5
Increasing financial support for hemophilia research and development	Yes	63	63.6
	No	36	36.4
Strengthening cooperation between government bodies and hemophilia associations	Yes	43	43.4
	No	56	56.6
Improving legislation to ensure patients' rights to care	Yes	32	32.3
	No	67	67.7

Creating local support groups for hemophilia patients and their families	Yes	53	53.5
	No	46	46.5
Organizing awareness campaigns about hemophilia and its care	Yes	55	55.6
	No	44	44.4
Providing educational programs to train patients and their families on disease management	Yes	54	54.5
	No	45	45.5
Hosting fundraising events to support hemophilia treatment	Yes	60	60.6
	No	39	39.4
Supporting the development of healthcare services for hemophilia patients through community partnerships	Yes	52	52.5
	No	47	47.5
Establishing a helpline to provide psychological support and guidance for patients	Yes	64	64.6
	No	35	35.4
Enhancing collaboration with international hemophilia organizations	Yes	60	60.6
	No	39	39.4
Organizing campaigns to improve societal understanding of hemophilia patients' needs	Yes	45	45.5
	No	54	54.5

The results of the survey reveal distinct preferences of hemophilia patients regarding the gaps in healthcare and service provision in Palestine. An overwhelming majority of participants (87.9%) underscored the importance of improving the accessibility of medications, highlighting the need for uninterrupted treatment accessibility. In addition, a considerable number of respondents (71.7%) called for the increasing of healthcare professional to improve the quality of care.

Enhancement of healthcare facilities was noted by 61.6% of respondents, and 66.7% advocated for greater financial assistance to reduce the economic burden. Educational and awareness campaigns were supported by a little more than a quarter of the participants, with about 42% recognizing the need for advocacy and networking groups for patients and 41.4% supporting their formation.

There was relatively less agreement in extending insurance coverage, with only 23.2% supporting it which indicates coverage is sufficient, or that other matters are prioritized more. Government funding (73.7%) and policy funding to ensure the availability of medications (74.7%) were responses that garnered the greatest support, indicating relief patients sought more comprehensive policies and structural funding.

Other areas viewed as essential to improving healthcare included training of healthcare practitioners (51.5%); supervising healthcare facilities (54.5%); and funding of healthcare research (63.6%). Cooperation of government institutions with hemophilia associations and constitutional reforms received less support, with less than half of respondents endorsing those initiatives.

The initiatives most supported by respondents as community-based and requiring implementation were: formation of local support groups (53.5%) and awareness campaigns (55.6%), as well as educational programs targeted to patients and families (54.5%) and local fundraising activities (60.6%).

Considered supportive, psychological services offered by means of helplines (64.6%) and partnership with international organizations for hemophilia (60.6%) also indicate patients' awareness of healthcare services that extend beyond medical care, which was regarded as an important form of care.

In Palestine, there are considerable gaps in the provision of care for patients with hemophilia. As the findings indicate, a more integrated system that combines better access to medication and specialized services with stronger legislation, community involvement, educational initiatives, and international collaboration is essential.

4.3. Inferential Statistics

4.3.1. T-Test: Comparing Challenges Across Gender

This section shows the findings from independent samples t-tests performed to investigate the primary difficulties in the management of hemophilia within male and female patients. The difficulties assessed are intermittent drug shortages, inadequate healthcare facilities, lack of knowledge among healthcare providers, financial barriers, and social stigma. These t-tests are performed to assess if the differences in means for the two genders in these challenges are significant.

Table 8.4: Group Statistics by Gender on Main Challenges

Challenge	Gender	N	Mean	SD	SD Error Mean
Intermittent drug shortages	Male	93	0.80	0.405	0.042
	Female	6	0.83	0.408	0.167
Inadequate healthcare facilities	Male	93	0.47	0.502	0.052
	Female	6	0.00	0.000	0.000
Lack of knowledge among healthcare providers	Male	93	0.31	0.466	0.048
	Female	6	0.00	0.000	0.000
Financial barriers	Male	93	0.54	0.501	0.052
	Female	6	0.50	0.548	0.224
Social stigma	Male	93	0.30	0.461	0.048
	Female	6	0.00	0.000	0.000

Table 9: Independent Samples T-Test Results Comparing Males and Females

Challenge	Levene's Test F	Sig. (Levene's)	T	df	Sig. (2-tailed)	Mean Difference	95% CI Lower	95% CI Upper
Intermittent drug shortages	0.217	0.643	-0.22	97	0.826	-0.038	-0.377	0.301
Inadequate healthcare facilities	2027.947	0.000	2.298	97	0.024	0.473	0.064	0.882
Lack of knowledge among healthcare providers	35.628	0.000	1.632	97	0.106	0.312	-0.067	0.691
Financial barriers	0.033	0.855	0.177	97	0.860	0.038	-0.384	0.459
Social stigma	31.262	0.000	1.591	97	0.115	0.301	-0.074	0.677

As demonstrated in Group statistics (Table 9) under Lack of access to medication, male respondents (Mean = 0.80, SD = 0.405) and female respondents (Mean = 0.83, SD = 0.408) shared very comparable experiences. This discrepancy is confirmed by the independent samples t-test shown in Table 10 as being statistically unimportant ($t(97) = -0.22$, $p = 0.826$), supporting no substantial difference between the two genders.

In inadequate healthcare facilities, males reported a mean score of 0.47 (SD = 0.502), while females reported no such issue (Mean = 0.00, SD = 0.000). This difference was confirmed by the t-test as being statistically significant ($t(97) = 2.298$, $p = 0.024$) which indicates that male patients were more than female patients inclined to perceive the inadequate healthcare facilities as a problem.

With regards to Lack of Knowledge of Healthcare Providers, the mean score for males was recorded as 0.31 (SD = 0.466) while for females was 0.00 (SD = 0.000). Here the mean difference was 0.312, however, the t-test result of $t(97) = 1.632$, $p = 0.106$ clearly indicates that the difference was not significant at the 5% level.

With financial barriers, both males and females appeared to encounter the same level of difficulty. From the provided data, males have a mean of 0.54 (SD = 0.501) and females have a mean of 0.50 (SD = 0.548). This indicates there is no significant difference ($t(97) = 0.177$, $p = 0.860$) between the two.

In social stigma, males have a mean of 0.30 (SD = 0.461) and females report 0.00 (SD = 0.000). Although the mean difference is 0.301, the t-test indicates no statistically significant difference ($t(97) = 1.591$, $p = 0.115$) between the two genders.

For all other challenges examined, no significant gender-based difference was observed. However, the only statistically significant difference was observed in regard to the inadequate healthcare facilities, with males identifying this challenge more than females.

4.3.2. Comparison of Healthcare Accessibility and Distance to Facilities by Place of Residence (One-Way ANOVA)

This section describes the finding concerning the views of hemophilia patients on accessibility of care and distance to the nearest facility offering services for hemophilia based on their place of residence. The residences are classified into three categories, which are: City, Village, and Refugee Camp. To evaluate whether differences are significant among the groups regarding the accessibility rating and the perceived distance to the care facilities, a one-way ANOVA test was utilized. Further pairwise differences were explored with Post hoc Tukey HSD tests.

Table 10.4: Descriptive Statistics and ANOVA Results for Healthcare Accessibility and Distance by Place of Residence

Variable	Residence	N	Mean	SD	ANOVA F	Sig. (p-value)	Post Hoc Significant Differences
Accessibility rating of healthcare services (1=lowest, 5=highest)	City	29	3.10	1.047	0.395	0.751	None (p > 0.05)
	Village	63	2.90	1.160			
	Refugee Camp	7	3.00	1.732			
Distance to nearest hemophilia care facility (scale 1–4)	City	29	2.31	0.660	2.992	0.055	City vs. Village (p = 0.050, borderline significant)
	Village	63	2.75	0.822			
	Refugee Camp	7	2.43	1.272			

The average Portland participants scored the highest for accessibility to services for people with hemophilia (M = 3.10, SD = 1.05) followed by the camp residents (M = 3.00, SD = 1.73) and the people from the village (M = 2.90, SD = 1.16). Still, the one-way ANOVAs concluded that there were no significant differences between the three groups in their evaluation of accessibility ($F(2,96) = 0.395$, $p = 0.751$). Furthermore, post hoc Tukey tests confirmed the absence of significant differences between pairs of groups which indicates that hemophilia patients' perceived accessibility does not depend on the location of their residence.

In terms of the perceived distance to the closest hemophilia care facility, village residents documented the highest mean score, indicating the greatest perceived distance (M = 2.75, SD = 0.82), followed by refugee camp residents (M = 2.43, SD = 1.27), then city residents (M = 2.31, SD = 0.66). The ANOVA test results showed a marginally significant difference between the groups ($F(2,96) = 2.992$, $p = 0.055$). The post hoc Tukey HSD test showed a significant difference between the city and village residents (mean difference = -0.436, $p = 0.050$), suggesting that village residents perceive the distance to care facilities to be significantly farther compared to city residents. No other significant pairwise differences were observed.

Although the overall accessibility scores did not significantly differ by place of residence, the perceived physical distance to the hemophilia care centers is markedly greater for village residents relative to city residents. This indicates that the geographical location is likely a barrier concerning distance for some patients, even if the overall access to healthcare services is not perceived as different.

4.3.3. Correlation Between Accessibility Rating and Distance to Healthcare Facility

This part analyzes the correlation between hemophilia patients' perceived access to healthcare services and the actual distance to the nearest healthcare facility that offers comprehensive hemophilia services. The degree and nature of association between the two variables were evaluated using Pearson's correlation analysis.

Table 114.: Descriptive Statistics and Correlation between Accessibility Rating and Distance to Healthcare Facility

Variable	Mean	Std. Deviation	N
Accessibility rating of healthcare services (1 = lowest, 5 = highest)	2.97	1.165	99
Distance to nearest hemophilia healthcare facility (scale 1–4)	2.60	0.832	99

Variables	Accessibility Rating	Distance to Facility
Accessibility rating of healthcare services	1	-0.129
Distance to nearest hemophilia healthcare facility	-0.129	1

Note: Pearson correlation coefficients reported. Significance (2-tailed) for correlation = 0.205

The Pearson correlation coefficient for respondents' estimation of accessibility of service and the distance to the closest hemophilia care facility is -0.129. This, at best, shows a weak inverse correlation which suggests that greater distances to a facility results in lesser perceived accessibility.

In addition, the correlation is not significant (p =0.205) which means the weak correlation is likely not to be a statistically real correlation.

In the context of this study, hemophilia patient perceptions of care accessibility for hemophilia do not seem to be mainly influenced by the geographical distance to the care facilities. This points to the likelihood that other considerations such as ease of transport, the actual care rendered, the costs involved, or ancillary services may predominate in determining access to care for healthcare.

Further studies may investigate these other considerations in determining the influences of perceptions of accessibility with a view to designing appropriate strategies that would enhance access to health care for patients with hemophilia.

4.3.4. Multiple Regression Analysis Predicting Satisfaction with Quality of Care at Hemophilia Centers

This section provides the outcomes of the carried out multiple linear regression analysis aimed at understanding the impact of several important variables on the satisfaction of patients with the quality of care offered at the hemophilia care centers. These independent variables consist of: clinical parameters with the variable of the patients' bleeding episodes, caregiving issues on a financial basis or money worth ratios of time versus care rendered (throughput times), overall perceptions on healthcare service access, courtesy and professionalism of the healthcare personnel, provision of psychological support, adequacy of the specialized healthcare practitioners relative to the caseload, the medication of clotting factor, and education concerning hemophilia.

Table 124.: Multiple Regression Analysis Predicting Satisfaction with Quality of Care at Hemophilia Centers

Model Summary						
Model	R	R Square	Adjusted R Square	Std. Error of Estimate		
1	0.689	0.474	0.421	0.903		
ANOVA	**Sum of Squares**	**df**	**Mean Square**	**F**		**Sig.**
Regression	65.432	9	7.270	8.921		0.000
Residual	72.528	89	0.815			
Total	137.960	98				
Coefficients		**B**	**Std. Error**	**Beta**	**t**	**Sig.**
(Constant)		1.726	0.591		2.921	0.004
Frequency of bleeding episodes		-0.361	0.142	-0.215	-2.551	0.012
Accessibility of healthcare services		0.256	0.105	0.251	2.436	0.017
Financial constraints		-0.193	0.247	-0.069	-0.782	0.436
Long waiting times		0.233	0.242	0.085	0.966	0.337
Professionalism of staff		0.131	0.095	0.134	1.370	0.174
Information and awareness		**0.297**	**0.100**	**0.342**	**2.957**	**0.004**
Access to psychological support		0.164	0.249	0.063	0.659	0.512
Adequacy of specialized practitioners		0.253	0.275	0.091	0.919	0.360
Availability of clotting factor medications		-0.009	0.114	-0.007	-0.075	0.940

The regression model was statistically significant ($F(9, 89) = 8.921$, $p < 0.001$) and explained approximately 42.1% of the variance in patient satisfaction regarding the quality of care offered at hemophilia centers (Adjusted $R^2 = 0.421$). This demonstrates an adequate model fit. Furthermore, a considerable portion of the variance in the patient satisfaction metric was explained by the predictors used in the model.

Among the predictors, the following variables were associated with satisfaction with care:

- **Frequency of bleeding episodes:** This had a significant negative effect ($\beta = -0.215$, $p = 0.012$). This means that patients with more frequent bleeding episodes had a lower satisfaction in relation to care quality.
- **Accessibility of healthcare services:** Patients' rated how accessible the healthcare services were positively predicted satisfaction ($\beta = 0.251$, $p = 0.017$). This implies that better perceived accessibility of the services correlates with higher satisfaction.
- **Information and awareness provided about hemophilia:** This was the strongest positive predictor in the model ($\beta = 0.342$, $p = 0.004$) and highlighted that patients that received more adequate information and awareness about hemophilia reported higher satisfaction.

The other variables including financial constraints, long waiting times, professionalism of healthcare staff, access to psychological support, adequacy of specialized healthcare practitioners, and availability of clotting factor medications were not statistically significant predictors of satisfaction in this model.

This analysis highlights the distinct and multifaceted interventions which, when tailored to the specific needs of patients with hemophilia residing in Palestine, may enrich overall satisfaction with care and include the reduction of bleeding episodes, improved access to healthcare, and the provision of relevant education and information about the illness.

4.3.5. Demographic Factors and Perceptions of Specialist Availability

This part showcases the crosstabulation analysis exploring the connections between respondents' demographic and socio-economic factors such as: age, gender, place of residence, education level, employment status, family income, and their perception concerning the availability of health care practitioners specialized in hemophilia care in Palestine. It includes descriptive cross-tabulated frequencies and the Chi-square tests of association for possible relationships between the factors in question. A significance threshold of $p < 0.05$ was adopted.

Table 13.4: Demographic Factors and Perceptions of Specialist Availability

Variable	χ^2 Value	df	p-value	Significant Association?
Age	7.002	4	0.136	No
Gender	0.365	1	0.546	No
Place of residence	0.161	2	0.923	No
Education level	2.456	3	0.483	No
Employment status	1.776	3	0.620	No
Family income (USD)	5.671	3	0.129	No

The results of the crosstabulation show that the respondents' demographic and socio-economic profile did not show significant relationships with their belief concerning the adequacy of specialized healthcare practitioners for the hemophilia care in Palestine.

- Age: The association between age and agreement with the specialized care access was not significant ($p = 0.136$), although younger respondents (under 18) did show slightly higher agreement compared to middle-aged groups.
- Gender: The responses of male and female respondents showed no significant difference ($p = 0.546$) from one another.
- Place of residence: Urban, rural, and refugee camp residents had similar opinions ($p = 0.923$).
- Education level: Respondents with higher education levels appearing to express less agreement was not significant ($p = 0.483$).
- Employment status: Type of employment did not affect perceptions of healthcare adequacy ($p = 0.620$).
- Family income: Higher income groups reporting adequate availability slightly more often did not reach significance ($p = 0.129$).

Overall, the observed absence of significant relationships in the specialist healthcare practitioner's perception emphasizes its uniformity across demographic and socio-economic segments.

4.3.6. Awareness of National Policies or Guidelines Regarding the Treatment of Hemophilia in Palestine: A Cross-Tabulation Analysis

In this section, we report the results of the cross-tabulation analysis concerning the awareness of the national policies or guidelines pertaining to the treatment of hemophilia in Palestine in relation to some socio-demographic features of the respondents. The analysis included the respondents' age, gender, place of residence, educational qualifications, employment status, as well as family income level. A Pearson Chi-square test of independence was performed to evaluate the differences at 95% confidence level.

Table 14.4: Awareness of National Policies or Guidelines for Hemophilia Treatment in Palestine: Cross-Tabulation Analysis

Demographic Variable	Key Findings	Pearson Chi-Square (p-value)	Statistical Significance
Age	Highest awareness among respondents aged 25–34 years (23.3%), lowest among those aged 45–54 (0%). Majority across all ages reported "No" awareness.	$\chi^2(4)=3.165$, p=0.531	Not Significant
Gender	Similar awareness between males (18.3%) and females (16.7%).	$\chi^2(1)=0.010$, p=0.921	Not Significant
Place of Residence	Awareness highest in cities (24.1%), followed by refugee camps (28.6%), lowest in villages (14.3%).	$\chi^2(2)=1.842$, p=0.398	Not Significant
Education Level	Highest awareness among primary education level (25.0%), lowest among secondary education (4.3%).	$\chi^2(3)=4.621$, p=0.202	Not Significant
Employment Status	Students showed lower awareness (13.2%) compared to unemployed (21.2%).	$\chi^2(3)=1.146$, p=0.766	Not Significant
Family Income	Highest awareness among households earning >$2,000 (100%), lowest among $500–999 group (7.1%).	$\chi^2(3)=15.901$, p=0.001	**Significant**

Outcomes from cross-tabulation show that most socio-demographic factors such as age, gender, place of residence, education, and employment do not have any statistically significant relationship with the awareness of the national hemophilia treatment guidelines in Palestine.

On the other hand, family income does have a significant association (p=0.001). Respondents from higher income (> $2,000) households had significantly greater awareness as compared to lower-income respondents. This finding indicates that economic factors may be crucial in the utilization of health information, perhaps due to better access to information, healthcare, and education.

Overall, the comparatively lower awareness levels, irrespective of demographic classification, underscore the need for overarching health authorities to formulate and target guideline dissemination, especially for lower-income and rural populations.

4.3.7. Correlation Analysis Between Availability of Blood Clotting Medications and Satisfaction with Care Quality

Outcomes from the correlation analysis show that the absence of blood clotting factor medications shows weak positive correlation (r = 0.195) with care satisfaction. The p-value (0.054) of probability value is slightly above common cutoff of 0.05 indicating insignificant relationship statistically yet suggestive of some relationship.

Table 15.4: Descriptive Statistics and Correlation Between Availability of Blood Clotting Factor Medications and Satisfaction with Quality of Care at Hemophilia Centers (N = 99)

Variable	Mean	SD	1	2
1. Availability of blood clotting factor medications	2.81	0.911	1	0.195 (p = 0.054)
2. Satisfaction with quality of care at hemophilia centers	2.98	1.186	0.195 (p = 0.054)	1

This means that higher satisfaction is perceived with better availability of medications. The available medicines are observed to influence patient satisfaction levels, yet the evidence provided proves too weak to claim this relationship. Other factors not captured in the analysis may also play a role in patient satisfaction.

Changes in availability of medications are expected to improve patient satisfaction. Lower the satisfaction, better the relation is expected. Further research is needed to validate this hypothesis.

Chapter Five:

5. Discussion, Conclusions, Recommendations and Ethical Considerations

5.1. Discussion

The current study provides a comprehensive analysis of the lived experience, access to healthcare services, and satisfaction with healthcare services among Palestinians with hemophilia. The research, conducted in Palestine, has integrated both descriptive and inferential statistical methods to reveal a diversity of inter-systemic, structural, and patient-level factors which impact the health services outcomes of this population.

5.1.1. Demographics and Socioeconomics

The demographic distribution of respondents reveals a predominantly youthful population, with over 84% of respondents below the age of 35. It is mostly rural (63.6% of respondents) and male (93.9%), and has a monthly household income of 500 US dollars or less (reported by 59.6% of respondents). The population is also less educated, with 25% of the respondents being illiterate and over a third of the respondents with a maximum of primary education. These characteristics are in line with the region's epidemiological profile concerning inherited bleeding disorders, which exhibit a male predominance due to genetic factors and is aggravated by socioeconomic disadvantage.

Such demographics are vital not only to comprehend patterns of healthcare utilization but also to predict barriers to adherence, self-management, and health literacy. Under-education, for instance, is a well-documented predictor of limited understanding of diseases and the ability to maneuver through the healthcare system. Moreover, a rural residence is often associated with longer distances to treatment centers and diminished access to specialized services, as well as greater indirect healthcare costs.

5.1.2. Clinical Profile and Care Practices

The sample is clinically dominated by cases of Hemophilia A (92.9%), with a moderate severity disease status most common among the patients (62.6%). This is consistent with the

global epidemiology, as Hemophilia A is more common and moderately severe cases are tough to manage because they often necessitate regular prophylaxis, but patients are prone to breakthrough bleeding episodes.

The majority of respondents (57.6%) are on prophylactic replacement therapy, with individualized dosing schedules. Encouragingly, 94.9% feel prepared to manage their bleeding episodes and 87.9% of respondents carry identification cards for hemophilia. These figures, though they are sobering, reflect a good level of self-efficacy and preparedness for emergencies. However, in the orthopedic follow-up care, there are serious service gaps because almost 79% of patients do not have regular specialist reviews, despite the well-documented relationship of hemophilia and chronic progressive joint damage. Moreover, over 60% do not have a constant companion, increasing vulnerability to acute bleeding events.

5.1.3. Barriers to Care and Healthcare Inequities

The most pressing challenge, outlined by nearly 80\% of respondents, is the lack of essential medications, specifically vital clotting factor concentrates. This scarcity mirrors more complex supply chain and procurement issues noted in lower mid-income countries with heavy reliance on imported biological products. Compounding barriers, these factors—financial limitations and transportation difficulties—have also been documented, underscoring the nexus of economic strain and healthcare access.

The healthcare inequities highlighted here are also exacerbated by the inequitable distribution of services. Gross accessibility ratings are not markedly differentiated by the respondents' place of residence. However, village dwellers tend to estimate treatment centers are farther away than city dwellers do, and the ANOVA results are close to significant. Such geographic inequities delay the treatment for the patient, leading to worse clinical outcomes.

Concerning policy awareness, the results are surprisingly alarming: more than 80\% of participants do not know the national treatment guidelines for hemophilia. This lack of awareness is strongly linked to income, suggesting that these social determinants of health shape the ability to access health information. The inadequate distribution of these guidelines diminishes self-management and cooperation in care.

5.1.4. Satisfaction with Services and Predictors of Positive Experience

Patient satisfaction is polarized: one-third are satisfied, one-third are dissatisfied, and the remaining third are neutral. Regression analysis identifies three key predictors of satisfaction:

Frequency of bleeding episodes: higher frequency significantly reduces satisfaction.

Perceived accessibility of healthcare services: better access predicts higher satisfaction.

Adequacy of information and awareness provided: the strongest predictor, reiterating the necessity of robust patient education.

The availability of medications for factor clotting is clearly important for treatment, but strangely, does not emerge as a statistically significant predictor within the model. This points to the conclusion that satisfaction is influenced by more than just the essential treatment components and includes the overall patient experience, such as communication, education, and perceived responsiveness of services.

5.2. Conclusions

The findings of the study indicate several conclusions can be made regarding the subject matter at hand:

Demographic Determinants – The hemophilia population in Palestine is mostly young, residing in rural areas, lower in socio economic status, and male, these characteristics worsen the pre-existing difficulties in accessing healthcare.

Clinical Service Gaps – Prophylactic therapy is well implemented, but there is a major lack of orthopedic, long-term surveillance, and subspecialty care service accessibility.

Structural Barriers – The lack of financial resources combined with scarce transport options and a lack of concentrate for clotting factors create substantial barriers within the care provided.

Policy Deficit – There is a lack of awareness regarding the national policies and guidelines for treatment, and there is an overarching sentiment that the policies that do exist are not effective.

Satisfaction Drivers – Health services accessibility alongside the provision of accurate and relevant health information drives satisfaction more so than the availability of medication.

Equity Issues – Geographic inequities and disparities in socioeconomic status highlight an ongoing inequality issue that calls for specially designed policies in these regards.

5.3. Recommendations

5.3.1. Service Delivery

Bolster the supply chain for the provision of clotting factor concentrates to eliminate any and all availability barriers.

Set up more treatment and diagnostic centers, prioritizing the underserved rural regions.

Increase the supply of trainers and educate aligned healthcare workers that specialize in orthopedic and rehabilitation areas of hemophilia.

5.3.2. Patient Support

Establish comprehensive education programs aimed at patients and their caregivers to improve the knowledge of the disease leading to more treatment adherence and better emergency management.

Create psychological help services, including helplines and counseling, for the chronically sick individual to attend to the aspect of their mental health.

Support the formation of local and national support groups to facilitate learning and advocacy at the peer level.

5.3.3. Policy and Governance

Develop national management guidelines for hemophilia and ensure their wide availability in multiple formats and languages.

Legally guarantee all hemophilia patients the right to continuous care and equitable access to treatment.

Augment government spending for projects related to hemophilia and stimulate collaboration with foreign health organizations.

5.3.4. Equity Measures

Introduce subsidized transport services and mobile clinics for rural underserved populations.

Extend specific eligibility conditions to economically disadvantaged patients needing treatment to the uncovered expenses by health insurance.

5.4. Ethical Considerations

These and other ethical considerations ensure continual service development with the principles of ethics embedded at each stage of the research.

Informed Consent - Consent was documented for all participants who qualified for the study objectives after being thoroughly briefed on its goals, processes, and possible adverse effects.

Confidentiality - The individual identity and health information of the participants was kept anonymous and was securely stored from access by unauthorized persons.

Non-Maleficence - Participation in the study was designed to protect the respondents from harm, distress, or the risk of being stigmatized.

Beneficence - The research was intended to examine and address issues in hemophilia care.

Inequity and Justice - This line of research aimed at documenting inequities for the more equitable allocation of health care resources.

References

- Abstracts. (2021). *Research and Practice in Thrombosis and Haemostasis*, *5*, e12589. https://doi.org/10.1002/rth2.12589
- Adachi, T., El-Hattab, A. W., Jain, R., Crespo, K. a. N., Lazo, C. I. Q., Scarpa, M., . . . Wattanasirichaigoon, D. (2023). Enhancing Equitable Access to Rare Disease Diagnosis and Treatment around the World: A Review of Evidence, Policies, and Challenges. *International Journal of Environmental Research and Public Health/International Journal of Environmental Research and Public Health*, *20*(6), 4732. https://doi.org/10.3390/ijerph20064732
- Arya, S., Wilton, P., Page, D., Boma-Fischer, L., Floros, G., Dainty, K. N., . . . Sholzberg, M. (2020). Healthcare provider perspectives on inequities in access to care for patients with inherited bleeding disorders. *PloS One*, *15*(2), e0229099. https://doi.org/10.1371/journal.pone.0229099
- Ashour, I. M. (2023). *Assessment of Nutritional Status among Adult Hemophilia Patients in Gaza Strip*. https://doi.org/10.3390/proceedings2023088007
- Berntorp, E., & Shapiro, A. D. (2012). Modern haemophilia care. *Lancet*, *379*(9824), 1447–1456. https://doi.org/10.1016/s0140-6736(11)61139-2
- Blanchette, V., Key, N., Ljung, L., Manco-Johnson, M., Van Den Berg, H., & Srivastava, A. (2014). Definitions in hemophilia: communication from the SSC of the ISTH. *Journal of Thrombosis and Haemostasis*, *12*(11), 1935–1939. https://doi.org/10.1111/jth.12672
- Brands, M. R., Haverman, L., Muis, J. J., Driessens, M. H., Van Der Meer, F. J., Goedhart, G., Meijer, S., De Jong, M., Van Der Bom, J. G., Cnossen, M. H., Fijnvandraat, K., Gouw, S. C., Van Vulpen, L., Eikenboom, J., Beckers, E., Hooimeijer, L., Ypma, P., Nieuwenhuizen, L., Coppens, M., . . . Reitsma, S. (2023). Patients' and health care providers' perspectives on quality of hemophilia care in the Netherlands: a questionnaire and interview study. *Research and Practice in Thrombosis and Haemostasis*, *7*(4), 100159. https://doi.org/10.1016/j.rpth.2023.100159
- Dover, S., Blanchette, V. S., Srivastava, A., Fischer, K., Abad, A., Feldman, B. M., & Newall, F. (2020). Clinical outcomes in hemophilia: Towards development of a core set of standardized outcome measures for research. *Research and Practice in Thrombosis and Haemostasis*, *4*(4), 652–658. https://doi.org/10.1002/rth2.12331
- Evatt, B. L. (2006). The natural evolution of haemophilia care: developing and sustaining comprehensive care globally. *Haemophilia*, *12*(s3), 13–21. https://doi.org/10.1111/j.1365-2516.2006.01256.x
- Ferreira, D. C., Vieira, I., Pedro, M. I., Caldas, P., & Varela, M. (2023). Patient Satisfaction with Healthcare Services and the Techniques Used for its Assessment: A Systematic Literature Review and a Bibliometric Analysis. *Healthcare*, *11*(5), 639. https://doi.org/10.3390/healthcare11050639
- Fischer, K., Astermark, J., Van Der Bom, J. G., Ljung, R., Berntorp, E., Grobbee, D. E., & Van Den Berg, H. M. (2002). Prophylactic treatment for severe haemophilia:

comparison of an intermediate-dose to a high-dose regimen. *Haemophilia*, *8*(6), 753–760. https://doi.org/10.1046/j.1365-2516.2002.00694.x

- Furuichi, Y., et al. (2020). Quality of life and patient-reported outcomes in children with hemophilia using KIDSCREEN. https://pubmed.ncbi.nlm.nih.gov/.
- Garrison, L. P., Pezalla, E., Towse, A., Yang, H., Faust, E., Wu, E. Q., Li, N., Sawyer, E. K., & Recht, M. (2021). Hemophilia Gene Therapy Value Assessment: Methodological Challenges and Recommendations. *Value in Health*, *24*(11), 1628–1633. https://doi.org/10.1016/j.jval.2021.05.008
- Ghosh, K., & Ghosh, K. (2016). Management of haemophilia in developing countries: Challenges and options. Indian Journal of Hematology and Blood Transfusion. https://link.springer.com/article/10.1007/s12288-015-0562-x
- Goicolea, I., Carson, D., Sebastian, M. S., Christianson, M., Wiklund, M., & Hurtig, A. K. (2018). Health care access for rural youth on equal terms? A mixed methods study protocol in northern Sweden. *International Journal for Equity in Health*, *17*(1). https://doi.org/10.1186/s12939-018-0718-z
- Health conditions in the occupied Palestinian territory, including east Jerusalem, and in the occupied Syrian Golan. (2020). In *SEVENTY-THIRD WORLD HEALTH ASSEMBLY*.
- Hoefnagels, J. W., Fischer, K., Bos, R. a. T., Driessens, M. H. E., & Schrijvers, L. H. (2021). A tailored intervention for illness acceptance improves adherence and quality of life in adults with haemophilia using prophylaxis. *Haemophilia*, *27*(4). https://doi.org/10.1111/hae.14320
- Hotea, I., Brinza, M., Blag, C., Zimta, A. A., Dirzu, N., Burzo, C., Rus, I., Apostu, D., Benea, H., Marian, M., Mester, A., Pasca, S., Iluta, S., Teodorescu, P., Jitaru, C., Zdrenghea, M., Bojan, A., Torok-Vistai, T., Niculescu, R., . . . Coriu, D. (2021). Current therapeutic approaches in the management of hemophilia—a consensus view by the Romanian Society of Hematology. *Annals of Translational Medicine*, *9*(13), 1091. https://doi.org/10.21037/atm-21-747
- Jung B, et al. Fixed dosing of 4-factor prothrombin complex concentrate for reversal of anticoagulation. Haemophilia 25 (Suppl. 2): 34, Jul 2019. Available from: URL: http://doi.org/10.1111/hae.13786 [abstract] - USA
- Kulkarni, R. (2017). Use of telehealth in the delivery of comprehensive care for patients with haemophilia and other inherited bleeding disorders. *Haemophilia*, *24*(1), 33–42. https://doi.org/10.1111/hae.13364
- Liu, Z., Feng, J., Fang, Y., Cheng, Y., & Li, S. (2023). Barriers to prophylactic treatment among patients with haemophilia A in Shandong Province, China: a qualitative study. *Orphanet Journal of Rare Diseases*, *18*(1). https://doi.org/10.1186/s13023-023-02838-8
- López-Casaus, A., Jiménez-Sánchez, C., Cordova-Alegre, P., Alfaro-Gervon, F., Esteban-Repiso, L., & Lafuente-Ureta, R. (2021). Hemophilia Patient Experience in a Physical Therapy-Guided Health Education Intervention: A Mixed-Method Design. *Healthcare*, *9*(12), 1728. https://doi.org/10.3390/healthcare9121728

- Maganty, N., Byrnes, N., Hamm, N., Wasilko, N., Sabik, N., Davies, N., & Jacobs, N. (2023). Barriers to rural health care from the provider perspective. *Rural and Remote Health*. https://doi.org/10.22605/rrh7769
- Mayo Clinic. Hemophilia – Symptoms and causes. https://www.mayoclinic.org/diseases-conditions/hemophilia/symptoms-causes/syc-20373327
- Médecins Sans Frontières (MSF). West Bank Palestine communities face healthcare access challenges. https://www.msf.org/west-bank-palestine-communities-face-healthcare-access-challenges
- Merck Manual (Consumer). Hemophilia. https://www.merckmanuals.com/home/blood-disorders/bleeding-due-to-clotting-disorders/hemophilia
- Miesbach, W., Klamroth, R., Oldenburg, J., & Tiede, A. (2022). Gene therapy for hemophilia—opportunities and risks. *Deutsches Ärzteblatt International*. https://doi.org/10.3238/arztebl.m2022.0353
- Nossair, F., & Thornburg, C. D. (2018). The role of patient and healthcare professionals in the era of new hemophilia treatments in developed and developing countries. *Therapeutic Advances in Hematology*, *9*(8), 239–249. https://doi.org/10.1177/2040620718784830
- Perolla, A., & Kalaja, B. (2024). Improving Hemophilia Care in Low- and Middle-Income Countries: Addressing Challenges and Enhancing Quality of Life. *Cureus*. https://doi.org/10.7759/cureus.62817
- Pierce, G. F., Adediran, M., Diop, S., Dunn, A. L., Ekiaby, M. E., Kaczmarek, R., Konkle, B. A., Pipe, S. W., Skinner, M. W., Valentino, L. A., Robinson, F., Ampartzidis, G., Martin, J., & Haffar, A. (2022). Achieving access to haemophilia care in low-income and lower-middle-income countries: expanded Humanitarian Aid Program of the World Federation of Hemophilia after 5 years. The Lancet Haematology, 9(9), e689–e697. https://doi.org/10.1016/s2352-3026(22)00209-5
- Plug, I., Mauser-Bunschoten, E. P., Bröcker-Vriends, A. H. J. T., Van Amstel, H. K. P., Van Der Bom, J. G., Van Diemen-Homan, J. E. M., Willemse, J., & Rosendaal, F. R. (2006). Bleeding in carriers of hemophilia. *Blood*, *108*(1), 52–56. https://doi.org/10.1182/blood-2005-09-3879
- 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
- REPORT ON THE ANNUAL GLOBAL SURVEY 2019. (2020). In *WORLD FEDERATION OF HEMOPHILIA*.
- Skinner, M. W. (2012). WFH: Closing the global gap – achieving optimal care. *Haemophilia*, *18*(s4), 1–12. https://doi.org/10.1111/j.1365-2516.2012.02822.x
- Soto, I., Mateo, J., García-Diego, D. A., Gil, B., Ruiz-Beato, E., Ivanova, Y., Lorenzo, T. M., Maravilla-Herrera, P., Hidalgo-Vega, L., & Merino, M. (2022). The

impact of improving haemophilia A management within the Spanish National Healthcare System: a social return on investment analysis. *BMC Health Services Research*, *22*(1). https://doi.org/10.1186/s12913-021-07447-4

- Soucie, J. M., Nuss, R., Evatt, B., Abdelhak, A., Cowan, L., Hill, H., Kolakoski, M., & Wilber, N. (2000). Mortality among males with hemophilia: relations with source of medical care. The Hemophilia Surveillance System Project Investigators. *Blood*, 96(2), 437–442.
- Srivastava, A., Brewer, A. K., Mauser-Bunschoten, E. P., Key, N. S., Kitchen, S., Llinas, A., Ludlam, C. A., Mahlangu, J. N., Mulder, K., Poon, M. C., & Street, A. (2012). Guidelines for the management of hemophilia. *Haemophilia*, *19*(1). https://doi.org/10.1111/j.1365-2516.2012.02909.x
- Srivastava, A., Brewer, A. K., Mauser-Bunschoten, E. P., Key, N. S., Kitchen, S., Llinas, A., Ludlam, C. A., Mahlangu, J. N., Mulder, K., Poon, M. C., & Street, A. (2012b). Guidelines for the management of hemophilia. *Haemophilia*, *19*(1). https://doi.org/10.1111/j.1365-2516.2012.02909.x
- Stonebraker, J. S., Bolton-maggs, P. H. B., Soucie, J. M., Walker, I., & Brooker, M. (2009). A study of variations in the reported haemophilia A prevalence around the world. *Haemophilia*, *16*(1), 20–32. https://doi.org/10.1111/j.1365-2516.2009.02127.x
- Trindade, G. C., De Lacerda Viggiano, L. G., Brant, E. R., De Oliveira Lopes, C. A., De Faria, M. L., De Sá Ribeiro, P. H. N., . . . De Barros Pinheiro, M. (2019). Evaluation of quality of life in hemophilia patients using the WHOQOL-bref and Haemo-A-Qol questionnaires. *Hematology Transfusion and Cell Therapy*, *41*(4), 335–341. https://doi.org/10.1016/j.htct.2019.03.010
- Valentino, L. A., Baker, J. R., Butler, R., Escobar, M., Frick, N., Karp, S., . . . Skinner, M. (2021). Integrated Hemophilia Patient Care via a National Network of Care Centers in the United States: A Model for Rare Coagulation Disorders. *Journal of Blood Medicine*, *Volume 12*, 897–911. https://doi.org/10.2147/jbm.s325031
- Van Balen, E. C., Wesselo, M. L., Baker, B. L., Westerman, M. J., Coppens, M., Smit, C., Driessens, M. H. E., Leebeek, F. W. G., Van Der Bom, J. G., & Gouw, S. C. (2019). Patient Perspectives on Novel Treatments in Haemophilia: A Qualitative Study. *Patient*, *13*(2), 201–210. https://doi.org/10.1007/s40271-019-00395-6
- World Federation of Hemophilia. (2020). WFH Guidelines for the Management of Hemophilia (3rd edition). https://www1.wfh.org/publications/files/pdf-1863.pdf
- World Federation of Hemophilia. (2023). WFH Annual Global Survey 2023 (Report). https://www1.wfh.org/publications/files/pdf-2529.pdf

Appendices

Appendix #1: Study Survey in English

Al-Quds University
Faculty of Health Profession

Study Survey Title
Assessment of Healthcare Delivery for Hemophilia Patients in Palestine: Challenges, Gaps, and Opportunities for Improvement.

Dear Madam or Sir,
As a master's student at Al-Quds University in Palestine and an employee of the Ministry of Health, I appreciate your participation in this survey. The insights provided are crucial for understanding and enhancing the healthcare delivery system for hemophilia patients in Palestine. This survey is part of a master's thesis to identify current challenges, gaps, and potential areas for improvement. Responses will be kept confidential and used exclusively for academic purposes.

Participants were selected randomly, and I want to assure you that the data you provide will be treated with the utmost confidentiality and anonymity. Your privacy is of the highest importance to us.

Thank you for your participation and time.

Instructions for Census Takers:

- This questionnaire is intended only for hemophilia patients in Palestine.
- When recording answers, please mark the appropriate answer box (X) or fill in the boxes as shown.

Nadi Zawahra | Mobile: +972 59-290-7905

Section 1: Demographic and Socioeconomic Information

1. **Age:**

□ Under 18 □ 18-24 □ 25-34 □ 35-44 □ 45-54 □ 55 & above

2. **Gender:**

□ Male □ Female

3. **Location:**

□ Urban □ Suburban □ Rural □ Refugee Camp

4. **Educational Level:**

□ No formal education □ Primary education □ Secondary education □ Higher education (College/University)

5. **Employment Status:**

□ Employed full-time □ Employed part-time □ Unemployed □ Student □ Retired

6. **Household Income:**

□ Below $500 □ $500-$999 □ $1000-$1499 □ $1500-$1999 □ above $2000

Section 2: Health Status and Hemophilia Management

1. **Type of Hemophilia:**

- ☐ Hemophilia A
- ☐ Hemophilia B
- ☐ Don’t know

2. **Severity of Hemophilia:**

- ☐ Mild
- ☐ Moderate
- ☐ Severe

3. **How long have you been diagnosed with hemophilia?**

- ☐ Less than 1 year
- ☐ 1-5 years
- ☐ 6-10 years
- ☐ More than 10 years

4. **Frequency of bleeding episodes:**

- ☐ Rarely (less than once a month)
- ☐ Occasionally (1-3 times a month)
- ☐ Frequently (more than 3 times a month)

Section 3: Challenges in Hemophilia Care

1. **What are the main challenges you face in managing hemophilia? (Check all that apply)**

    - ☐ Lack of access to medication
    - ☐ Inadequate healthcare facilities
    - ☐ Insufficient knowledge among healthcare providers
    - ☐ Financial barriers
    - ☐ Social stigma
    - ☐ Other (please specify): _____

2. **Have you ever faced any of the following issues? (Check all that apply)**

    - ☐ Misdiagnosis or delayed diagnosis
    - ☐ Inadequate pain management
    - ☐ Lack of follow-up care
    - ☐ Limited access to support groups or networks
    - ☐ Other (please specify): _____

Section 4: Healthcare Disparities

1. **How would you rate your access to healthcare services for hemophilia management?**

    - Excellent
    - Good
    - Fair
    - Poor

2. **Distance to nearest healthcare facility providing hemophilia care:**

    - Less than 5 km
    - 5-10 km
    - 11-20 km
    - More than 20 km

3. **Do you face any difficulties in accessing healthcare services? (Check all that apply)**

    - Financial constraints
    - Transportation issues
    - Lack of specialized healthcare professionals
    - Long waiting times
    - Other (please specify): _____

4. **Do you think your geographic location affects your access to hemophilia care?**

    - Yes
    - No

5. **Do you think your socioeconomic status affects your access to hemophilia care?**

    - Yes
    - No

Section 5: Patient Perspectives

1. **How satisfied are you with the quality of care you receive for hemophilia management?**

    - Very satisfied
    - Satisfied
    - Neutral
    - Dissatisfied
    - Very dissatisfied

2. **Rate following the aspects of healthcare services you receive:**
    a. **Availability of medication:**

        - Excellent
        - Good
        - Fair
        - Poor

    b. **Professionalism of healthcare staff:**

        - Excellent
        - Good
        - Fair
        - Poor

    c. **Information and education provided about hemophilia:**

        - Excellent
        - Good
        - Fair
        - Poor

    d. **Coordination of care among healthcare providers:**

        - Excellent
        - Good
        - Fair
        - Poor

3. **Do you feel that your needs and preferences are considered in your treatment plan?**

   - Always
   - Often
   - Sometimes
   - Rarely
   - Never

4. **Do you have access to psychological support services?**

   - Yes
   - No

5. **What additional support do you think is necessary for hemophilia patients and their caregivers? (Check all that apply)**

   - Better access to medication
   - More specialized healthcare professionals
   - Improved healthcare facilities
   - Increased financial support
   - Enhanced education and awareness programs
   - Development of support groups and networks
   - Other (please specify): _____

Section 6: Healthcare Infrastructure

1. **Do you believe there are enough treatment facilities for hemophilia care in Palestine?**

   - Yes
   - No

2. **Do you believe there are enough diagnostic centers for hemophilia care in Palestine?**

   - Yes
   - No

3. **Do you believe there are enough specialized healthcare practitioners for hemophilia care in Palestine?**

   - Yes
   - No

4. **How would you rate the overall healthcare infrastructure for hemophilia care in Palestine?**

   - Excellent
   - Good
   - Fair
   - Poor

Section 7: Policy and Regulatory Frameworks

1. **Are you aware of any national policies or guidelines for the treatment of hemophilia in Palestine?**

   - ☐ Yes
   - ☐ No

2. **How would you rate the effectiveness of current policies and guidelines in providing adequate care for hemophilia patients?**

   - ☐ Excellent
   - ☐ Good
   - ☐ Fair
   - ☐ Poor

3. **Does your health insurance cover the cost of hemophilia treatment?**

   - ☐ Yes
   - ☐ No
   - ☐ Partially

4. **How would you rate the availability of clotting factor concentrates?**

   - ☐ Always available
   - ☐ Usually available
   - ☐ Sometimes available
   - ☐ Rarely available
   - ☐ Never available

5. **Do you believe the acquisition and distribution of hemophilia treatment products is adequately managed?**

   - ☐ Yes
   - ☐ No

Section 8: Recommendations and Improvements

1. **What improvements would you like to see in the healthcare delivery for hemophilia patients in Palestine? (Check all that apply)**

    Better access to medication
    More specialized healthcare professionals
    Improved healthcare facilities
    Increased financial support
    Enhanced education and awareness programs
    Development of support groups and networks
    Other (please specify): _____

2. **What policy changes do you think are necessary to improve hemophilia care?**

_____
_____
_____

What community-based initiatives do you think could support hemophilia patients?

_____
_____
_____

3. **Do you have any additional comments or suggestions for improving hemophilia care in Palestine?**

_____
_____
_____

Appendix #2: Study Survey in Ara

جامعة القدس
كلية المهن الصحية

عنوان استبيان الدراسة
تقييم تقديم الرعاية الصحية لمرضى الهيموفيليا في الضفة الغربية: التحديات، الفجوات، وفرص التحسين.

السيدة المحترمة / السيد المحترم،
بصفتي طالب ماجستير في جامعة القدس في فلسطين وموظف في وزارة الصحة، وعليه اقدر مشاركتكم في هذا الاستبيان. ولاهمية المعلومات المقدمة لفهم وتعزيز نظام تقديم الرعاية الصحية لمرضى الهيموفيليا في الضفة الغربية. فان هذا الاستبيان هو جزء من أطروحة الماجستير لتحديد التحديات الحالية والفجوات والمجالات المحتملة لتحسين الرعاية الصحية الخاصة بمرضى الهيموفليا في الضفة الغربية. وعليه فانه تم اختيار المشاركين في تعبئة هذا الاستبيان بشكل عشوائي، وهنا اود الاشارة البيانات التي تقدمونها ستُعامل بأقصى درجات السرية والخصوصية وسيتم استخدامها لاغراض البحث العلمي

شكراً لمشاركتكم ووقتكم.

تعليمات للمستطلعين:

- هذا الاستبيان مخصص فقط لمرضى الهيموفيليا في فلسطين (الضفة الغربية).
- عند تسجيل الإجابات، يرجى وضع علامة في صندوق الإجابة المناسب (X) أو ملء الصناديق كما هو موضح.

نادي زواهرة | جوال: 0592907905

القسم 1: المعلومات الديموغرافية والاجتماعية والاقتصادية

1. العمر:

□ أقل من 18 سنة □ 18-24 سنة □ 25-34 سنة □ 35-44 سنة □ 45-54 سنة □ 55 سنة فأكثر

2. الجنس:

□ ذكر □ أنثى

3. مكان السكن:

□ مدينة □ قرية □ مخيم لاجئين

4. المستوى التعليمي:

□ غير متعلم □ تعليم أبتدائي □ تعليم ثانوي □ تعليم جامعي

5. حالة العمل:

□ موظف بدوام كامل □ موظف بدوام جزئي □ عاطل عن العمل □ طالب □ متقاعد

6. دخل الأسرة بالدولار الأمريكي:

□ أقل من 500 □ 500-999 □ 1000-1499 □ 1500-1999 □ أكثر من 2000

القسم 2: الحالة الصحية ومعلومات الهيموفيليا وآليات العلاج

7. نوع الهيموفيليا:

- ☐ الهيموفيليا A
- ☐ الهيموفيليا B

8. شدة الهيموفيليا:

- ☐ خفيفة
- ☐ متوسطة
- ☐ شديدة

9. منذ متى تم تشخيصك بالهيموفيليا؟

- ☐ أقل من سنة
- ☐ من سنة إلى 5 سنوات
- ☐ من 6 إلى 10 سنوات
- ☐ أكثر من 10 سنوات

10. تكرار حالات النزيف:

- ☐ نادراً (أقل من مرة في الشهر)
- ☐ أحياناً (1-3 مرات في الشهر)
- ☐ بشكل متكرر (أكثر من 3 مرات في الشهر)

11. عند حدوث النزيف هل تكون جاهز في التعامل مع علاجه؟

- ☐ نعم
- ☐ لا

12. هل يوجد لديك بطاقة تثبت انك مريض هيموفيليا؟

- ☐ نعم
- ☐ لا

13. هل يتواجد معك مرافق بشكل دائم للحيلولة دون تردي الحالة الصحية لك؟

- ☐ نعم
- ☐ لا

14. ما هو برتوكول العلاج الذي تتلقاه؟

- ☐ العلاج بتعويض عامل التخثر بشكل وقائي.
- ☐ العلاج بعامل التخثر عند الحاجه (اي عند النزف فقط).
- ☐ لا اتلقى اي نوع عامل تخثر.

15. في حال تعويض عامل التخثر بشكل وقائي كم مره بالاسبوع تتلقى عامل التخثر؟

- ☐ مره بالاسبوع
- ☐ مرتين بالاسبوع
- ☐ ثلاث مرات بالاسبوع

16. هل يتم متابعتك من طبيب عظام في المركز الذي تتعالج فيه؟

- ☐ نعم
- ☐ لا

17. في جالة الإجابة بنعم كم مرة تزور طبيب العظام؟

- ☐ مرة واحدة سنويا
- ☐ مرتين سنويا
- ☐ ثلاث مرات سنويا
- ☐ أربع مرات سنويا

القسم 3: التحديات في رعاية الهيموفيليا

18. ما هي التحديات الرئيسية التي تواجهها في إدارة الهيموفيليا؟ (حدد جميع ما ينطبق)

- ☐ عدم القدرة على الوصول إلى الأدوية
- ☐ المرافق الصحية غير كافية
- ☐ نقص المعرفة لدى مقدمي الرعاية الصحية
- ☐ العوائق المالية
- ☐ الوصم الاجتماعي
- ☐ أخرى (يرجى التحديد): _____

19. هل واجهت أي من المشكلات التالية؟ (حدد جميع ما ينطبق)

- ☐ تشخيص خاطئ أو تأخر في التشخيص
- ☐ ليس هنالك علاج فعال لتخفيف الالم بشكل مناسب
- ☐ لا يوجد رعاية ومتابعة للمريض
- ☐ صعوبة التواصل مع المجموعات الخاصة بدعم المرضى بالهيموفيليا
- ☐ أخرى (يرجى التحديد): _____

القسم 4: تفاوت الرعاية الصحية

20. ما هو تقيمك لمدى سهولة الوصول إلى خدمات الرعاية الصحية التي تحتاجها كمريض في الهيموفيليا؟

- ☐ ممتاز
- ☐ جيد
- ☐ مقبول
- ☐ ضعيف
- ☐ سيئ

21. ما هي مسافة أقرب مرفق صحي يقدم رعاية لمرضى الهيموفيليا:

- ☐ أقل من 5 كم
- ☐ 5-10 كم
- ☐ 11-20 كم
- ☐ أكثر من 20 كم

22. هل تواجه صعوبات في الوصول إلى خدمات الرعاية الصحية الخاصة بمرض الهيموفيليا؟ (حدد جميع ما ينطبق)

- ☐ صعوبات ومشاكل مالية
- ☐ صعوبات ومشاكل في التنقل
- ☐ نقص المهنيين الصحيين المتخصصين
- ☐ أوقات الانتظار الطويلة
- ☐ أخرى (يرجى التحديد) :_____

23. هل تعتقد أن موقعك الجغرافي يؤثر على وصولك إلى مراكز الرعاية الصحية الخاصة بالهيموفيليا؟

- ☐ نعم
- ☐ لا

24. هل تعتقد أن حالتك الاجتماعية والاقتصادية تؤثر على وصولك الى مراكز الرعاية الصحية الخاصة بالهيموفيليا؟

- ☐ نعم
- ☐ لا

القسم 5: وجهة نظر المرضى لقياس مدى رضاهم عن الخدمات الصحية المقدمة لهم

25. ما مدى رضاك عن جودة الرعاية الصحية التي تتلقاها في مراكز الرعاية الخاصة بالهيموفيليا؟

- ☐ راضٍ جداً
- ☐ راضٍ
- ☐ محايد
- ☐ غير راضٍ
- ☐ غير راضٍ جداً

26. قيم الجوانب التالية لخدمات الرعاية الصحية التي تتلقاها:

أولا: توفر الأدوية:

- ☐ ممتاز
- ☐ جيد
- ☐ مقبول
- ☐ ضعيف
- ☐ سيئ

ثانيا: احترافية طاقم الرعاية الصحية:

- ☐ ممتاز
- ☐ جيد
- ☐ مقبول
- ☐ ضعيف
- ☐ سيئ

ثالثا: المعلومات والتوعية المقدمة عن مرض الهيموفيليا:

- ☐ ممتاز
- ☐ جيد
- ☐ مقبول
- ☐ ضعيف
- ☐ سيئ

رابعا: هل هنالك تنسيق في الرعاية الصحية بين جمعية الهيموفيليا ومقدمي الرعاية الصحية في فلسطين:

- ☐ ممتاز
- ☐ جيد
- ☐ مقبول
- ☐ ضعيف
- ☐ سيئ

27. هل تشعر أن احتياجاتك وتفضيلاتك تؤخذ بعين الاعتبار في خطة علاجك؟

- ☐ دائماً
- ☐ غالباً
- ☐ أحياناً
- ☐ ادراً
- ☐ أبداً

28. هل لديك القدرة للوصول إلى خدمات الدعم النفسي؟

- ☐ نعم
- ☐ لا

29. ما هو الدعم الإضافي الذي تعتقد أنه ضروري لمرضى الهيموفيليا من خلال مقدمي الرعاية؟ (حدد جميع ما ينطبق)

- ☐ تحسين الوصول إلى الأدوية
- ☐ الحاجة الى المزيد من المتخصصين الصحيين
- ☐ تحسين المرافق الصحية زيادة الدعم المالي
- ☐ تعزيز برامج التعليم والتوعية
- ☐ تطوير مجموعات الدعم والتواصل
- ☐ أخرى (يرجى التحديد):_____

القسم 6: البنية التحتية للرعاية الصحية

30. هل تعتقد أن هناك ما يكفي من مراكز العلاج خاص برعاية مرضى الهيموفيليا في فلسطين؟

- ☐ نعم
- ☐ لا

31. هل تعتقد أن هناك ما يكفي من مراكز التشخيص لمرض الهيموفيليا في فلسطين؟

- ☐ نعم
- ☐ لا

32. هل تعتقد أن هناك ما يكفي من الممارسين الصحيين المتخصصين لرعاية مرضى الهيموفيليا في فلسطين؟

- ☐ نعم
- ☐ لا

33. كيف تقيم البنية التحتية العامة للرعاية الصحية لمرضى الهيموفيليا في فلسطين؟

- ☐ ممتازة
- ☐ جيدة
- ☐ مقبولة
- ☐ ضعيفة
- ☐ سيئة

القسم 7: الأطر السياسية والتنظيمية من قبل الدولة

34. هل أنت على دراية بأي سياسات أو إرشادات وطنية لعلاج الهيموفيليا في فلسطين؟

- ☐ نعم
- ☐ لا
- ☐

35. كيف تقيم فعالية السياسات والإرشادات الحالية في تقديم رعاية كافية لمرضى الهيموفيليا؟

- ☐ ممتازة
- ☐ جيدة
- ☐ مقبولة
- ☐ ضعيفة
- ☐ سيئة

36. هل يغطي تأمينك الصحي تكلفة علاج مرض الهيموفيليا؟

- ☐ نعم بشكل كامل.
- ☐ تعم بشكل جزئي.
- ☐ لا يغطي تكاليف العلاج.

37. كيف تقيم توفر أدوية ومنتجات تركيز عوامل تجلط الدم التي يحتاجها مريض الهيموفيليا؟

- ☐ متاحة دائماً
- ☐ متاحة عادةً
- ☐ متاحة أحياناً
- ☐ متاحة نادراً
- ☐ غير متاحة أبداً

38. هل تعتقد أن إدارة وتوزيع أدوية علاج الهيموفيليا تتم بشكل مناسب وعادل؟

- ☐ نعم
- ☐ لا

القسم 8: التوصيات والتحسينات

39. ما هي التحسينات التي تود أن تراها في تقديم مراكز الرعاية الصحية لمرضى الهيموفيليا في فلسطين؟ (حدد جميع ما ينطبق)

- ☐ تحسين الوصول إلى الأدوية
- ☐ المزيد من المتخصصين الصحيين
- ☐ تحسين المرافق الصحية
- ☐ زيادة الدعم المالي
- ☐ تعزيز برامج التعليم والتوعية
- ☐ تطوير مجموعات الدعم والشبكات
- ☐ أخرى (يرجى التحديد):_____

40. ما هي التعديلات السياسية التي تعتقد أنها ضرورية لتحسين رعاية مرضى الهيموفيليا في فلسطين؟

- ☐ تحسين تغطية التأمين الصحي لعلاج الهيموفيليا
- ☐ زيادة التمويل الحكومي لبرامج علاج الهيموفيليا
- ☐ تطوير سياسات لضمان توفير الأدوية والعلاجات بشكل منتظم
- ☐ تحسين تدريب مقدمي الرعاية الصحية على التعامل مع الهيموفيليا
- ☐ تعزيز الرقابة والتفتيش على مرافق الرعاية الصحية الخاصة بالهيموفيليا
- ☐ زيادة الدعم المالي للبحث والتطوير في علاج الهيموفيليا
- ☐ تعزيز التعاون بين الهيئات الحكومية والجمعيات الخاصة بمرضى الهيموفيليا
- ☐ تحسين التشريعات التي تضمن حقوق المرضى في الحصول على الرعاية
- ☐ أخرى (يرجى التحديد):_____

41. ما هي المبادرات المجتمعية التي تعتقد أنها قد تدعم مرضى الهيموفيليا في فلسطين ؟

- ☐ إنشاء مجموعات دعم محلية لمرضى الهيموفيليا وعائلاتهم
- ☐ تنظيم حملات توعية للتعريف بالهيموفيليا وأهمية الرعاية
- ☐ تقديم برامج تعليمية لتدريب المرضى وأسرهم على إدارة المرض
- ☐ تنظيم فعاليات لجمع التبرعات لدعم علاج الهيموفيليا
- ☐ دعم تطوير خدمات الرعاية الصحية لمرضى الهيموفيليا من خلال الشراكات المجتمعية
- ☐ إنشاء مركز اتصال لتقديم الدعم النفسي والإرشاد للمرضى
- ☐ تعزيز التعاون مع الجمعيات العالمية المتخصصة في الهيموفيليا
- ☐ تنظيم حملات توعية لتعزيز فهم المجتمع لاحتياجات مرضى الهيموفيليا
- ☐ أخرى (يرجى التحديد): _____

شكرا جزيلا لكم ونتمنى لكم السلام دائما وأبدا

تقييم تقديم الرعاية الصحية لمرضى الهيموفيليا في الضفة الغربية /فلسطين

التحديات ،الفجوات ،وفرص التحسين

إعداد: نادي حسن عبد عيد زواهرة

إشراف: د.محمد نجاجرة

الملخص

تُعد اضطرابات النزف مثل الهيموفيليا من الأمراض الوراثية النادرة، إلا أنها تتطلب رعاية صحية متخصصة ومتعددة التخصصات على مدار الساعة للوقاية من المضاعفات الخطيرة والحفاظ على مستوى مقبول من جودة الحياة. وفي البيئات محدودة الموارد والمقيدة سياسياً مثل فلسطين، لا تزال عملية تقديم رعاية شاملة لمرضى الهيموفيليا تواجه تحديات كبيرة. وعليه، هدفت هذه الدراسة إلى تقييم واقع تقديم الرعاية الصحية لمرضى الهيموفيليا في الضفة الغربية، وتحديد التحديات الرئيسية والفجوات القائمة في الرعاية، إضافة إلى استكشاف فرص تحسين إمكانية الوصول إلى الخدمات الصحية ومستوى جودتها، وتعزيز العدالة في تقديم الرعاية للمرضى ذوي الموارد المحدودة.

أُجريت دراسة مقطعية باستخدام منهجية البحث المختلط خلال الفترة من مارس 2024 وحتى أغسطس 2025. تم جمع البيانات الكمية من خلال استبيان منظم شمل 99 مريضاً مشخصين بالهيموفيليا من النوع (A) أو(B) ، وهو ما يمثل نحو 28% من إجمالي المرضى المسجلين في الضفة الغربية. تم اختيار المشاركين بطريقة قصدية من عدة محافظات. وكان غالبية المشاركين من الذكور (93.9%)، وأقل من 35 عاماً (84.8%)، ويقيمون في المناطق الريفية (63.6%)، وينتمون إلى أسر ذات دخل منخفض يقل عن 500 دولار أمريكي شهرياً (59.6%). جرى تحليل البيانات باستخدام برنامج (SPSS)من خلال الإحصاءات الوصفية والاستدلالية، بما في ذلك اختبار(t) ، وتحليل التباين الأحادي (One-way ANOVA)، وتحليل الارتباط، والانحدار الخطي المتعدد. كما تم إجراء تحليل موضوعي للبيانات النوعية المستخلصة من الأسئلة المفتوحة لدعم النتائج الكمية.

كشفت النتائج عن نواقص جوهرية في تقديم الرعاية الصحية لمرضى الهيموفيليا. حيث أفاد 79.8% من المرضى بوجود نقص متكرر في توفر مركزات عوامل التخثر. كما أشار 53.5% إلى وجود عوائق مالية، في حين عانى 77.8% من مشكلات متعلقة بالمواصلات. وتلقى 57.6% من المشاركين علاجاً وقائياً لتعويض عوامل التخثر، في حين أظهر 94.9% استعداداً كافياً للتعامل مع نوبات النزف. إلا أن 78.8% من المرضى لا يتلقون متابعة منتظمة من طبيب العظام، و70.7% لا يحصلون على دعم

نفسي. وأفاد أكثر من 80% من المرضى بعدم كفاية مراكز علاج الهيموفيليا، ومراكز التشخيص، وعدد الكوادر الصحية المتخصصة. كما أظهرت نتائج الدراسة تبايناً في مستوى رضا المرضى عن الخدمات الصحية، حيث أفاد 35.3% فقط بالرضا عن جودة الرعاية المقدمة. وأوضحت نتائج تحليل الانحدار المتعدد أن تكرار نوبات النزف، وسهولة الوصول إلى الخدمات الصحية، ومستوى التثقيف الصحي المقدم للمريض كانت من العوامل المتنبئة بشكل معنوي بالرضا عن جودة الرعاية .($p<0.05$) كما لوحظ انخفاض مستوى الوعي بالسياسات الوطنية الخاصة بعلاج الهيموفيليا (18.2%)، وكان هذا الوعي مرتبطاً بمستويات الدخل المنخفضة.

وخلاصة القول، تواجه رعاية مرضى الهيموفيليا في الضفة الغربية تحديات متعددة تشمل نقص الأدوية، وقلة الخدمات المتخصصة، وضعف البنية التحتية الصحية، ومحدودية التثقيف الصحي للمرضى، وضعف نشر السياسات الوطنية ذات الصلة. وتستلزم معالجة هذه التحديات تعزيز استدامة سلاسل توريد الأدوية، وإنشاء مراكز علاج متخصصة، وتحسين تدريب مقدمي الرعاية الصحية، وتعزيز التثقيف الصحي والدعم النفسي للمرضى، واعتماد إرشادات وطنية واضحة ومتكاملة لعلاج الهيموفيليا، بما يسهم في تحسين العدالة الصحية والنتائج الصحية لمرضى الهيموفيليا في فلسطين.

الكلمات الدالة: الهيموفيليا أ و ب، رعاية الهيموفيليا، نظم تقديم الرعاية الصحية، الوصول إلى خدمات الرعاية الصحية، تحديات النظام الصحي، السياسات الصحية والعدالة، مراكز علاج الهيموفيليا، الضفة الغربية، فلسطين.