LIVING WITH HEMOPHILIA IN LATIN AMERICA: AN EVALUATION OF YOUTH DEVELOPMENT INTERVENTIONS TO IMPROVE QUALITY OF LIFE

by

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(Under the Direction of Pamela Orpinas)

ABSTRACT

Inherited bleeding disorders affect the blood's ability to clot; they are expensive to treat and have no cure. Most young people with inherited bleeding disorders in low-income countries suffer debilitating pain, severe joint damage, disability, and early death. The disorders affect their ability to cope, progress normally through the stages of adolescent development, socialize, and develop self-efficacy skills. The purpose of this study was to identify positive youth development factors that could improve the quality of life of young adults diagnosed with inherited bleeding disorders in Latin America.

Thirty-seven participants from 7 countries in the region completed an online survey with two scales: 1) the HemoLatin-Qol survey to ascertain the extent that symptoms of that inherited bleeding disorders interfere with youth development in Latin America and 2) the Chinese Youth Positive Development Scale (CYPDS) to assess attributes of positive youth development. In addition, participants answered open-ended questions about their experience living with a bleeding disorder in Latin America and provided recommendations for program improvements.

The HemoLatin-Qol results showed that nine respondents had negative z-scores in every domain of the survey. Using z-scores to compare the relative impact of the constructs showed that the barriers to living with hemophilia, such as the ability to access treatment and care, negatively impacted most participants. The lowest overall quality of life index z-score was more than two standard deviations below the average (-2.06). The CYPDS survey revealed that participants believed they are resilient and able to adapt to life and health challenges (M=4.35; SD=.58). However, their self-efficacy scores were low (M=2.95; SD=.57), indicating that they feel helpless when facing life difficulties. Findings from the open-ended responses yielded five themes: Living with a bleeding disorder 1) is a constant challenge, 2) teaches you to adapt, 3) means finding your community, 4) involves dealing with unmet needs, and 5) is transformative.

Developing policies and programs at every level of the socio-ecological framework for young adults living with inherited bleeding disorders in Latin America is essential. Increasing training for healthcare providers, developing regional level peer mentoring programs and providing psychosocial support will promote their well-being.

INDEX WORDS: hemophilia, bleeding disorders, positive youth development, socio-ecological framework, quality of life, Latin America.

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DEDICATION

This study is dedicated to the brave young people in Latin America who shared their time and lived experiences with me. Thank you for trusting me with your stories and giving voice to your truth.

To my mother, who worked tirelessly to provide opportunities for me to develop confidence, competence, connection, caring, and character as I grew up. ¡Gracias por todo!

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CHAPTER 1:

Introduction

Inherited bleeding disorders are rare coagulopathies that affect the blood's ability to clot. Approximately 400,00 individuals around the world have hemophilia and other inherited bleeding disorders, and more than 75% of them receive little to no treatment (World Federation of Hemophilia, 2001).

Most children with hemophilia and other inherited bleeding disorders in low-income countries suffer debilitating pain, severe joint damage, disability, and early death. In low-income countries of Latin America, the situation is made worse by a lack of access to diagnostic services, a lack of a national registry of patients, a lack of trained hematologists to care for these patients, and a lack of services that address the psycho-social burdens associated with hemophilia (World Federation of Hemophilia, 2001).

In a study of 13 countries in Latin America, Montaño et al., (2014) estimated that more than 40% of expected hemophilia and other inherited bleeding disorders cases remained undiagnosed. Furthermore, these countries had limited economic resources to prioritize funds to improve the physical, emotional, and mental well-being of patients diagnosed with bleeding disorders.

For young adults with hemophilia and other inherited bleeding disorders, especially in developing countries, it is essential to understand how living with the disorder impacts their quality of life and related social determinants of health (Maslow et al., 2013). The intricate relationship among systems, community, and interpersonal factors in the life of young adults

impacted by hemophilia and other inherited bleeding disorders necessitates the implementation of interventions that apply an integrated Positive Youth Development model (PYD), using a socio-ecological framework to address health disparities associated with poverty, lack of resources, and hopelessness (Atkiss et al., 2011).

Pain, physical capability, emotional functioning, social skills, mental health, and environment conditions affect the quality of life of Latin American youth diagnosed with hemophilia and other inherited bleeding disorders (Remor, 2016). Developing positive assets in young adults with chronic health conditions is essential for their improved quality of life.

1.1 Research Aims

The present study aims to identify positive youth development factors that will improve the quality of life of young adults diagnosed with bleeding disorders in Latin America. The central hypothesis is that participating in a socio-ecologically based Positive Youth Development Program will enhance participants' resilience and help them build competence, confidence, connection, caring, and character. These five assets are collectively known as the 5Cs of PYD. This study has four specific aims related to young adults with hemophilia and other inherited bleeding disorders in Latin America:

Specific Aim 1: Ascertain the extent that symptoms of hemophilia and other inherited bleeding disorders interfere with youth development in Latin America. I hypothesize that the physical manifestations of the disorders will be associated with feelings of helplessness and reduced emotional and social functioning.

Specific Aim 2: Using the socio-ecological model, examine how individual, interpersonal, and community barriers interact with living as a young adult with an inherited bleeding disorder in Latin America.

Specific Aim 3: Identify the components of the PYD model that participants associated with improvements in their social and emotional functioning. I hypothesize that participating in a youth development program based on a PYD model will enhance resilience and build the 5 Cs of PYD in participants.

Specific Aim 4: Identify participants' recommendations for program improvements. Implementing a participatory evaluation approach will capture actionable information that program implementers can use to inform programmatic enhancements.

1.2 Public Health Implication

In Latin American countries with limited economic resources prioritizing funds to enhance the physical, social, and mental well-being of patients diagnosed with hemophilia is usually not part of the discussions at the Ministry of Health (Montaño et al., 2014). The World Federation of Hemophilia awards small competitive grants to implement capacity-building projects in under-resourced regions of the world. However, none of these programs have been evaluated with a specific focus on developing Positive Youth Development assets based on a socio-ecological framework. I expect to identify the PYD factors that will improve outcomes for young adults with hemophilia and other inherited bleeding disorders in Latin America.

This study will inform the implementation and goals of the World Federation of Hemophilia capacity-building grants to address the social determinants of health that impact the lives of young adults diagnosed with inherited bleeding disorders in Latin America.

CHAPTER 2:

Literature Review

This chapter covers topics relevant to studying the burden of illness in bleeding disorders for young adults in Latin America. This chapter is composed of four sections. The first section provides an overview of bleeding disorders, including their definition, prevalence, treatment, barriers to care, and the health and social impact of the disease on patients. The second section provides an overview of programs and services for people with bleeding disorders. The third section provides an overview of the programs and services of the World Federation of Hemophilia. The fourth section explains the theoretical basis for this study, including an overview of the positive youth development model and its integration with the socio-ecological framework.

2.1 Overview of Bleeding Disorders

Definition and Epidemiology of Bleeding Disorders

Rare diseases are those that affect a small portion of the population in a particular area. The European Union defines rare diseases as those with a prevalence of 50 or fewer people per 100,000 population. In the United States, rare disorders are defined as affecting less than 200,000 people in the same region (Boat & Field, 2011). The normal clotting function is disrupted for people with rare inherited bleeding disorders, resulting in episodes of spontaneous bleeding into their muscles, joints, or other body parts. Known inherited bleeding disorders are hemophilia, rare clotting factor deficiencies, vonWillebrand disease, and inherited platelet disorders (World

Federation of Hemophilia, 2012). This literature review provides an overview of hemophilia and vonWillebrand disease.

Hemophilia

Hemophilia is an X-linked recessive disorder. The abnormal gene is carried on the X chromosome, one of the two sex chromosomes. Males have one X chromosome and one Y chromosome. The presence of this abnormal gene on the X chromosome of a male indicates that he has a factor deficiency. Females have two X chromosomes; the presence of the abnormal gene on one X chromosome may not result in hemophilia as the other X chromosome has the gene that codes for the normal production of factor proteins. In some cases, females may have bleeding disorder symptoms. Men with hemophilia will pass on the affected chromosome to their female offspring, who can then pass the gene to a son who will have hemophilia or to a daughter who will be a carrier of the disorder. Usually, the mutation that causes hemophilia is inherited, but in some rare cases, patients can acquire it.

There are 13 clotting factor proteins, identified by roman numerals, which control bleeding during an injury. These factor proteins come together during a process called the coagulation cascade. If a blood vessel is injured, each of the 13 clotting factor proteins turns on in sequence and begins a chemical process to form a blood clot and stop the bleed. In people with hemophilia, one of the clotting factor proteins in the sequence does not function properly, preventing the cascade formation (World Federation of Hemophilia, 2012).

A diagnosis of hemophilia is made by studying a patient's family history of bleeding and conducting laboratory testing to assess clotting factor levels. Hemophilia is rare and occurs in about 1 of every 10,000 births. According to a 2019 global survey by the World Federation of Hemophilia, the total number of diagnosed individuals with hemophilia worldwide was 195,263;

of these, 28% occur in the Americas (Stonebraker et al., 2020). The most common types of hemophilia are Hemophilia A, caused by a dysfunction of the factor VIII clotting protein, and Hemophilia B, caused by a dysfunction of the factor IX clotting protein.

The severity of hemophilia is determined by the percentage of clotting factor protein active in a person's blood. There are three levels of severity, the lower the percentage of factor activity, the more severe the presentation and impact of hemophilia on an individual. Table 2.1 lists the percentage of factor activity in the blood and their presentation.

Table 2.1 Levels of Hemophilia

Level	Percentage of Factor activity in the blood	Presentation
Normal range	50-150%	No hemophilia diagnosis or symptoms
Mild hemophilia	5-40%	In people with hemophilia, bleeding may occur due to surgery or significant injury. Some may not experience problems associated with having hemophilia.
Moderate hemophilia	1-5%	People with moderate hemophilia may experience monthly bleeding episodes and/or prolonged bleeding after dental procedures, injury, or surgery.
Severe hemophilia	Less than 1%	People with severe hemophilia may experience spontaneous bleeding episodes. They may bleed one to two times per week into their muscles and joints

Note. Adapted from Stonebraker et al. (2020)

Recurrent bleeding episodes into the joints cause pain, reduce the regular function and motion of the joint, and result in arthropathy. Bleeding into the brain and head can lead to seizures and paralysis. Repeated bleeding is the principal cause of hemophilic mortality, morbidity, disability, and poor quality of life in people affected by the disorder (Poon et al., 2012). Hemophilia has no cure.

Treatment for hemophilia consists of replacing the missing clotting factor in the blood. This process is known as an infusion; worldwide, only 25% of people living with hemophilia receive adequate infusion therapy. The optimal infusion treatment product for hemophilia is

factor concentrates which can be recombinant, made from genetically engineered cells that carry human factor genes, or plasma-derived made from human blood. The advantage of receiving infusion with factor concentrates manufactured by pharmaceutical corporations is that they have been treated to inactivate blood-borne viruses and effectively treat hemophilia A and B. Another option for treatment is cryoprecipitate, made from blood collected at local blood centers. Cryoprecipitate contains concentrated factor VIII proteins and can be used to treat bleeds in people with hemophilia A. However, it has a higher risk of viral contamination than factor concentrates and is harder to administer to patients. In some countries, the only available treatment for hemophilia is fresh frozen plasma, which is made by removing the red cells from the blood and leaving the clotting factors. This method requires the infusion of large amounts of plasma which can lead to complications, such as developing an inhibitor (World Federation of Hemophilia, 2016).

People affected by hemophilia are susceptible to developing an immune response related to clotting factor replacement therapy. This reaction, known as inhibitor development, occurs when the immune system of a person with hemophilia recognizes the factor replacement concentrate as a foreign substance, and antibodies form in the blood to defend against the foreign agent. Inhibitor development primarily occurs in childhood when patients receive their first clotting factor treatment. Inhibitors impact the ability of the factor replacement therapy to operate as prescribed. People who develop inhibitors experience more bleeding, pain, and arthropathy in their joints because the factor replacement treatment does not work effectively. Inhibitor development decreases the effectiveness of treatment and influences morbidity, mortality, and the quality of life of patients (Montaño, 2014).

Patients who develop an inhibitor may attempt to overcome its effect through a procedure known as immune tolerance induction. Immune tolerance induction requires treating the patient multiple times with an increased volume of factor concentrate and additional therapeutic interventions, which is extremely costly (Montaño, 2014). A study examining Medicaid claims data in the United States from 2002 – 2008 found that clotting factor medication for adult patients with hemophilia cost on average $106,000USD a year; for patients with inhibitor complications, the cost jumped to more than $287,000USD a year (Chen, 2016).

vonWillebrand Disease

vonWillebrand disease, commonly referred to as vWD, is an inherited bleeding disorder in which the von Willebrand factor protein does not work correctly. People with vWD have low von Willebrand factor protein levels, which prevents a clot from forming to stop a bleed. Symptoms of vWD can manifest as recurring nose bleeds, bleeding from the gums, easy bruising, heavy or prolonged menstrual bleeding, bleeding in the gastrointestinal tract, and prolonged bleeding after surgery, dental work, or childbirth. Worldwide, vWD is the most common bleeding disorder affecting about 1% of the population. vWD disease affects both men and women. There are three types of vWD, each with differing severity levels. Table 2.2 lists the types of vWD and their presentation (World Federation of Hemophilia, 2016).

Table 2.2 Types of vonWillebrand Disease

Type of vWD	Presentation
Type 1 vWD	The most common type of vWD, usually caused by low levels of the vonWillebrand factor protein. People with Type 1 vWD have mild symptoms
Type 2 vWD	People with Type 2 vWD have defective vonWillebrand factor proteins. This type is further sub-divided into four types with moderate symptoms.
Type 3 vWD	The most severe type of vWD is caused by little to no vonWillebrand factor protein. The symptoms are severe and include bleeding into joints and muscles.

Note. Adapted from National Center on Birth Defects and Developmental Disabilities (2021)

The type of vWD a person has determines the symptoms and treatment. The most common type among those affected by the disorder is Type 1 vWD; often, they experience little to no symptoms and do not even realize they have a bleeding disorder. People with Type 1 vWD who experience traumatic injury, surgery, or dental procedures are often treated with a synthetic drug called Desmopressin to control heavy or prolonged bleeding. People with vWD Type 2 and Type 3 who experience more moderate and severe bleeding episodes require treatment with factor concentrates containing the vonWillebrand factor protein. Women with vWD often experience increased or prolonged bleeding during their menstrual cycles. To help control this bleeding, doctors may prescribe birth control pills as hormone therapy to girls and women with vWD (World Federation of Hemophilia, 2016).

2.2 Living with Hemophilia

Quality of Life and Hemophilia

The Centers for Disease Control and Prevention defines quality of life as the subjective evaluation of life's negative and positive attributes. How these attributes are evaluated and measured differs for different groups of people (National Center for Chronic Disease Prevention and Health Promotion, 2018). For people with chronic health conditions, such as hemophilia,

quality of life is often measured by the disorder's impact on their life. This impact is often called the burden of illness and includes the disease's negative physical and psycho-social manifestations on an individual (National Collaborating Centre for Infectious Diseases, 2016). It is vital for young adults with hemophilia and other inherited bleeding disorders to identify how coping, social support, cost of treatment, and lack of educational and employment opportunities impact their ability to lead productive lives. It is important to consider the lack of access to care and the inherent danger in the available treatments that influences the burden of illness for this population.

Blood Borne Infections and Hemophilia

Hemophilia is a rare congenital bleeding disorder that manifests as spontaneous or post-traumatic bleeding episodes that can cause joint damage, disability, and even early death. In the first half of the 20th century, doctors treated it by transfusing patients with fresh blood. Depending on blood transfusion for survival was problematic and led to most people with severe manifestations of the disease dying in childhood (Franchini & Mannucci, 2012). In the mid-1960s, researchers identified that cryoprecipitate from frozen plasma contained more of the factor needed to treat patients, and this therapy was adapted to control bleeding in patients. This discovery led to advancement in disease management and hope for a better quality of life for patients in high-income countries (Franchini & Mannucci, 2012).

While treatments had advanced, patients were still dependent on blood products derived from thousands of donors. An estimated 70% of people with severe hemophilia became infected with the human immunodeficiency virus (HIV) from contaminated blood products during the AIDS epidemic of the 1980s. Unfortunately, at the same time, most people with hemophilia (mild, moderate, and severe) were also infected with the hepatitis C virus transmitted by factor

concentrates manufactured from plasma pooled from thousands of donors (Franchini & Mannucci, 2012).

Diagnosis and treatment for hemophilia in Latin America are less than ideal. Early diagnosis and access to care are the exceptions, not the rule. Furthermore, the cost of modern commercially produced factor concentrates is cost-prohibited for many countries, leaving these countries reliant on fresh frozen plasma and cryoprecipitate. These sub-optimal therapies also risk exposing patients to blood-borne infections (Santiago-Borrero et al., 1999).

Hemophilia life in Latin America

In 2008 ten principles were developed to set the minimum standard of care in Europe for people with bleeding disorders. Table 2.3 lists the ten principles.

Table 2.3 Principles of Care for Hemophilia in Europe

1)Central organization with the support of local groups	6)Home treatment and delivery
2)National registry of people with hemophilia	7)Access to prophylaxis
3)Centers of integrated care	8)Coordination of specialized and emergency care
4)Partnerships for decision-making	9)Management of inhibitors
5)Safe and effective concentrates at optimal treatment levels	10)Education and research

Note. Adapted from Boadas et al. (2018)

To identify the strengths and areas of improvement of bleeding disorder care in Latin America, Boadas and colleagues (2018) utilized the European ten principles of care as the basis of their assessment in Argentina, Brazil, Chile, Colombia, Costa Rica, El Salvador, Mexico, Panama, Dominican Republic, and Venezuela. The researchers found that while there is a centralized organization with the support of local groups for most countries participating in their study, this organization was localized mainly in the capital or large cities. Additionally, in many participating countries, national registries were partial or nonexistent.

National registries are essential for identifying the number of cases in a country and facilitating resource allocation to improve health outcomes for people with bleeding disorders.

Access to treatment was also limited. In many countries participating in the study, treatment, if available, was provided as part of general hospital system care and not in hemophilia-specific treatment centers (Boadas et al., 2018). Furthermore, if a supply of factor concentrate was available for patients, it was centralized in large cities. Most countries reported restricted access to prophylactic treatment, which is essential for optimal management of the disorder and to prevent morbidity and mortality. The researchers concluded that in Latin America, the basis of hemophilia care focuses on basic elements such as establishing diagnostic laboratories, applying therapies, and gathering adequate financial resources to care for patients.

Prophylactic treatment is the gold standard of care in hemophilia. The GLAITH Group (The Latin American Group for the Promotion of Hemophilia Treatment) found that assessing the number of patients with hemophilia and their management does not conform to established standards in Latin America. Furthermore, the study by GLAITH found that in Latin America, 85-95% of patients receive on-demand treatment for traumatic events. The GLAITH group concluded that lack of access to prophylactic treatment led to a high proportion of patients in Latin America developing hemophilic arthropathy. Repeated bleeding into joints without access to treatment causes permanent joint disease accompanied by chronic pain, reduced ambulatory function, limited range of motion, and poor quality of life for patients (Mijares & De Sánchez, 2015).

Joint disease, chronic pain, and mobility challenges are common in young adults with hemophilia in low-income countries with limited access to treatment. A common outcome of the physical manifestations of the burden of illness of the disorder in young adults is stigmatization.

Young men in Latin America with hemophilia who develop hemophilic arthropathy and use assisted mobility devices (crutches or wheelchairs) may develop a diminished view of their masculine image. Furthermore, their education may be interrupted as repeated bleeding episodes may prevent them from attending school or may cause force them to have extended hospitalizations. These adverse events impact the ability of youth to socialize and develop friendships, leading to isolation, loneliness, and a diminished quality of life compared to their non-hemophilic peers (Guzmán et al., 2016).

2.3 World Federation of Hemophilia

Bleeding disorders impact people in all countries of the world. National characteristics influence outcomes for people with bleeding disorders in every country. To improve outcomes across the world, an international not-for-profit organization was established in 1963. The World Federation of Hemophilia (WFH), headquartered in Montreal, Canada, is a global network of bleeding disorder organizations. The mission of the WFH is to "improve and sustain care for people with inherited bleeding disorders around the world." (World Federation of Hemophilia, 2001).

The World Federation of Hemophilia is composed of 147 national member organizations that work with the WFH to represent the needs of people with bleeding disorders in each country. National member organizations in each country partner with the WFH to advocate for access to care and treatment, educate medical providers on bleeding disorders, inform patients of the management of bleeding disorders, and mitigate the disorder's impact on their quality of life. WFH has several programs to introduce, improve, and maintain care worldwide for people with bleeding disorders. These programs focus on understanding and improving the individual, interpersonal, organizational, community, and public policy impact of the disorder in each

country. For the present study, I will focus on WFH global training programs aimed at improving the quality of life of young people impacted by bleeding disorders.

During the mid-1990s, WFH realized the need to develop an intentional training program to provide resources and strategies to its members to help improve care for people living with a bleeding disorder. This identified need led to the creation of the *WFH Twinning Program*. Twinning is a collaborative project between two members of the worldwide hemophilia network. WFH pairs an established and well-developed hemophilia organization with an emerging organization; they share best practices and help strengthen the emerging organization's national hemophilia care program (World Federation of Hemophilia, 2001).

This formal partnership usually pairs a high-income country with access to advance treatments and a national hemophilia program with an emerging organization in a low- or middle-income country. This formal collaboration is a two-way agreement between the organizations to exchange knowledge in patient education, outreach, fundraising, medical care, and all other aspects of operating a successful national bleeding disorder member organization (World Federation of Hemophilia, 2001).

Twinning can be established between hemophilia treatment centers, hemophilia organizations, or hemophilia youth groups. After many years of implementing organizational and Hemophilia Treatment Center Twinning, the World Federation of Hemophilia recognized the need for twinnings with a specific focus on youth groups, launching the first pilot Youth Group Twinnings in 2018. Youth Group Twinnings aims to "pair emerging and established youth groups to share knowledge in areas such as youth leadership, good governance activities, effective communication, and public speaking, to help foster the next generation of leaders in the

bleeding disorders community" (World Federation of Hemophilia, 2017, p.3). Twinning programs foster collaboration, a sense of belonging, and partnership among participants.

In addition to Youth Twinnings, WFH also implements a worldwide Youth Leadership Program to develop the next generation of in-country leaders. The program is predicated on the premise that an early investment in building the capacity of young adults in developed and developing countries will ensure continuity in the succession of leaders in national organizations. WFH provides travel fellowships to applicants to attend training to share their experiences and learn from each other. Additionally, participants discuss fundraising, public speaking, managing a bleeding disorder, and working with government officials.

At the country level, WFH member countries with an established national hemophilia program offer recreational camps for youth with bleeding disorders. Therapeutic and recreational camp programs provide rest, respite, and enjoyment for children and families living with chronic illnesses. Investigators who studied the effect of camp attendance on children with chronic diseases from 15 different countries found improvements in physical disease symptoms, affect (i.e., an increase in positive affect and a decrease in negative affect), and self-esteem. Apart from clear improvements in affective constructs like social support, anxiety, affect, and self-esteem, camp programs also improve health-related quality of life and practically oriented cognitive and behavioral outcomes. Participants in a camp for children with chronic illnesses experienced improved measures in many domains of health-related quality of life (Békési et al., 2011).

For hemophilia as a specific chronic illness of interest, the benefits of camp programs are generally similar to those of other chronic diseases. Increased perceived social support, self-worth, and self-esteem are among the most commonly reported benefits of attending a hemophilia camp. Research has corroborated that a feeling of belonging, a sense of community,

and a high level of social support are powerful agents of positive change in hemophilia camp programs (Mehta et al., 1991). The high level of social interaction, encouragement, and support at hemophilia camps increases self-esteem and perceived self-worth (Thomas & Gaslin, 2001). Hemophilia is a complex and costly to manage chronic disease. National hemophilia programs increase the life expectancy of people with hemophilia and other related bleeding disorders (World Federation of Hemophilia, 2020). National Hemophilia Organizations and the World Federation of Hemophilia work together to establish programs to improve outcomes for all.

2.4 Theoretical Frameworks

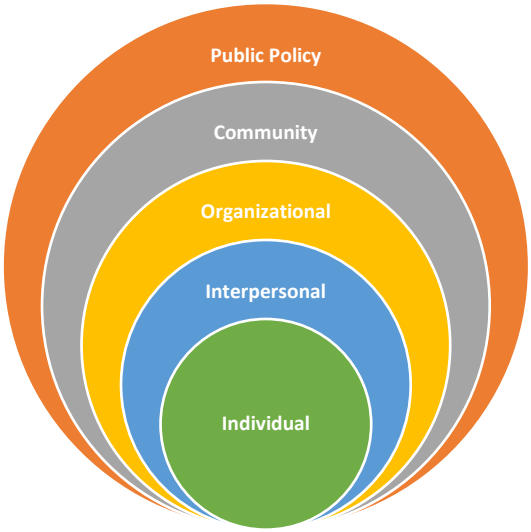
Socio-ecological Framework

This research study is guided by the socio-ecological model, illustrated in figure 2.1, which emphasizes that individual behaviors and health outcomes are rooted within interactions at the individual, interpersonal, organizational, community, and public policy levels (Glanz et al., 2008; Sallis, 2015). At the individual level, a person's knowledge, attitude, and skills play a pivotal role in managing a chronic condition. Social networks and connections (interpersonal level), the environment, and community characteristics (organizational level) influence the development of assets between individuals and the community. Community values and norms (community level) affect youth's risk and protective factors as they grow and develop. Research shows that unhealthy communities lead to unhealthy individuals, creating more threats within communities (Early, 2016). Lastly, public policies that dictate access to care and treatment influence disease prevention and health promotion.

The socio-ecological model is based on Bronfenbrenner's Ecological Systems Theory. Bronfenbrenner described child development as a system of complex interconnected levels that

impact youth in the places they live, schools they attend, social networks, community, and peer groups (Bronfenbrenner, 1977).

Figure 2.1 Socio-Ecological Model



Note. Adapted from National Center for Injury Prevention and Control (2021)

Organizations such as the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) recognize the importance of addressing the social determinants of health via the socio-ecological framework (Centers for Disease Control and Prevention, 2018). Researchers have used the socio-ecological framework as a basis for many disease prevention and health promotion programs. Mentoring youth with disabilities (DuBois & Karcher, 2005), decreasing youth substance use and risky sexual behaviors (Elkington et al., 2011), encouraging physical activity and improving the body image of college students (Kahan, 2011), promoting school psychology (Edwards et al., 2007), and preventing sexual assault in youth (Smothers & Smothers, 2011) have all benefitted from using the socio-ecological framework.

The socio-ecological framework is particularly relevant for children with chronic diseases or special healthcare needs. As children with chronic illness transition from childhood to

adulthood, they are a part of several systems. Each of these systems has specific age expectations and requirements before these young people can transition to the next system in the process (Gorter et al., 2011). The care system for children with chronic illness is more intense at every level of the socio-ecological framework. In turn, their development is not as linear as those without special healthcare needs. Youth with chronic health conditions generally have a decreased quality of life. The socio-ecological framework can be used to develop interventions to increase self-efficacy and self-esteem, identify social support systems, and increase coping skills in these young people (Bullinger & von Mackensen, 2008). Youth development for these youth must take into account their ecological needs to be effective.

For young adults with hemophilia, especially in developing countries, it is essential to understand that the disorder impacts their quality of life and related social determinants of health (Maslow et al., 2013). Hemophilia and other related bleeding disorders can have a substantial impact on an individual's life. People with inherited bleeding disorders face increased morbidity and early mortality due to their illness (Barr et al., 2002). The life expectancy of an individual with hemophilia who receives all proper and appropriate treatment is approximately ten years shorter than the average person. People with hemophilia who do not have access to adequate treatment; die before adulthood (World Federation of Hemophilia, 2012). In addition to the decreased physical quality of life, financial instability affects mental health due to the cost of care and self-efficacy regarding how to manage their disorder (Gringeri et al., 2003).

Considering the intersection of the problems previously mentioned, some researchers have implemented interventions that combine a socio-ecological framework with a Positive Youth Development (PYD) model to address the "…ecology of disparities…" that youth with chronic health conditions face (Edberg et al., 2017, p.489).

Positive Youth Development Model

Positive Youth Development (PYD) is an intentional approach that engages youth in their communities to build the skills, competencies, and abilities necessary to grow and thrive (Moore, 2016). Youth Power, a project of the US Agency for International Development aimed at improving the capacity of youth development efforts in low- and middle-income countries; states that Positive Youth Development "engages youth along with their families, communities and/or governments so that youth are empowered to reach their full potential. PYD approaches build skills, assets, and competencies; foster healthy relationships; strengthen the environment and transform systems." (Hinson et al., 2016, p.15).

Many of the characteristics and components of PYD span several levels of the socio-ecological framework and focus on working collaboratively with youth to improve their assets, agency, contributions, and supportive environment (2016). Catalano and colleagues(Catalano et al. 2004) stated that PYD programs are defined by their aim to meet one or more of the following objectives:

1. Promote bonding
2. Foster resilience
3. Promote social competence
4. Promote emotional competence
5. Promote cognitive competence
6. Promote behavioral competence
7. Promote moral competence
8. Foster self-determination
9. Foster spirituality

10. Foster self-efficacy
11. Foster clear and positive identity
12. Foster belief in the future
13. Provide recognition for positive behavior
14. Provide opportunities for prosocial involvement
15. Foster prosocial norms

The present study is guided by Lerner's 5Cs model of Positive Youth Development, based on an ecological perspective (2005). Lerner's model focuses on five constructs essential for positive youth development: competence, confidence, connection, character, and caring. Table 2.4 details the five constructs and their definitions in this study.

Table 2.4 Lerner's 5Cs of Positive Youth Development

Subscale	Definition
Competence	is the ability to succeed or have efficiencies in a particular area, such as health or academics
Confidence	is a positive internal sense of overall self-efficacy and self-worth
Connection	is comprised of positive reciprocal bonds with people and institutions
Character	is having integrity, morality, and respecting the norms of culture and society
Caring	is having sympathy and empathy for others

Note. The definitions were from Promoting positive youth development: Theoretical and empirical bases (Lerner, 2005).

PYD focuses on the positive attributes of adolescent development rather than the negative aspects that youth should avoid (e.g., substance use, risky sexual behavior, violence, etc.). The PYD framework has become popular in programs aimed at improving the quality of life of youth (Bowers et al., 2010).

Hemophilia is a chronic health condition with no cure and expensive medical treatments. This disorder severely affects the quality of life of youth affected by it. It damages their ability to cope, progress normally through the stages of adolescent development, socialize and develop self-efficacy skills (Bullinger & von Mackensen, 2008). In addition to life-long health problems, youth diagnosed with chronic health conditions "… often struggle in their transitions related to education, vocation, and finance" (Maslow et al., 2013, p. 180). Frequently these young people do not complete their education, have difficulties getting employment, and have lower income streams when compared to their counterparts.

Interventions based on the PYD model promote developmental assets such as competence, social connection, and confidence. Growing these assets in youth can lead to improved self-care, interpersonal relationships, and well-being. A principle of PYD is empowering youth to participate actively and improve their social environment (Frasquilho et al., 2018).

Developing positive assets in young people with chronic health conditions is essential for their transition to adulthood and improved quality of life. Pain, physical functioning, emotional functioning, social functioning, mental health, and environment conditions were the domains that affected the quality of life of Latin American youth diagnosed with hemophilia (Remor, 2016). Previous interventions that integrated a PYD and socio-ecological model have stressed the importance of providing youth with opportunities to identify the challenges and resources in their communities to affect change, which builds feelings of self-efficacy and resilience and improves their health outcomes (Atkiss et al., 2011).

In a study conducted by McBride, Johnson, Olate & O'Hara in Latin America, researchers found that service-learning volunteer opportunities for youth can be very useful in

addressing local community needs while developing knowledge, skills, and solidarity among youth. Moreover, programs that provided an environment for positive adult-youth relationships in which youth were responsible for the planning and implementation of the volunteer project were shown to improve self-confidence, efficacy, and community engagement in youth (McBride et al., 2011).

Young people in these programs were seen not only as participants but as owners. Youth engaged in the leadership and administration of the program, in addition to providing direct services and helping each other learn and grow. The programs in the countries studied focused not only on developing technical skills in youth but also on developing the value of collective social impact through solidarity, which helps youth see themselves as agents of positive change in their communities (McBride et al., 2011).

Programs that promote PYD utilizing a socio-ecological framework provide opportunities for youth with chronic health conditions to participate as leaders, develop essential life skills, influence their community, and create sustainable positive adult-youth relationships (Maslow et al., 2013).

Integration of Frameworks

Although the socio-ecological model and Positive Youth Development frameworks are often used individually for youth programs, research on a program model that intentionally integrates the frameworks to maximize positive outcomes for young people is scarce. However, these frameworks complement each other, as the United States Agency for International Development Youth Power points out:

> "As a philosophy, PYD views youth as precious assets to be nurtured and developed rather than as problems to be solved. The approach that flows from this philosophy works

> on building mutually beneficial relationships between youth and their family, peer groups, schools, workplaces, communities, other government institutions, society, and culture to provide opportunities for youth to enhance their knowledge, interests, skills, and abilities. Youth transition through a critical developmental phase, rapidly evolving socially, emotionally, and physically within a complex world. Multiple factors influence how they develop and thrive or struggle. Recognizing youth development as a function of and interaction between complex environments and systems can help us better respond to youth and to program effectively" (Hinson et al., 2016, p.15).

To successfully achieve the objectives listed in the previous section, program developers need to understand the program participants' ecological context while encouraging them to enhance their ecological self-awareness. Youth development, by nature, takes on an ecological approach that requires participating youth to engage in their environments to identify the strengths and challenges that contribute to community concerns. In the context of health, development programs encourage youth to recognize the needs and assets in each ecosystem that lead to individual and community health problems (Bronfenbrenner, 1977).

The Search Institute's Framework of Developmental Assets comprises 40 internal and external positive supports and strengths young people need to succeed (Search Institute, 2019). Resilience, which is a component of positive youth development, "is derived from three primary sources: (1) within-child factors, e.g., cognitive ability, self-control, and positive temperament; (2) within-home factors, e.g., consistent parenting and secure attachment and (3) outside-home factors, e.g., school environments that encourage socially appropriate behavior" (Edwards et al., 2007). The ability of young people to identify the needs and assets in their ecosystems and utilize the skills they build through positive youth development to address those needs represents a

perfect integration of the socio-ecological and PYD frameworks. Young people build resilience when they are empowered to identify problems and resources to overcome them. Acting as empowered change agents helps them improve their competence and health outcomes. (Atkiss et al., 2011).

Similar to the present study, one group of researchers integrated the Development Assets and socio-ecological frameworks to create the Youth Health Action Board. This board was developed from existing health promotion efforts and implemented by high school youth. Students developed education and advocacy projects based on the needs and assets they identified in their school and community. Participants reported increased commitment to learning and positive values while gaining social competencies and a positive identity. External asset growth reported by participants included support, empowerment, clear boundaries and expectations, and constructive use of time; these assets fall within the higher levels of the socio-ecological framework. Growth in the internal and external developmental assets is associated with reductions in risky behavior, increased engagement in thriving behaviors, and maintenance of healthy behaviors. Integrating the socio-ecological and PYD frameworks should improve participants' health outcomes (Atkiss et al., 2011).

Researchers must "learn more about how to align the specific assets of young people and their ecological settings in ways that promote thriving" (Lerner, 2017, p.29). Programs based on a PYD framework should include a socio-ecological component to maximize positive outcomes. The central hypothesis of this study is that participating in a socio-ecologically based Positive Youth Development Program will improve the quality of life of Hispanic youth diagnosed with hemophilia and other bleeding disorders. Table 2.5 displays possible World Federation of

Hemophilia and or country-level skill-building activities by socio-ecological level linked to the Positive Youth Development Construct addressed.

Table 2.5 Multilevel Activities Linked to Positive Youth Development Construct

Program or Activity	Socio-ecological Model Level	PYD Construct
Attend Youth Leadership Training Participate in Youth Twinning Project Attend Advocacy/Public Speaking Training Attend Bleeding Disorder 101 Workshops Attend Sexuality and Bleeding Disorder Workshops Attend Mentorship Training	Individual	Competence Confidence Character
Plan and implement Mentoring Initiative Establish Facebook/WhatsApp Support Group Establish Youth Groups	Interpersonal	Connection Caring
Establish Youth Leadership Program Develop Program Guidelines/Bylaws Plan Youth Camp	Organizational	Contribution Connection Competence
Plan and implement Bleeding Disorder Education Workshops Plan and implement Youth Camp Plan and implement Social Media Education Campaign	Community	Connection
Plan and implement Advocacy/Public Awareness Campaign Advocate for health care diagnostic centers with the ministry of health Advocate for access to treatment with the ministry of health	Public Policy	Competence Contribution

Gathering participants' viewpoints and knowledge on their lived experience is a core component of understanding the impact of living with inherited bleeding disorders in Latin America.

CHAPTER 3:

Methods

The long-term goal of the study was to identify positive youth development factors that could improve the quality of life of young adults diagnosed with inherited bleeding disorders in Latin America. The purpose of this study is to 1) ascertain the extent that symptoms of hemophilia and other inherited bleeding disorders interfere with youth development in Latin America, 2) using the socio-ecological framework, examine how individual, interpersonal, and community barriers interact with living as a young adult with a bleeding disorder in Latin America, 3) identify the components of the Positive Youth Development model that participants associated with improvements in their social and emotional functioning, and 4) collect participant's recommendations for program improvements. This study will inform the implementation and goals of programs to address the social determinants of health that impact the lives of young adults diagnosed with bleeding disorders in Latin America. This chapter details the methodology of this study, including the study's design, participants, measures, procedures, data analysis, and subjectivity statement.

3.1 Study Design

The purpose of this study's surveys and open-ended questions was to help understand the effect of bleeding disorders on the day-to-day lived experience of young adults living in under-resourced areas of the world. The measures in this study considered the cultural, contextual, and individual perspectives that impact positive youth development.

Participants completed an online consent form, a demographic survey, two self-reported questionnaires, and open-ended questions using Qualtrics. The first questionnaire was the HemoLatin-QoL Questionnaire (Remor, 2016), a disease-specific measure that provides an overall index of quality of life for people with hemophilia in Latin America. The second questionnaire consisted of selected scales from the Chinese Youth Development Scale (Shek et al., 2007) to measure youths' perceptions of empowerment, control, and outlook.

Open-ended questions collected participants' feedback on program components that enhanced their resilience and helped them build competence, confidence, connection, caring, and character, leading to improved management of their bleeding disorder.

3.2 Participants

Bleeding disorders are rare in the population; identifying individuals diagnosed with these uncommon disorders is even more difficult in under-resourced areas of the world. Thus, this study used a purposive sampling strategy. In purposive sampling, participants are invited because they can provide information relevant to a researcher's questions on the topic of study (Padgett, 2011). Participants from ten Latin American affiliates of the World Federation of Hemophilia were invited to participate in the study from January – March 2022. However, no one from Chile, Panama, or Peru chose to participate. Table 3.1 shows profiles for the original ten countries, with information on the United States included for comparison purposes.

Table 3.1 Characteristics of Countries Represented in the Study

Country	Population	GDP per capita USD	Health Expenditure per capita USD	Life Expectancy at Birth	Literacy Rate	People with Hemophilia	People with von Willebrand Disease	People with Other Bleeding Disorders
Argentina	45 million	$8,441	$1,989	77 years	99%	2,771	397	10
Bolivia	11 million	$3,143	$496	72 years	93%	180	3	3
*Chile	18 million	$13,231	$2,305	80 years	96%	1,763	492	825
Colombia	49 million	$5,332	$1,155	77 years	95%	3,588	3,391	700
Cuba	11 million	$ 9,099	$2,519	79 years	100%	490	398	3,640
Dominican Republic	10 million	$7,268	$1,017	74 years	94%	475	42	55
Honduras	9 million	$2,405	$496	75 years	87%	376	19	2
México	128 million	$8,346	$1,065	75 years	95%	5,853	39	61
*Panamá	4 million	$12,269	$1,856	79 years	95%	314	15	101
*Perú	32 million	$6,126	$776	77 years	97%	887	71	19
United States	335 million	$63,543	$10,623	79 years	99%	18,008	12,394	4,809

Note. The data for population and literacy rate are from *The World Factbook* by CIA 2021. The data for GDP, Health Expenditure, and Life Expectancy at birth is from *The Data Bank* by World Bank 2021. The data for people with hemophilia, Von Willebrand Disease, and people with Other Bleeding Disorders is from the *2019 Annual Global Survey* by the World Federation of Hemophilia 2021. *No persons from Chile, Panama, or Peru chose to participate in the study.

Participants from each country were invited based on their ability to provide feedback on the study questions. Study participants were identified through professional networks and referrals. Once identified, participants received an invitation email to take part in the study. The inclusion criteria for study participants were:

a) be young adults ages 18-30 years

b) be diagnosed with a bleeding disorder

c) have obtained care at the local hemophilia treatment center within two years prior to study enrollment
d) speak Spanish and live in Latin America
e) have access to a computer, smartphone, or tablet and the internet

3.3 Measures

This section details the demographic information, quantitative surveys, and open-ended questions.

Demographic Information

The online Qualtrics survey included the following demographic information: date of birth, age, gender, country of origin, the country where they currently live, race, ethnicity, education level, employment status, bleeding disorder diagnosis, the severity of the bleeding disorder, bleeding disorder treatment (current/historical), inhibitor status, comorbidities, and history of orthopedic surgery. Appendix A presents the demographic survey.

HemoLatin-Qol

The HemoLatin-Qol survey is a 27-item patient self-reported questionnaire that measures perceived health-related quality of life. The instrument, developed in Latin America, considers regional contextual and cultural attributes to capture idiosyncrasies for participants aged 16-80 living with hemophilia (Remor, 2016). The questionnaire contains six domains of perceived quality of life and an overall well-being index for people living with bleeding disorders. Dr. Remor provided consent to utilize the HemoLatin-QoL to ascertain the extent that symptoms of hemophilia interfere with youth development in Latin America. Respondents self-report the effects of the disorder on their day-to-day functioning using response categories that range between 0 and 4, with different response options depending on the item. For all scales, higher

scores indicate better quality of life. For example, a higher score would indicate less pain in the pain subscale. Table 3.2 lists the six domains, defines them, and provides a sample statement.

Table 3.2 Domain and Sample Statements - HemoLatin-QoL

Domain	Definition	Sample Statement
Pain	The intensity/frequency of the experience of pain related to the presence of hemophilia symptoms or illness consequences	To what extent has the pain you experienced, in the case that you have experienced pain, limited your life?
Physical functioning	The extent that symptoms of hemophilia interfere with daily life activities, physical activity, or work	To what extent have hemophilia or its consequences hindered your sexual activity?
Emotional Functioning	The extent that symptoms of hemophilia interfere with emotional functioning, including increasing levels of dependence, self-stigma, isolation, or losing control	To what extent do you think that hemophilia imposes limitations on the realization of your goals and desires for your life?
Social Functioning	The extent that symptoms of hemophilia interfere with social adjustment, interpersonal relationships, social participation, and social support	To what extent have you experienced prejudice or difficulties in finding work due to your hemophiliac condition?
Mental Health	The extent that hemophilia symptoms or consequences affect everyday living and the sense of happiness, including increasing negative moods and or signs of distress	How often have you felt sad or depressed by the problems associated with hemophilia?
Environment Condition	The extent that environment conditions aggregate difficulties or barriers to living with hemophilia, as well as the ability to access treatment and care	To what extent is it difficult to get transportation to go where you need to?

Note. Dr. Remor does not allow displaying the entire survey. These sample statements are from the appendix of the published article.

Chinese Positive Youth Development Scale (CYPDS)

Shek and colleagues (2007) define positive youth development as the growth, cultivation, and nurturance of adolescents' developmental assets, abilities, and potential. To evaluate positive assets in youth, Shek developed the CYPDS, a 90-item questionnaire grouped into 15 subscales that assess attributes of positive youth development. In this study, participants responded to 19 statements of the questionnaire that measured seven constructs: resilience, social competence,

emotional competence, cognitive competence, self-determination, self-efficacy, and belief in the future. Table 3.3 details the seven constructs, their definitions, and the number of items.

Table 3.3 Selected Subscales from the Chinese Positive Youth Development Scale

Subscale	Definition	# of Statements
Resilience	One's ability to adapt to life changes and stressful events healthily and flexibly	3
Social Competence	The range of skills used to interact with others, including communication (verbal and non-verbal and listening), assertiveness, conflict-resolution, and negotiation strategies—these skills help to integrate feelings, thinking, and actions to achieve specific social and interpersonal goals	2
Emotional Competence	The ability to identify and respond positively to feelings and emotional reactions in oneself and others	2
Cognitive Competence	The ability to identify an issue, absorb information from multiple sources, and evaluate options to reach a reasonable conclusion—includes problem-solving, planning, decision-making, and critical thinking	2
Self-determination	Self-thinking and the consistency between action-taking and thinking	2
Self-efficacy	Belief in one's abilities to do many different things well (particularly the things that are the focus of the intervention)	5
Belief in the future	Hope and optimism about one's future potential, goals, options, choices, or plans.	3

Note. Subscales and definitions were adapted from Shek, Siu, & Lee (2007).

Respondents self-reported their agreement with each statement using a 5-point scale. The response categories were: 1 = *strongly disagree*, 2 = *disagree*, 3 = *slightly agree*, 4 = *agree*, and 5 = *strongly agree.* Each scale was computed as the average of items, with high scores indicating stronger support for the construct.

Open-Ended Questions

Identifying participants' perspectives on how the disorders and the youth leadership program impacted their social and emotional development is essential. The open-ended questions allowed participants to discuss the program's components that enhanced their resilience and helped them build competence, confidence, connection, caring, and character, leading to improved management of their bleeding disorder.

The open-ended questions created a space for participants to discuss 1) the individual, interpersonal, and community barriers that interact with living as a young adult with a bleeding disorder in Latin America, 2) components of the PYD model that participants associated with improvements in their social and emotional functioning, 3) changes in participants' knowledge and management of their bleeding disorder, and 4) participant recommendations for improvements of the programs. Table 3.4 details the eight open-ended questions mapped to the study's specific aims; each question focused on gathering information from the participants' perspectives on their lived experiences.

Table 3.4 Open-Ended Questions Mapped to the Specific Aims of the Study

Specific Aim	Open-ended Question
Aim 1: Ascertain the extent that symptoms of hemophilia and other inherited bleeding disorders interfere with youth development in Latin America.	1)What challenges and opportunities have you had living with a bleeding disorder? 2)Can you share an example of how you have changed because you participated in the program for young people with bleeding disorders?
Aim 2: Using the socio-ecological model, examine how individual, interpersonal, and community barriers interact with living as a young adult with a bleeding disorder in Latin America.	3)What types of community support help you cope with your bleeding disorder? For example, participation in your church or a support group? 4)What community support is needed to cope with a bleeding disorder where you live?
Aim 3: Identify the components of the PYD model that participants associated with improvements in their social and emotional functioning.	5)How has participating in the program for young people with bleeding disorders helped you meet these challenges? 6)How do you use the things you learned in the program to help others?
Aim 4: Identify participants' recommendations for program improvements.	7)Can you name 3 things (or more) that you would tell the World Federation of Hemophilia to keep doing or add to youth programs?
Additional Comments	8)Is there anything else you'd like to share that you haven't talked about?

Note. PYD = Positive Youth Development

3.4 Procedures

The University of Georgia Institutional Review Board approved the study procedures. Young adults who agreed to participate in the study received an email explaining the study's purpose and a link to access the study consent form in Qualtrics. After reading the consent, participants clicked "Submit" to indicate their desire to participate in the study. Appendix B presents the consent form. Once participants completed the quantitative surveys in Qualtrics, they had several options to respond to the open-ended questions about living with a bleeding disorder in Latin America: 1) participants could choose to enter their responses to the open-ended questions in Qualtrics, 2) participants could choose to self-record themselves responding to the open-ended questions and upload their answers to a folder in One Drive, or 3) participants had the option to choose to set a time to meet with the study coordinator to live record their responses to the open-ended. The open-ended questions aimed to empower participants to share in their own voices their experience living with a bleeding disorder in Latin America. For study participants who chose to live record their answers, the interviews were recorded on the Zoom platform. The voice recordings for each interview were downloaded, transcribed using a transcription service, and translated from Spanish to English.

3.5 Data Analysis

Quantitative Surveys

All quantitative analyses were conducted using IBM® SPSS® statistical analysis software, version 24. First, I described the clinical and socio-demographic characteristics of the sample. Second, I included the results for the HemoLatin-QoL; all data collected in Qualtrics was entered into a secure online data collection tool maintained by the author (Remor, 2016). Dr. Remor provided baseline results of the mean composite score for participants. I then converted

these into a standard score to compare the participants' scores across subscales of the HemoLatin-QoL measure. A standard score, also known as Z-score, represents the number of standard deviations a data point is away from the group's mean. If a z-score is positive, its value is above the mean. If the z-score is negative, its value is below average (Gerstman, 2008). Standardizing the values of the raw score allowed the comparison of scores between subscales. Third, I presented the results of the descriptive statistics (mean and standard deviation) for each statement of the CYPDS, as well as the mean and standard deviation for each subscale. Scales were calculated as the mean of items, with higher scores indicating stronger support for the construct. Table 4.5 details the statements of each CYPDS construct defined in Table 3.3.

Open-Ended Questions

Open-ended questions give researchers a more thorough understanding of the participants' perspectives. The thematic analysis process developed by Virginia Braun and Victoria Clarke; includes six steps: 1) familiarizing yourself with the data, 2) generating initial codes, 3) generating themes, 4) reviewing themes, 5) defining and naming themes, 6) producing the report; was implemented to identify and organize patterns and themes across the qualitative response dataset (Braun & Clarke, 2006). Each participant's response was carefully coded and categorized to identify relevant themes interpreted in relation to the research aims.

Step 1: Familiarizing Yourself with Your Data. Open-ended question responses were downloaded from Qualtrics, deidentified, and translated. This translation methodology combined literal and communicative techniques, whereby interpreted words reflect the exact corresponding terms and contextual expressions. By combining these approaches, the natural flow of the participant's native language (Spanish) was considered without excluding response authenticity. This iterative approach required in-depth knowledge of the subject and context, increasing the

overall understanding of response content and allowing for a thorough data review. The initial deidentification process involved giving each respondent a numeric ID number.

Step 2: Generating Initial Codes. Once translated and deidentified, the responses were transferred to a new Excel workbook. The workbook contained a tab with all the open-ended questions, followed by a tab with the entire translated dataset. Then each open-ended question and corresponding responses were transferred to a separate tab. Included in the individual tabs for each open-ended question were a few nominal variables: gender, country of origin, residence, relationship status, parenting, education, employment, and bleeding disorder diagnosis. Responses were reviewed using a line-by-line and semantic approach, deriving content explicitly from the data to extract words and phrases representing the main idea of the response.

Step 3: Generating Themes. Once the code words were captured, an inductive coding technique and latent approach were employed to identify patterns and repeated concepts generated from the data. These themes were interpreted and assigned to terms by the researcher. The clustered segmented responses continued to be linked until all synonymous codes fit within a corresponding theme. The initial thematic categories are presented in the results section and address the dissertation's specific aims. Open-ended question seven, "Can you name three things (or more) that you would tell the World Federation of Hemophilia to keep doing or add to youth programs?" was not included in this analysis as its purpose was to elicit recommendations for the organization and was analyzed separately. Each recommendation was noted independently, and those that were similar in content and objective were combined into one point.

Step 4: Reviewing Themes. After categorizing the response themes, an additional review using a deductive approach, based on Table 2.5's mapped socio-ecological model layers, provided a framework to address this dissertation' specific aims.

Step 5: Defining and naming themes. Lerner's Positive Youth Development constructs were used to map each open-ended question to a socio-ecological layer, as presented in Table 4.6. This process permitted each response to reflect one or more PYD indicators: competence, confidence, connection, character, and caring. By grounding the themes within the two models, each response aligned with a specific pre-defined main idea (Table 2.4) and represented the objective sought by this research's third aim.

Step 6: Producing the Report. Chapter 4 presents the findings, detailing the main themes captured in the analysis, quotes, and excerpts selected from the transcripts.

3.6 Subjectivity Statement

Subjectivity statements summarize the researcher's relation to the study and its participants (Padgett, 2011). The study examined youth development programs for people with bleeding disorders in Latin America. I must speak to my subjectivity with this work.

I approached this work as a doctoral candidate at an institution of higher learning in the United States of America. As a fully bilingual (Spanish/English) public health practitioner, I believe it is my obligation to empower people to improve health and outcomes in their communities.

I am currently employed at an organization focused on supporting people with inherited bleeding disorders in the state. This position affords me access to the latest clinical and scientific information on bleeding disorder care. Furthermore, I served as the Chair of Organizational and Youth Twinnings for the World Federation of Hemophilia. I had access to and firsthand knowledge of the experience of people with bleeding disorders in low-resourced areas of the world.

As a proud Afro-Latina woman who plans to work at a leadership level to empower communities, I know that my ethnicity, educational and professional background impacted how I designed, implemented, and interpreted this study. The academic and professional experiences in my life have inclined me to be invested in developing programs and services that involve community participation to build sustainable change in under-resourced communities. During this work, it was essential that I managed my passion, potential bias, and excitement for this study to allow the voice of the participants to guide my understanding and interpretation of the data they provided.

CHAPTER 4:

Results

This chapter has four sections. The first section describes the clinical and socio-demographic characteristics of the participants. The second and third sections present the result of the HemoLatin-QoL Questionnaire (Remor, 2016) and the Chinese Youth Development Scale (Shek et al., 2007) surveys. The last section details the findings of the participants who completed the open-ended questions.

4.1 Demographic and Clinical Characteristics

Sixty-one persons accessed the link to "Vivir con Hemofilia" in Qualtrics; of those, 47 consented to participate in the study by clicking submit. Following the guidelines in the inclusion criteria discussed in the methods chapter, 9 participants were excluded because of being older than 30 years of age, and 1 participant was excluded because of not having a bleeding disorder diagnosis. Thus, the final sample consisted of 37 respondents from 7 countries: Argentina (3), Bolivia (4), Colombia (2), Cuba (1), Dominican Republic (17), Honduras (8), and Mexico (2). Of the 37 participants in the final sample, 32 responded to the open-ended questions. The mean age was 28.8 (SD 3.24) years old. Most participants were male (n=34) and resided in large cities in their respective countries (78%). Over two-thirds of the participants (68%) reported attending college or completing a university degree. The majority of participants reported being in a relationship, and 13% of those were married. However, only 16% of respondents reported parenting. Table 4.1 details the socio-demographic characteristics of the sample.

Table 4.1 Socio-demographic Characteristics of Study Participants (N=37)

	n	%
Education		
High School	5	13.5
Technical School	1	2.7
College	25	67.6
Graduate School	6	16.2
Employment		
Employed Full Time	15	40.5
Employed Part Time	5	13.5
Student	13	35.1
Unemployed	4	10.8
Relationship Status		
Partnered	30	81.1
Married	5	13.5
No Answer	2	5.4
Residence		
Urban	29	78.4
Rural	8	21.6

Most participants had hemophilia; 73% had hemophilia A, 16% had hemophilia B, and the remaining 10% reported having von Willebrand Disease. Less than 46% of respondents reported having received prophylactic treatment for their bleeding disorder at some point in their life (Table 4.2).

Table 4.2 Clinical Characteristics of Study Participants (N= 37)

	n	%
Bleeding Disorder Diagnosis		
Hemophilia A Male	27	73.0
Hemophilia B Male	5	13.5
Hemophilia B Female	1	2.70
von Willebrand's Disease Male	2	5.40
von Willebrand's Disease Female	2	5.40
Severity		
Mild Hemophilia	7	24.3
Moderate Hemophilia	10	27.0
Severe Hemophilia	18	48.6
Treatment History		
Prophylactic Tx Yes	17	46.0
Prophylactic Tx No	20	54.0
Surgery		
BD Related Yes	9	24.3
BD Related No	28	75.7

4.2 HemoLatin-QoL

Dr. Remor provided the baseline results of mean composite scores for each domain of the instrument. The average overall score of the QOL Index was 47.11 (SD=17.94). Table 4.3 displays the participants' scores provided by Dr. Remor.

Table 4.3 HemoLatin-Qol Results (N=36)

Domain	Number of Items	Cronbach's Alpha	Actual Min-Max	Mean (SD)	Median
Pain	3	0.812	0-9	4.03 (2.71)	4.5
Physical functioning	6	0.872	0-18	10.33 (5.02)	10.0
Emotional functioning	6	0.760	1-18	9.58 (4.19)	10.0
Social functioning	5	0.661	3-17	12.00 (2.79)	12.0
Mental health	4	0.828	0-12	6.44 (3.30)	6.5
Environment conditions	3	0.696	0-9	4.11 (2.60)	4.0
QOL INDEX	27	0.948	10-82	47.11 (17.94)	48.0

Note. All response categories are on a 5-point scale ranging from 0 to 4,
with high scores indicating a better outcome (e.g., less pain, better social functioning).

After converting raw scores in the data set to z-scores, nine respondents had negative z-scores in every domain of the HemoLatin-Qol. Using z-scores to compare the relative impact of the constructs showed that the barriers to living with hemophilia, such as the ability to access treatment and care, negatively impacted most participants. In the social functioning construct, one participant's z-score was more than three standard deviations below the average (-3.21), indicating that hemophilia symptoms severely interfered with interpersonal relationships and social support. The lowest overall quality of life index z-score was more than two standard deviations below the average (-2.06). Table 4.4 shows the range of z-scores for the HemoLatin-Qol.

Table 4.4 HemoLatin-Qol Minimum and Maximum Z-scores and Proportion of the Sample with a Negative Z-scores for the Total Scale (N=36)

Domain	Minimum	Maximum	% Below Zero
Emotional functioning	-2.048	2.008	41.6%
Social functioning	-3.216	1.787	41.6%
Pain	-1.707	1.605	50.0%
Mental health	-1.948	1.679	50.0%
Physical functioning	-2.056	1.525	52.7%
Environment conditions	-1.578	1.876	63.8%
Overall QOL INDEX	-2.067	1.943	50.0%

4.3 Chinese Positive Youth Development Scale (CYPDS)

Selected items from the CYPD Scale were used to measure respondents' perspectives about their sense of empowerment, control, and outlook. In general, participants rated themselves positively; for example, they agreed that they are resilient and able to adapt to life and health challenges (M=4.35; SD=.58). Respondents expressed high social competence, concurring that they could communicate with others and understand their perspectives on their lived experiences, (M=4.21; SD=.83). Most participants rated their self-determination above average (M=4.04;

SD=.63). However, over half rated not being able to do much to change things in their life as the lowest. Participants' self-efficacy scores were low (M=2.95; SD=.57), indicating that they feel helpless when facing life difficulties. Nevertheless, most rated their confidence to solve future problems high (M=3.47; SD=.47). Table 4.4 details the results of the CYPDS.

Table 4.5 CYPDS Results (N=37)

Statements	Mean (SD)
Resilience	**4.35 (0.58)**
When I face difficulty, I will not give up easily	4.49 (0.84)
When I face adversity, I remain optimistic.	4.08 (0.73)
I believe problems in life can be solved.	4.44 (0.73)
Social Competence	**4.21 (0.83)**
I know how to communicate with others.	4.03 (1.04)
I know how to listen to others.	4.37 (0.94)
Self-Determination	**4.04 (0.63)**
I am able to make wise choices.	3.94 (0.80)
I am confident about my decisions.	4.14 (0.68)
Emotional Competence	**3.93 (0.75)**
When I have a conflict with others, I can manage my emotions.	3.89 (0.83)
I can see the world from the perspectives of other people.	4.00 (0.89)
Cognitive Competence	**3.88 (0.68)**
I know how to find the causes of and solutions to a problem.	3.86 (0.77)
I know how to develop plans to achieve my objectives.	3.94 (0.98)
Beliefs in the Future	**3.47 (0.47)**
I have the confidence to solve my future problems.	4.06 (0.86)
I have confidence that I will be a useful person when I grow up.	4.44 (0.77)
It is not possible for me to have satisfaction in the future.	1.86 (0.94)
Self-Efficacy	**2.95 (0.57)**
I do not have any solutions for some of the problems I am facing.	2.47 (0.68)
I cannot do much to change things in my life.	2.25 (1.22)
When I face life difficulties, I feel helpless	2.69 (1.03)
I believe things happening in my life are mostly determined by me.	3.33 (1.01)
I can finish almost everything that I am determined to do.	4.00 (0.71)

Note. All response categories for the Chinese Positive Youth Development Scale are on a 5-point scale ranging from 1 to 5, with high scores indicating a better outcome. Table 3.3 defines each construct.

4.4 Open-Ended Questions

Thirty-two participants answered the Living with Hemophilia study open-ended questions. One of the 32 respondents elected to live record the responses to the open-ended questions via the Zoom platform. Table 4.6 shows the number of responses per country of residence.

Table 4.6 Respondents of Open-Ended Questions by Countries Represented in the Study

Country	#Survey Respondents	#Open-Ended Question Respondents
Argentina	3	3
Bolivia	4	2
Colombia	2	2
Cuba	1	0
Dominican Republic	17	15
Honduras	8	7
México	2	2
Total	37	32

All four aims were addressed through a systematic analysis of the open-ended responses. Table 4.7 details the codes and themes yielded for each open-ended question. Five main themes emerged from this systematic analysis: Living with a bleeding disorder 1) is a constant challenge, 2) teaches you to adapt, 3) means finding your community, 4) involves dealing with unmet needs, and 5) is transformative.

To respect participants' privacy and provide an added layer of anonymity, the quotes presented were labeled by the participant's age and region within Latin America rather than country: Central America, South America, and the Caribbean.

Table 4.7 Codes and Themes for Open-Ended Questions

Aims	Open-Ended Questions	Codes	Themes
Aim 1: Ascertain the extent that symptoms of hemophilia and inherited other bleeding disorders interfere with youth development in Latin America.	**Q1**: What challenges and opportunities have you had living with a bleeding disorder? (Lived Experiences -Challenges)	Self-Care, Physical Health Participation, Persistent threats, Lack of Opportunities and Treatments	**Living with a bleeding disorder:** 1) is a constant challenge 2) teaches you to adapt 3) means finding your community 4) involves dealing with unmet needs 5) is transformative
Aim 1: Ascertain the extent that symptoms of hemophilia and other inherited bleeding disorders interfere with youth development in Latin America.	**Q1**: Lived Experiences -Opportunities **Q2**: How has participating in the program for young people with bleeding disorders helped you meet these challenges? (Meeting Challenges)	Community, Perspective Experience, Adaptability Shared Experience Connection, Perspective Support	
Aim 2: Using the socio-ecological model, examine how individual, interpersonal, and community barriers interact with living as a young adult with a bleeding disorder in Latin America	**Q3**: What community support is needed to cope with a bleeding disorder where you live? (Community Support- Current)	Church, Friends Hemophilia Association Support Group	
Aim 2: Using the socio-ecological model, examine how individual, interpersonal, and community barriers interact with living as a young adult with a bleeding disorder in Latin America	**Q4**: What community support is needed to cope with a bleeding disorder where you live? (Community Support- Needed)	Access, Awareness, Advocacy, Mental Health	
Aim 3: Identify the components of the PYD model that participants associated with improvements in their social and emotional functioning	**Q5**: How do you use the things you learned in the program to help others? (Conveying Experience)	Counsel, Advocate	
Aim 3: Identify the components of the PYD model that participants associated with improvements in their social and emotional functioning	**Q6**: Can you share an example of how you have changed because you participated in the program for young people with bleeding disorders? (Transformation)	Leadership, Perspective, Outlook, Motivation	
Aim 4: Identify participants' recommendations for program improvements	**Q7**: Can you name 3 things (or more) that you would tell the World Federation of Hemophilia to keep doing or add to youth programs?	Access, Awareness Mental Health Health promotion	

Living with a bleeding disorder is a constant challenge.

Living with a bleeding disorder was a constant and difficult challenge in the participants' life. A 22-year-old young man with hemophilia who lives in the Caribbean stated that "Every day is a new challenge; I think about how I should walk, sit, what I can lift and what I can't" [*Todos los días es un desafío nuevo, pienso en cómo debo de caminar, sentarme, qué puedo levantar y que no*.] Hemophilia presented daily health challenges for most participants. A respondent from Central America shared, "Well, every day is a challenge since at any time I can have a bleed." [*Pues cada día es un desafío ya que en cualquier momento puedo tener un sangrado.*] The debilitating impact of the disorder was a common refrain for participants, with one participant remarking that he spent "6 months in bed" due to his bleeding disorder. Another participant from the Caribbean shared that "…I lost vision in one eye because I did not know that I was a hemophiliac." [*...perdí la visión de un ojo por no saber que era hemofílico.*]

Access to care and treatment is a real and present challenge for many of the participants. A 26-year-old male living in Central America mentioned on this, "Access to treatment in the country is very limited, I must travel to another city to receive my treatment and the procedures are very complicated…" [*El acceso al tratamiento en el país es muy limitado, debo viajar a otra ciudad para recibir mi tratamiento y los trámites son muy complicados.*] Other participants remarked on the constant stress that limited access to treatment presents. A 25-year- old living in the Caribbean commented, "Challenges for me is to have to stay healthy when there is not enough medicine, except for emergencies… so for me it is a challenge to stay healthy having to go to work." [*Desafíos para mí ha sido tener que mantenerme sano cuando no hay medicamento suficiente, nada más para emergencias…entonces para mí es un desafío mantenerme sano teniendo que ir a trabajar.*].

Living with a bleeding disorder presented daily challenges across the interconnected ecosystem in which respondents live and develop. Many participants commented on the restrictive impact of the disease on physical activity. A 21-year-old young woman in Central America stated that "playing sports" [*practicar deportes*] was challenging for her. A 25-year-old man in Central America echoed this sentiment, saying, "Doing sports is the biggest challenge" [*Hacer deportes es el desafío más grande.*]

Most respondents related that their ability to engage and participate in everyday tasks, such as working and going to school, was constrained due to their disorder. A young college student in Central America stated, "Well, the challenge has been to study, since at the university where I study, I climb stairs, and it is complicated because of my knee." [*Pues el desafío ha sido estudiar, ya que en la universidad en que estudio se sube en escaleras y es complicado por mi rodilla*.]

Living with a bleeding disorder teaches you to adapt.

Having a bleeding disorder pushed many participants to adapt in ways that would otherwise not be needed; a 25-year-old participant from South America shared, "I have had to adapt to situations, and that has helped me face up to other situations in life…" [*He debido adaptarme a situaciones y eso me ha servido para enfrentar otras situaciones en la vida…*] Participants shared that living with a bleeding disorder forces them to see life through a different perspective weighing both the negative and positive aspects of their lived experience. This shared sentiment was conveyed by one of the oldest respondents, a 30-year-old South American who stated, "I consider that it (bleeding disorder) has increased my possibilities to grow on a personal level giving me a vision of the world that I would not have if I did not have my disease, its why it becomes my greatest advantage…" [*pienso que ha incrementado mis posibilidades*

para crecer a nivel personal dándome una visión del mundo qué no podría tener en caso de no tener mi enfermedad, es por ello que se hace como mi mayor ventaja…]

Adapting to living with a bleeding disorder was part of everyday living, "Well, every day is a challenge…but that does not stop me from continuing with my goals." [*Pues cada día es un desafío…pero eso no me detiene a seguir con mis metas.*] commented a respondent from Central America. His comment is an example of a sentiment shared by many participants who refused to let the bleeding disorder impact their aspirations.

A 25-year-old grad-school student from the Caribbean shared that adapting for him meant learning to rebut the perceptions of others "discussions due to prejudices or misinterpretations of others regarding my abilities…has led me to know how to argue and describe the most crucial and necessary points to undermine these prejudices" [*discusiones por prejuicios o malinterpretaciones de los demás referente a mis capacidades…me ha llevado a saber argumentar y describir los puntos más cruciales y necesarios para socavar dichos prejuicios*.] Like him, other participants shared that part of adapting to living with hemophilia was learning to speak with others and share a different perspective on possibilities so that their disorder was not perceived as limiting their abilities. A South-American young man with a bleeding disorder stated, "…childhood challenges to include myself in society…thinking all the time about my condition, give me today the opportunity to always have another point of view..." [*…los desafíos de niño para incluirme a la sociedad…pensando todo el tiempo en mi condición, me brindan hoy en día la oportunidad de contar siempre con otro punto de vista…*]

Living with a bleeding disorder means finding your community.

Adapting to the reality of living with a bleeding disorder provided many participants with a community they would not have known about otherwise. A 27-year-old from South America

shared, "…(having a bleeding disorder) gave me the opportunity to meet people who practically became my family, and that made everything easier…" [*… eso (trastorno de coagulación) me dio la oportunidad de conocer personas que prácticamente se convirtieron en mi familia y eso hizo que sea todo más fácil…*]

The sense of community and shared experience was commonly reported as a source of support and respite within the challenges of living with a bleeding disorder. A young man from the Caribbean stated, "well, it has given me a lot of strength to know that I am not the only one who suffers from this…" [*pues me ha dado muchas fuerza el saber que no soy solo yo el que padece de esto…*] This shared communal experience goes beyond respite. It provides a lift to help participants cope with living with a bleeding disorder. A 30-year-old respondent from Central America explained it best, "It has helped me to know that I am not alone, that it is not only I who go through this... and that together we can overcome these challenges, that we must not give up and always fight" [*Me ha ayudado a saber que no estoy solo, que no solo yo paso por esto... y que unidos podemos superar esos desafíos, que no debemos rendirnos y luchar siempre.*] The idea of learning from each other's experiences was a common refrain shared by participants, both male and female, with a 30-year-old Caribbean participant stating, "…being in contact with other people with the same condition…allows us to exchange experiences, connect more with ourselves." [*estar en contacto con otras personas con la misma condición pues nos permite intercambiar experiencias, conectar más con nosotros mismos.*]

Community was a source of strength, motivation, and empowerment for the respondents across Latin America. One of the youngest respondents, a 20-year-old from the Caribbean, stated, "It has helped me… because it motivates me to keep going and never give up." [*Me ha ayudado … porque me motiva a seguir adelante y a nunca rendirme*.] Even when problems such

as lack of access to care and no cure for hemophilia are a part of the lived experience of participants, being part of the community of people with inherited bleeding disorders is comforting to most. A young man from the Caribbean shared, "I'm still the same, but it feels good to be with people who understand you since they also deal with the same thing…" [*Sigo igual pero se siente bien estar con personas que te entienden ya que también lidian con lo mismo, unos más que otros.*] The sense of empowerment through community was shared by a 26-year-old from Central America who remarked, "(the) emotional support is great and the advice we give ourselves among patients helps to have a better attitude facing difficulties." [el apoyo emocional es grande y los consejos que nos damos entre los pacientes ayuda a tener una mejor actitud ante las dificultades.]

Living with a bleeding disorder involves dealing with unmet needs.

Some participants also reflected on their lack of community. Not everyone had access to a community of peers who understood their situation; a participant from South America reflected, "I do not have a community support group." [*No tengo un grupo de apoyo comunitario.*]

In some instances, the lack of community was due to geographic location, with participants stating that where they live, they are the only person they know living with a bleeding disorder "...around where I live, I am the only one who suffers from it" *[…por mi lugar, soy el único que lo padece*] shared a 23-year-old participant from the Caribbean.

This feeling of isolation reflects a real unmet need in the community of people living with inherited bleeding disorders in Latin America. When asked if there were any community support systems that could help cope with a bleeding disorder, another participant stated that "at

the moment, I do not verify anything that can help." [*de momento no verifico nada que pueda ayudar*.]

Respondents identified the lack of social networks, advocacy groups, and general lack of knowledge of inherited bleeding disorders as unmet needs they face living with hemophilia in their country. The youngest participant, a 19-year-old from the Caribbean, expressed it best when he stated that he needed "a bleeding disorders awareness group" [*un grupo de concientización de trastornos hemorrágicos.*] The participants highlighted that their need for the larger community to know of them (people with hemophilia) goes beyond society's general lack of knowledge of inherited bleeding disorders. A 20-year-old from the Caribbean commented that they (people with hemophilia) need to be recognized as a person "more people that know about the disorder…that we have" [más personas que conozcan la enfermedad…que tenemos]; because recognition will lead to feelings of "empathy" [empatía] by the greater community.

This need for belonging is not limited to neighborhoods. It also extends to places of worship, employment, and schools. A 28-year-old participant from South America revealed a need for, " awareness groups in schools so that they can understand in schools or any other place, so that people can know about us and our situation." [*grupos de concientización en colegios para que le den a entender en los colegios u cualquier otro lugar que den a conocer nuestro estado.*]

Feeling unseen or not being recognized in the greater community extends to the availability of public health services for respondents in their community. Many participants shared that access to trained medical personnel in hospitals and emergency rooms is an unmet need, especially in smaller cities. A 25-year-old from the Caribbean express that there was a need for "…training to clinics and small hospitals so that in any emergency… they recognize the condition and can at least know how to help a hemophiliac…" [*capacitación a clínicas y*

hospitales pequeños para que en cualquier emergencia … reconozcan la condición y puedan por lo menos saber cómo ayudar a un hemofílico...]

Unmet medical needs were a recurring theme in the findings. Many participants stated they lacked access to physical therapy and rehabilitation services. A 21-year-old female respondent from Central America shared her need for "trained places where specialized exercise can be done for people with inherited bleeding disorders" [*lugares capacitados donde se puedan hacer ejercicio especializados para personas con trastornos hemorrágicos*]. Participants also expressed unmet needs in the area of mental health. A 20-year-old from the Caribbean shared, "I think there should be more mental health professionals in the area of hemophilia." [*Creo que deberían existir más profesionales de la salud mental en el área de hemofilia.*] These unmet physical, mental, and medical needs impacted their entire life. A 21-year-old from Central America shared, "It should be taken into account that problems with self-esteem can affect a person's life to the same extent as physical problems." [*Se debe tomar en cuenta que los problemas relacionados con la autoestima pueden afectar la vida de una persona en la misma medida que los problemas físicos.*]

Living with a bleeding disorder is transformative.

Many respondents experienced life-changing transformations from participating in leadership programs for people with inherited bleeding disorders. A 25-year-old from Central America shared, "I have matured a lot; my mental and emotional stability has been improving in a surprising way; I went from having depression to being a very happy person." [*He madurado mucho; mi estabilidad mental y emocional ha ido mejorando de manera sorprendente; pasé de tener depresión a ser una persona muy feliz*.] As previously discussed, living with a bleeding disorder can be isolating; however, many participants felt seen and supported as a result of their

participation in programs with their peers. A 25-year-old from the Caribbean stated that participating in the leadership program changed him and gave him a new perspective on his disorder, “Before, I thought I was the only one, then I met all my peers, and I integrated and felt like family, I felt normal” [*Antes creía que era el único, luego conocí a todos los compañeros y me integré y me sentí en familia, me sentí normal.*]

Participation in leadership and capacity-building programs impacted participants' unmet needs. A 26-year-old from Central America shared how participation in the program transformed his mental health and self-esteem, “Before I was shy and had low self-esteem, now I have more confidence in myself, and I have improved my interpersonal relationships.” [*Antes era más tímido y tenía baja autoestima, ahora tengo más confianza en mí mismo y he mejorado mis relaciones interpersonales.*] Many participants shared that they have used the knowledge and experience gained through participation to connect with others in the community. A 26-year-old woman from Central America shared, “I am more sociable, and I have understood that having this disorder does not prevent me from being able to relate naturally with other people.” [*Soy más sociable y he comprendido que tener este trastorno no impide que pueda relacionarme de forma natural con las demás persona*s.]

A 25-year-old from the Caribbean shared, “It (participation) has changed my way of thinking, of living, even of behaving.” [*(participar) Ha cambiado mi forma de pensar, de vivir, hasta de actuar.*] Personal transformation in participants' social and emotional functioning was also noted. A 25-year-old male from the Caribbean shared that participating in the program “has reinforced certain values and skills necessary for my personal development.” [*me ha reforzado ciertos valores y destrezas necesarias para mi desarrollo personal.*] The same participant also affirmed that as a result of participation, “I have taken more control of my life and the decisions

regarding the goals that I already had set but that I felt some uncertainty about achieving them." [*He tomado más control de mi vida y las decisiones referente a las metas que ya tenía planteadas pero que sentí cierta incertidumbre sobre lograrlas o no.*] Transformation through participation was deeply personal and helped participants develop lifelong values. A 25-year-old participant from Central America shared, "It's about values. I think it's perseverance. The one who perseveres achieves. And knowing yourself is very important because you learn about your limits." [Se trata de valores. Creo que definitivamente es perseverancia. El que persevera alcanza. Y conocerte a ti mismo es muy importante porque aprendes sobre tus límites.]

Participating in bleeding disorder leadership programs helped respondents develop individual-level skills such as gaining the confidence to speak about their disorder competently, providing counsel, and advocating for others with inherited bleeding disorders in the greater community. A 23-year-old male from South America shared, "The main thing that (participating) generated in me was to be able to establish greater empathy with other groups of young people from the branch of my city… providing help with my skills…." [*Lo principal que me generó participar fue el poder entablar mayor empatía con otros grupos de jóvenes…brindando ayuda con mis capacidades…]* Empathy was transformed into action for a 28-year-old from South America "The association and the national hemophilia foundation encourage me to defend my rights and constantly self-improve." [La asociación y la fundación nacional de hemofilia me animan a defender mis derechos y auto superarme constantemente.]

Transformation through participation imbued participants with confidence as they developed professionally. A 19-year-old participant from the Caribbean shared, "Well, before, I did not know how to lead a work team so that it could move forward. Now I can transform the team in my own way so that it moves forward smoothly." [*Pues antes, no sabía cómo liderar un*

equipo de trabajo, para que saliera adelante. Ahora puedo transformar el equipo a mi manera para que avance sin problemas.] Participating in leadership programs and learning from the experience of others transformed the perspective of many participants within personal areas of their lived experience. As a 30-year-old South American explains it, "Knowing the experience of other young people has been fundamental to grow on a personal level and observe life from another perspective that I did not have previously—such as creating a family and the possibility of becoming a father" [*Conocer la experiencia de otros jóvenes ha sido fundamental para crecer a nivel personal y observar la vida desde otra perspectiva que no tenía previamente—como la concepción de la familia y la posibilidad de ser padre.*]

CHAPTER 5:

Discussion

The purpose of this study was to identify positive youth development factors that could improve the quality of life of young adults diagnosed with inherited bleeding disorders in Latin America. A total of 37 participants from 7 countries in the region completed a quality of life and positive youth development survey. Of those, 32 responded to open-ended questions about their experience living with a bleeding disorder in Latin America.

The researcher hypothesized that participating in a socio-ecologically based Positive Youth Development program could enhance participants' resilience and help them build the 5Cs of Positive Youth Development: competence, confidence, connection, caring, and character. This study provides insight into the experience of young people living with a bleeding disorder in Latin America: 1) everyday life was challenging, 2) challenges and opportunities occur at each level of the socio-ecological model, and 3) community is the foundation for positive youth development.

First, everyday life was a challenge for young people living with hemophilia in Latin America. Most respondents of the present study reported that their ability to engage and participate in everyday tasks such as getting up and moving, working, going to school, and playing sports were limited due to their disorder, causing them to miss out on personal and professional opportunities. Previous research has highlighted that arthropathy caused by bleeding is a major contributor to pain and disability among people living with hemophilia (Poon et al., 2012). As noted in a quality-of-life study conducted with hemophilia patients in Colombia, joint

disease and pain were associated with low scores in emotional and social functioning (Arteaga-Rubiano & García-Valencia, 2021). The current study was conducted with participants from seven countries in Latin America, and half of these respondents had an overall negative quality of life index score. Furthermore, the findings of the open-ended questions supported the idea that living with hemophilia in Latin America is a constant challenge. A 22-year-old man with hemophilia who lives in the Caribbean asserted, "Every day is a new challenge; I think about how I should walk, sit, what I can lift and what I can't." [*Todos los días es un desafío nuevo, pienso en cómo debo de caminar, sentarme, qué puedo levantar y qué no*.]

Second, people with bleeding disorders in Latin America encountered challenges and opportunities at each level of the socio-ecological framework (Figure 2.1). Health outcomes for young people result from the dynamic relationship between individual behavior, availability of assets, and community standards (Atkiss et al., 2011). In this study, participants shared via the open-ended questions that living with hemophilia in Latin America was challenging at the individual level of the socio-ecological framework as it impacted their ability to care for themselves and fully participate in society. These findings align with similar research that found only 5-15% of patients with hemophilia in Latin America receive prophylactic treatment (Mijares & De Sánchez, 2015).

At the interpersonal level of the socio-ecological framework, living with a bleeding disorder presented challenges in the lack of social networks and the isolation some participant experience. Lack of adequate access to optimal therapy for young people with hemophilia in Latin America is detrimental as repeated bleeding episodes lead to joint pain and potential disability. These negative impacts also have implications for the community level of the socio-ecological framework, as joint pain and disability are associated with increased levels of school

or work absenteeism, depression, increased medical costs, and decreased quality of life (Isidro de Pedro, 2002).

The organizational level of the socio-ecological framework reveals how the environment, systems, and characteristics of the community influence the association between community resources and residents (Shek et al., 2019). The lowest scores in the Hemo-Latin Qol survey were in the environment conditions domain. Lack of access to trained medical personnel in hospitals and emergency rooms was a recurrent unmet need shared by participants. A 25-year-old from the Caribbean express that there was a need for "…training to clinics and small hospitals so that in any emergency… they recognize the condition and can at least know how to help a hemophiliac…" [*capacitación a clínicas y hospitales pequeños para que en cualquier emergencia … reconozcan la condición y puedan por lo menos saber cómo ayudar a un hemofílico...*] More than three-quarters of the responses to the open-ended questions focused on the need for medical resources. These results are similar to those found in other studies focused on access to medical centers for people with hemophilia. Arya and colleagues (2020) observed that people with hemophilia living in rural areas experienced significant delays in diagnosis and decreased access to care due to the long distance to hemophilia treatment centers.

Third, community is the foundation for positive youth development for young people living with a bleeding disorder in Latin America. The results of the inductive coding technique generated codes (Table 4.7) that illustrated how the five constructs of the positive youth development model were expressed in the lived experience of participants. For many respondents of this study, living with a bleeding disorder gave them a connection to a supportive community. This feeling was exemplified by a 30-year-old respondent from Central America who shared "It has helped me to know that I am not alone, that it is not only I who go through

this... and that together we can overcome these challenges, that we must not give up and always fight" [*Me ha ayudado a saber que no estoy solo, que no solo yo paso por esto... y que unidos podemos superar esos desafíos, que no debemos rendirnos y luchar siempre.*]

Risk and protective factors influence youth as they grow and develop in their communities (Early, 2016). At the community level of the socio-ecological model, participants in Latin-American countries with a local hemophilia foundation shared the value of having the organization in their community, as it supported their growth and development. Connection was a building block for participants showing empathy or caring for those they bonded with via their local hemophilia organization. A 26-year-old from Central America remarked, "the emotional support is great and the advice we give ourselves among patients helps to have a better attitude facing difficulties." [*El apoyo emocional es grande y los consejos que nos damos entre los pacientes ayuda a tener una mejor actitud ante las dificultades*.]

Patients who perceive they are part of a solid support network have higher levels of well-being (Spilsbury, 2004). Respondents shared examples of competence that helped them advocate for themselves and others to influence the actions of the Ministry of Health in their countries to improve access to care and treatment for youth with bleeding disorders. A 28-year-old from South America stated, "The association and the national hemophilia foundation encourage me to defend my rights and constantly self-improve." [*La asociación y la fundación nacional de hemofilia me animan a defender mis derechos y auto superarme constantemente.*]

Researchers have established that support networks enhance the quality of life, and the patient's perception of this support determines its impact (Muñoz Grass & Palacios-Espinosa, 2015). A 25-year-old participant from Central America shared that his character changed due to participating in the leadership program "It's about values. I think it's perseverance. The one who

perseveres achieves. And knowing yourself is very important because you learn about your limits." [*Se trata de valores. Creo que definitivamente es perseverancia. El que persevera alcanza. Y conocerte a ti mismo es muy importante porque aprendes sobre tus límites.*]

This project had some limitations. The recruitment of study participants was challenging. The sample for the study was primarily male; only 3 of the 37 respondents were female. However, this gender distribution is not surprising, given the genetic characteristics of the disease. While 37 respondents from 7 countries in Latin America participated in the study, a small sample size prohibited conducting a more robust statistical analysis. Additionally, given the lack of diagnostic services in the region, the study was limited to young people with a confirmed diagnosis. All participants were self-selected young people connected to a local bleeding disorder organization, implying that they were already willing to participate in positive youth development activities. In addition, most participants in this study lived in large urban centers and had a college education. To control for possible self-selection bias, future studies could be done on a larger scale to include more young women, suburban and urban participants, and participants with diverse educational backgrounds.

A further limitation of the study was the uneven distribution of the countries represented in the sample. Access to a computer/smart device, internet, and electricity was required to respond to the study. In some countries in Latin America, rolling blackouts and lack of internet access are daily realities that may have limited participation, especially from those in rural areas.

5.1 Policy Recommendations

Policy and program recommendations can be implemented at every level of the socio-ecological framework (Figure 2.1) to promote the well-being of young adults living with an inherited bleeding disorder in Latin America. Based on the findings of this study, three recommendations for policymakers, healthcare providers, and other stakeholders emerged. These recommendations can be the foundation for future research and program development.

A) Develop programs and policies to increase training for healthcare providers

The gold standard of care for people with inherited bleeding disorders is comprehensive care administered at a specialized hemophilia treatment center by a team that includes a hematologist, a nurse coordinator, a physical therapist, and a social worker or psychologist. Unfortunately, many people in Latin America do not have access to specialized treatment centers to receive even the most elemental diagnostic care and services (Isidro de Pedro, 2002).

The International Hemophilia Training Centre Fellowship Program (IHTC) facilitates hands-on training for fellows at one of 34 World Federation of Hemophilia-designated training centers around the world. IHTC fellows train for up to 2 months to manage a hemophilia treatment center, provide diagnostic services, and deliver comprehensive care for patients (Tezanos Pinto & Ortiz, 2004). Policymakers and healthcare providers in Latin America should advocate for developing regional cooperative education programs between universities and healthcare institutions. Former IHTC fellows could provide formal coaching and mentorship to healthcare students across the region to increase training and interest in specializing in one of the disciplines that are part of the comprehensive care team.

Each member of the comprehensive care team for people with inherited bleeding disorders plays a pivotal role in educating and empowering patients to manage their disorder. A

person's ability to positively view their capacity to accomplish goals in life is directly influenced by their thoughts and capability to implement what they think (Shek et al., 2019). Developing confidence in managing their bleeding disorder can significantly improve patient's quality of life, reduce the risk of disabilities, and reduce long-term costs. It is essential that care providers advocate for, raise awareness of, and develop policies that increase training for healthcare providers to improve patients' quality of life (Montaño et al., 2014). Studies have found that patients diagnosed with an incurable inherited bleeding disorder with access to comprehensive care perceived they have a better quality of life, as demonstrated by their high median and average scores in quality of life surveys (Arteaga-Rubiano & García-Valencia, 2021).

B) Develop formal regional peer mentoring programs

Peer mentoring programs educate, increase connection, and empower patients. To guide program development, Breaky and colleagues (2018) interviewed youth with hemophilia in Canada to identify their peer mentoring needs. Youth in that study stated that participating in a peer mentoring program would help them feel that they were not alone in dealing with their disease as the main benefit of receiving mentorship. The findings in the Canadian study corroborate the responses shared by participants of the current study.

Connection, or the ability to form bonds with others, was the most identified Positive Youth Development construct in the current study by respondents. This multi-dimensional construct influences relationships with family, friends, and community (Shek et al., 2019). A 22-year-old living with hemophilia in the Caribbean stated the disorder gave them (people with a bleeding disorder) a connection to a community of peers that provided them with "…unconditional support and you learn how to live with the disorder…" [*…un apoyo incondicional y se aprende a cómo convivir con el trastorno…*] The World Federation of

Hemophilia recommends peer mentoring to combat feelings of isolation and strengthen resilience (Srivastava et al., 2020).

Formal peer mentoring policies and programs implemented by local hemophilia-serving organizations should include structured plans that require participants to volunteer their time to learn the skills needed to support and serve their community successfully. Empathizing with members of their local bleeding disorder community can motivate participants to support, counsel, and care for people in disparate areas of Latin America with very different access and support levels. This desire to support their peers can be leveraged to cultivate empowered social change agents who actively advocate for improved access to care and treatment for people with inherited bleeding disorders. Peer mentoring programs allow participants to advocate for improving their quality of life while gaining cognitive, social, academic, and vocational skills and competence through participation (Naudeau, Cunningham, Lundberg, & McGinnis, 2008).

The policy for the peer mentoring program should consider different delivery modalities, including in-person, telephone, and web-based (Breakey et al., 2018). Respondents of the current study identified geographic isolation and long distances as challenges to living with hemophilia in Latin America. An option for web-based delivery of the peer mentoring program would help overcome this challenge and allow participants to connect and identify socio-culturally as members of the local, national, and global bleeding disorder community.

C) Provide psychosocial and emotional support

Participants across all regions of Latin America in this study made multiple recommendations for mental health resources and support. Bleeding disorders impact all aspects of daily living for patients and their families, including economic burdens that lead to additional emotional distress. As respondents of the current study shared, the pain they experience can be

debilitating. The physical manifestations of the disorder can lead to feelings of depression, sadness, and fear for their future (Guzmán et al., 2016).

Psychosocial providers can assist patients in multiple ways. First, identifying financial resources to cover the cost of care and treatment for their disorders. Second, assisting patients in finding employment opportunities that consider their physical limitations and provide adequate accessibility. Third, help patients understand and navigate issues associated with personal relationships, sexuality, and reproductive care (Spilsbury, 2004). Fourth, provide strategies to manage pain.

The World Federation of Hemophilia Guidelines for the Management of Hemophilia emphasizes that care providers at hemophilia treatment centers should educate patients on the emotional, physical, economic, and psychological aspects of living with a bleeding disorder (Srivastava et al., 2020). Psychosocial support is essential to help combat and prevent feelings of ostracism and loneliness that people with bleeding disorders may experience in under-resourced areas of the world. Moreover, psychosocial support epitomizes the social policy values of "justice and equality of access" (Spilsbury, 2004, p.26).

In most countries, efforts around access to psychosocial support for patients are centered on the premise that specialized hemophilia treatment centers should deliver these services. However, given the lack of specialized centers in Latin America, policies should be enacted to encourage the provision of these services by professional counselors, social workers, and psychologists that work in local community health centers, general hospitals, or schools (Spilsbury, 2004). Considering the multifaceted needs of patients with inherited bleeding disorders, policies that leverage the varied community providers who can deliver resources to support and empower patients and improve their health outcomes should be enacted. The World

Federation of Hemophilia Guidelines for the Management of Hemophilia recommends obtaining psychosocial support from local providers when social workers are unavailable at treatment centers (Srivastava et al., 2020).

Policy and programmatic recommendations for providing psychosocial support must include the delivery of individual direct counseling to patients and access to mental health support groups for people and families impacted by hemophilia and other inherited bleeding disorders. Optimal hemophilia psychosocial care policies should include guidelines that recommend psychosocial professionals who are not members of specialized hemophilia treatment centers receive basic training about bleeding disorders, learn about living with a bleeding disorder from their patients, and consider the stages of cognitive development as they provide support and care to people with inherited bleeding disorders (Cassis, 2007).

5.2 Implications for Public Health Practice

Even though several programs and policies offer resources to participants in Latin America, survey results showed that resources are not available equally throughout the region. As the leading organization in hemophilia advocacy, The World Federation of Hemophilia is well-positioned to address several of the survey respondents' recommendations through policy change. The policy and program recommendations discussed in this section provide the foundation to consider two implications for public health practice: 1) the implementation of targeted interventions based on constructs of the Positive Youth Development model at each level of the socio-ecological framework to improve outcomes and 2) the development of intersectoral regional collaborative approaches to address common health goals.

The first implication for public health practice is the potential to implement targeted interventions that impact outcomes at each level of the socio-ecological framework.

Policymakers, public health practitioners, and healthcare providers should acknowledge that for young people living with a bleeding disorder in Latin America, the physical manifestations of the disorder are associated with pain, feelings of helplessness, and reduced emotional and social functioning. Stakeholders must recognize that young adults in the region are valuable assets and should partner with them to develop programs for the bleeding disorder community in Latin America. Enacting policies that integrate the socio-ecological model and Positive Youth Development framework into interventions for young people living with a bleeding disorder in Latin America would allow for the creation of patient-provider collaborative programs. Studies have shown that community-based participatory research and engage participants as valuable assets to support local, national, and regional goals focused on improving outcomes (Atkiss et al., 2011).

The second implication for public health practice is the development of intersectoral regional collaborative approaches to address common health goals. The Pan American Health Organization (PAHO) works to improve regional health outcomes in Latin America. To achieve this goal, PAHO developed the *Sustainable Health Agenda for the Americas 2018-2030* (PanAmerican Health Organization, 2017), a series of 11 goals to improve health and well-being. Goals three and nine of PAHO's agenda complement the policy recommendations of this study and provide an opportunity for collaboration across the region.

Goal three calls for strengthening human resources for health in the region. Specifically, PAHO recommends collaborations between health-serving organizations and educational institutions to address the population's needs. Policymakers working to increase resources to train healthcare providers to serve patients with bleeding disorders should collaborate with PAHO to leverage their resources. Leveraging PAHO resources would help augment scarce

financial resources and offer significant connections for the World Federation of Hemophilia to establish regional relationships and partnerships with key stakeholders in the region's education and healthcare arenas.

Goal nine, specific to non-communicable disorders, focuses on reducing morbidity, disabilities, and mortality from noncommunicable diseases, injuries, violence, and mental health disorders (PanAmerican Health Organization, 2017). Participants' responses regarding mental health needs in this study emphasized the need for programs and policies that address their psychosocial needs. The World Federation of Hemophilia and its member organizations in Latin America should collaborate with PAHO to develop specific mental health strategies and policy initiatives for people with bleeding disorders. Partnering with PAHO would give the WFH access to the resources needed to improve mental health and psychosocial support services for people living with inherited bleeding disorders in the region (PanAmerican Health Organization, 2017).

5.3 Conclusion and Future Directions

This study provides substantive contributions to understanding the challenges and needs of young adults living with inherited bleeding disorders in Latin America. A strength of this study was collecting responses in the participants' own language and voice. The study elicited recommendations for programmatic improvements directly from the consumers of these public health programs. Engaging participants as active collaborators in designing and developing programs to improve outcomes is a foundational principle of positive youth development (Atkiss et al., 2011). Policymakers and stakeholders should utilize the findings of this study to consider several questions to guide their integration of the PYD and socio-ecological framework in future program development: 1) what type of program outcome is desired, 2) which level(s) of the

socio-ecological framework will be addressed/impacted by the program, 3) which construct(s) of the PYD model will be targeted for development in the program, 4) what difference will the program make in the lived experience of participants, 5) how will program participants collaborate in the development and evaluation of the program, and 6) how will program participants and developers work together to promote and implement the program.

A basic tenet of PYD is that youth should be considered valuable assets and experts in program and policy development (Shek et al., 2019). This ideology is similar to principles in decolonizing research methodology, which provides a space for the development of research practices and programs that engage often marginalized ethnic groups to guide knowledge and program production to counter the superiority of western ideas and values in research and program development (Bermúdez et al., 2016).

For respondents of this study, their Latino culture and values provided a solid foundation to develop traditional PYD constructs such as connection. Youth in this study repeatedly listed a shared sense of community as a source of strength. This sense of community hearkens back to the Latino value of *familismo* (familism), where support networks that expand beyond the nuclear family and include extended family members and friends are developed (Adames et al., 2014).

Latinos are relationship-centered and place prominence on their connections with others. Values such as familismo, personalismo (personalism), respeto (respect), and confianza (trust) are integral to Latino culture (Adames et al., 2014). These values can influence PYD development for young adults in the region. Further studies that consider a decolonizing methodology to create a more inclusive research field that includes values inherent to Latino

participants are needed to develop integrated PYD and Socio-ecological frameworks to improve outcomes for young people with inherited bleeding disorders in Latin America are needed.

This study provided a holistic view of the challenges and opportunities experienced by participants in the region, opening a window into the participant's experience across the complex interconnected socio-ecological system in which people live. The findings of this study will be presented at regional meetings in Latin America and worldwide conferences to share results with young adults impacted by bleeding disorders, healthcare providers, and policymakers in the community. This study offers stakeholders in the region a framework to collaborate with young people to develop programs and services to improve their health outcomes. Future programs based on integrating the PYD and Socio-ecological frameworks should be tailored to the community in which they are implemented. The needs of the young adults in these areas will vary depending on their available resources and assets.

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Appendix A – Demographic Survey

Thank you for agreeing to participate in the research study "Living with Hemophilia in Latin America." Your participation will help strengthen programs for youth with bleeding disorders in Latin America.

1. Name _____
2. Year of Birth _____
3. Age _____
4. What is your gender? _____
5. What is your ethnicity? Select all that apply.
   - ☐ Native/Indigenous
   - ☐ Black or Afro Caribbean
   - ☐ White/Caucasian
   - ☐ Asian
   - ☐ Please Specify: _____
6. What is your country of origin? _____
7. In what country do you live? _____
8. Do you live in a big city or rural small town? _____
9. What is your relationship status?(single, dating, married, etc.) _____
10. Are you a parent? Yes _____ No_____
11. What is your highest educational level? (completed elementary school, high school degree, how many years in college) _____
12. What is your current employment status?
    Please choose all that apply
    - ☐ Full Time
    - ☐ Part Time
    - ☐ Student
    - ☐ Receiving support because of disability
    - ☐ Homemaker
    - ☐ Volunteer
    - ☐ Not Employed
13. What is your bleeding disorder diagnosis?
    Please choose one
    - ☐ Factor V Deficiency
    - ☐ Factor VII Deficiency
    - ☐ Factor VIII Deficiency

- ☐ Factor IX Deficiency
- ☐ Factor X Deficiency
- ☐ Factor XI Deficiency
- ☐ Factor XIII Deficiency
- ☐ Glanzmann Thrombasthenia
- ☐ Platelet Function Disorder
- ☐ Platelet Storage Pool Disorder
- ☐ von Willebrand Disease
- ☐ Other Bleeding Disorder _____

14. What is the severity of your hemophilia diagnosis?
    Please choose one
    - ☐ Mild
    - ☐ Moderate
    - ☐ Severe

15. Have you received prophylactic treatment?
    - ☐ No
    - ☐ Yes
    - ☐ Not sure

16. Have you ever had an inhibitor?
    - ☐ No
    - ☐ Yes
    - ☐ Not sure

17. Do you have any other disorders?
    - ☐ No
    - ☐ Yes _____

18. Have you had any surgeries related to your bleeding disorder?
    - ☐ No
    - ☐ Yes (please specify) _____

Appendix B – Consent Form

CONSENT FORM

"Living with Hemophilia in Latin America" is a research study to identify positive youth development factors that will improve the quality of life of youth diagnosed with bleeding disorders in Latin America. I am inviting you to tell me about your experience as a person with a bleeding disorder.

What will I do? You will complete a demographic survey, two questionnaires and answer a few questions about living with a bleeding disorder. It will take 15-20 minutes to complete the survey and questionnaires. You can answer the questions at the end of the survey online, or you can record your answer and upload them, or you can schedule a time to record your answers. Please answer the survey within the next week.

What are the benefits? Your participation will help strengthen programs for youth with bleeding disorders in Latin America.

Are there any risks? Some young people may feel uncomfortable discussing their bleeding disorder care. At any point, you may refuse to participate, skip any questions, or withdraw from the study. Your decision will not have any negative consequences and will not impact any relationship you may have with your local hemophilia organization or the World Federation of Hemophilia. If you decide to withdraw from the study, your feedback will continue to be used unless you ask me to destroy it. Your participation is entirely voluntary.

Will you ask for personal information? Personal information is kept confidential and separate from the results of the questionnaires. Private, identifiable information (such as your name or country) will be kept confidential. Given the group's small size, the description of participants is very generic (e.g., young people with bleeding disorders). The research team can only break confidentiality if participants report immediate harm to themselves or others. Demographic information is only used to describe the sample. No personal information will ever be linked to any report or publication. Keep in mind that because you are completing the questionnaire online, there is a limit to the confidentiality that can be provided.

Who should I ask if I have questions? Please contact Deniece Chevannes (xxxxxxx@uga.edu; or WhatsApp 1-xxx-xxx-xxxx) or Dr. Pamela Orpinas (xxxx@uga.edu) from the College of Public Health, University of Georgia. Additional questions or problems regarding your rights as a research participant should be addressed to the Chairperson, Institutional Review Board, University of Georgia: Phone 1-706-542-3199, Email IRB@uga.edu.

By clicking SUBMIT below, I acknowledge that I agree to participate and that I have a bleeding disorder, I live in Latin America, and my age is between 18 and 30 years old.

SUBMIT
Do not submit