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Utilization of Mental Health Services for Caregivers of Hemophiliacs

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This is to certify that the doctoral dissertation by

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Abstract

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Dissertation Submitted in Partial Fulfillment

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Abstract

The utilization of mental health services for caregivers of hemophiliacs is an underserved area. Andersen's behavioral model of utilization was the conceptual framework in this generic qualitative study. I used surveys and semi-structured interviews to obtain 20 participants' information for nonprobability sampling, specifically purposive sampling. Narrative analysis was used as the foundation of the coding process The study findings revealed seven themes: cultural impact/stigma of mental health services; normalizing mental health services in the hemophilia community (national impact); inconsistencies in hemophilia treatment centers' (HTCs') service delivery; clarity of the role of the HTC social worker; member organizations emphasis on mental health (local impact); guilt and shame of seeking services because of "strength messaging"/resiliency of community (past generations had it worse so stop complaining/showing weakness); and ease of service delivery. Participants voiced a strong desire to utilize mental health services; but a great resistance to the stigma that comes along with it. The positive social change for caregivers includes the knowledge and resources of mental health services as part of their caregiving experiences.

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Dedication

WITH GOD ALL THINGS ARE POSSIBLE

I dedicate this completed dissertation to Bishop Edward Gabriel Bell, Sr. and Anna Grace Bell who were the absolute best parents a little girl raised in Palmer Park, Maryland could have ever dreamed of. Their unwavering support, encouragement, faith, and belief that I could do anything that I set my mind to has catapulted me to complete my doctoral journey.

To my husband, Kerry and daughter, Zionna who were understanding of late nights and missed adventures and to my spiritual family that has prayed me out of giving up and throwing in the towel, your love and support has been invaluable.   To my support network of strong African American Female PhD's in my circle and on this journey with me, thank you for reminding me that perseverance and sheer will can breed great results.

For all my clients, foster children, families, and seniors I have worked with over the years, thank you for trusting me with your care and providing me with purpose in my life. Please remember your environment does not dictate who you are and what you can achieve. Obstacles breed strength. YOU WERE NOT BUILT TO BREAK!!!!

Lastly, I dedicate this completed dissertation to the Hemophilia Community. Your willingness to embrace and utilize my gifts and skill set has been a huge blessing. You have opened doors that I never imagined I would walk through. Your resilience and strength, in the face of insurmountable obstacles, inspires me daily to walk in my purpose, healing those who are in need. There is NOTHING that will keep me from that work; so, I ABSOLUTELY, WHOLEHEARTEDLY, THANK YOU!!!!!!

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Chapter 1: Introduction to the Study

The topic of my study is the utilization of mental health services for caregivers of hemophiliacs. As Dockery et al. (2015) shared, informal caregiving has become a very frequent phenomenon in families. Given this information from Dockery et al., understanding the utilization or underutilization of mental health services for caregivers within the hemophilia population will assist service providers and medical professionals with providing care to the entire family system.

Understanding caregivers' attitudes and experiences and the identification of themes and patterns when it comes to the utilization and underutilization of mental health services for caregivers of hemophiliacs will provide a framework for better service delivery options and opportunities for this population. The positive social change for caregivers includes the knowledge and resources of mental health services as part of their caregiving experiences. This research can also provide a positive social impact to the hemophilia community as a whole impacting and informing the medical community regarding holistic treatment options that encompass medical and mental health services.

This chapter will begin with background information of relevant historical literature related to utilization, hemophilia, and mental health. A statement of the problem will illuminate the study's purpose. A research question will guide this study, and I will explore the conceptual framework to provide a context for explaining the research data collected. I will describe the nature of the study and definitions that explain key terms. I will address the study's assumptions, scope, and delimitations and explore any

limitations. This chapter will end with the relevancy and significance of the study and a brief summary, which will lead to Chapter 2.

Background

Ploeg et al. (2016) noted the increase in informal caregivers who are responsible for providing care to an increasing population of persons who suffer from chronic illness or cognitive impairment. These scholars concluded that caregiver stress increases as the caregiver population increases, and the need to provide mental health services to caregivers would increase. Javalkar et al. (2017) noted that caregivers of children with chronic illnesses such as cystic fibrosis, asthma, and diabetes often experience poor sleeping habits, family conflict, anxiety, depression, financial stress, and lower quality of life. This study examined interventions to assist with the issue's caregivers face, including mental health interventions.

Peterson et al. (2018) indicated the importance of integrating mental health into chronic care. The study asserted that the treatment of medical conditions must be accompanied by mental health interventions for the entire family system. South Africa developed a comprehensive healthcare plan to ascertain patients' mental health needs and provide resources and referrals for the entire family that will support the healthcare needs of persons with chronic care needs. This study recognized the need to assess the whole family in the process of managing the chronic disease, discovering all pertinent needs, including support services for the family (i.e., caregivers).

Shidhaye et al. (2015) discussed the importance of providing treatments that involve medical as well as mental health needs. The study highlights the underutilization

of mental health services in the traditional medical model of care and the importance of integrating mental health in primary care as a service to patients and caregivers. This study indicated the need to address both physical and psychological health needs instead of the traditional medical model of care. The study touched on the obligation to provide a comprehensive medical plan for patients managing chronic diagnosis, including their families, that would include the utilization of mental health services.

Hermans et al. (2015) discussed the many components of managing hemophilia as a lifelong illness. This study compiled multiple topics covered at the 5th Global Hemophilia Summit. This study focused on the various challenges associated with hemophilia and its overall effects on the patient, including economic, familial, caregiver stress, and treatment options. This study provided a comprehensive look at challenges associated with hemophilia, including caregiver stress and opportunities to alleviate stress, such as mental health interventions.

Kumar et al. (2016) provided information about the patient's and caregiver's quality of life, including risk factors and complications that hinder mental health treatment. This study covered difficulties in seeking mental health treatment for patients with chronic illnesses as well as their caregivers. Kent et al. provided information regarding the patient-caregiver dyad, which involves both the patient and caregiver receiving supports together that will improve the well-being and quality of life of both individuals while receiving treatment for chronic diseases.

Hong and Harrington (2016) discussed the importance of social work research and practice on how to protect caregivers' physical and mental health. This study

illuminated the importance of developing systems that will help address issues that affect caregivers who assist persons with chronic medical conditions. Phillips et al. (2018) discussed healthcare usage using the behavioral model of utilization. The study asserted that it is critical to analyze the factors associated with patients' utilization of healthcare services to develop better systems that would encourage better use of services. This study provided a conceptual framework to study healthcare utilization.

I have not been able to find research related explicitly to the utilization of mental health services for caregivers of hemophiliacs. There is documented research on various aspects of caregiver stress concerning taking care of a person with chronic health concerns (Khanna et al., 2015), as well as research on caregivers' quality of life, which encompasses the standard of health, comfort, and happiness individual caregivers experience (Devlin et al., 2018). However, I have been unable to locate research that speaks to the experiences of caregivers of hemophiliacs regarding the utilization of mental health services.

It is vital to ensure caregivers' well-being as society moves to the philosophy of holistic healing where treating a multiplicity of illnesses is common practice. Understanding the utilization, or underutilization, of mental health services for caregivers will illuminate the issue and contribute to the existing body of literature regarding improving the quality of life for those charged with caring for persons with a chronic diagnosis. Kinchen (2014) and Roymeke and Stummer (2015) asserted that caregivers who can take care of their own needs and maintain a good quality of life can provide better care to those living with chronic diseases.

Problem Statement

Hemophilia is a life-threatening illness resulting from the inability of the blood to

form clots, which can increase the occurrence of life-threatening hemorrhaging

(Hemophilia Federation of America [HFA], n.d.). Hemophilia is a recessive disorder that

occurs in 1:5,000 to 1:10,000 persons depending on the various types of hemophilia

(Centers for Disease Control and Prevention, 2017a). Hemophilia is both physically and

mentally challenging for the diagnosed hemophiliac as well as for their caregiver (Peng et

al., 2017).

Caregiving can be physically, emotionally, and financially demanding work,

which can lead to high caregiver burden (Miravitlles et al., 2015). Caregiver burden may

be associated with a decrease in quality of life, which can significantly impact caregivers'

physical and mental health (Miravitlles et al., 2015). Some factors that contribute to

caregivers' emotional strain include the longevity of the sickness, life-threatening effects

of the ailment, and the patient's inability to engage in work and social activities. These

factors further the caregiver's responsibilities and transform the roles within the family

(Akgul & Ozdemir, 2015; Oksuz et al., 2017).

Srivastava et al. (2016) found that caregivers of persons with dementia

experienced strain and burden resulting from the rigorous activity of caregiving, which

can have a negative impact on their physical, psychological, and social quality of life.

Kaschowitz and Brandt (2017) indicated that caregivers of persons with chronic disease

experienced burdens in areas such as expectation, privacy, management, embarrassment,

anger, personal and social relationships, fear, dependence, finance, incompetence,

uncertainty, and avoidance. The stress of caregiving as well as the duration of caring for a loved one increases caregivers' chances of developing depression and other illnesses.

The above research provides insight specific to the physical, emotional, and mental well-being of caregivers who take care of people with chronic illness. During the early 1980s, almost 50% of hemophiliacs living in the industrialized world were infected by the human immunodeficiency virus (HIV) because their blood-based medications were HIV-contaminated. Those in the hemophilia community call this period the hemophilia holocaust (Keshavjee et al., 2017). As this community became aware that they were sick or dying, they reacted with anger, grief, resignation, desperation, shock, and fear; and although those emotions were very present, the necessary time to effectively process those feelings and emotions was short or nonexistent (Kirp, 2016).

Managing feelings of loss, guilt, and depression was extremely difficult for caregivers during this time, who were often hemophiliacs themselves, especially when mental health services that were available for those not "officially diagnosed with mental health diseases" were limited. As hemophiliacs progressed from that period of severe loss and grief, those who lived through that era and lost generations of family members still suffer from those memories. Although these families are still managing grief and loss as well as mental health difficulties, the utilization of mental health services for persons managing chronic illnesses has not historically been a priority (Assari et al., 2015).

I have not been able to find research related explicitly to the utilization of mental health services for caregivers of hemophiliacs. There is documented research on various aspects of caregiver stress concerning taking care of a person with chronic health

concerns (Khanna et al., 2015), as well as research on caregivers' quality of life, which encompasses the standard of health, comfort, and happiness individual caregivers experience (Devlin et al., 2018). However, I have been unable to locate research that speaks to the experiences of caregivers of hemophiliacs regarding the utilization of mental health services.

Purpose of the Study

For families affected by hemophilia, the emphasis has historically been on the management of pain and quality of life for the hemophiliac (Gringeri et al., 2016; Kumar et al., 2016; McLaughlin et al., 2017). I aimed to understand caregivers' perceptions and experiences regarding their utilization of mental health services, as the role of caregiving can be demanding, requiring constant vigilance and numerous changes to one's lifestyle (Schwartz et al., 2017). In addition, caregivers often forego their own physical and mental health to address their caregiving role (Klassen et al., 2016). This study afforded the opportunity to obtain caregivers' first-hand accounts and their beliefs and attitudes regarding their utilization of mental health services.

Research Question

What are the experiences of the utilization of mental health services among caregivers of persons with hemophilia?

Conceptual Framework

The behavioral model of utilization Ronald Andersen (1967) developed discusses three stages in which predisposing, enabling, and need components are used to explain families' widely differing uses of medical care services. The model postulates that usage

takes place where (a) a family is predisposed to receive medical care, (b) conditions make health services available to the family, and (c) the family perceives a need for these services and responds to that need.

According to Babitsch et al. (2015), healthcare utilization often relies not only on the availability of services, or a family who perceives the need for the services, but also on the incorporation of health services in a regular routine of healthcare delivery and utilization. These services would be more of an expectation and norm. For caregivers of hemophiliacs, managing burnout and mental health counseling may be perceived as an "added service array" that does not take precedence over the day-to-day medical treatments and caregiving responsibilities of their daily lives.

According to Bradley et al. (2018), in families providing care to relatives with dementia and Alzheimer's, the psychosocial factors such as guilt, depression, and anxiety were determinants in their decision-making surrounding caregiving maintenance or the placement into long-term care facilities. These same psychosocial factors may also be present for caregivers of hemophiliacs. Bradley et al. referred to caregivers not seeking counseling to manage these psychosocial stressors, thereby struggling with their self-care while providing care to their loved ones. This model is a valuable contribution towards understanding caregivers' attitudes and experiences and the identification of themes and patterns when it comes to the utilization and underutilization of mental health services for caregivers of hemophiliacs.

Nature of the Study

Generic qualitative inquiry is an appropriate research design as I am seeking to understand caregivers' experiences. Percy et al. (2015) stated generic qualitative data collection seeks information from representative samples of people about real-world events and processes or their experiences. Semi-structured interviews allowed for an objective analysis of subjective experiences (Percy et al., 2015). Interview questions included inquiry into the challenges of caregiving as well as the importance and relevance of mental health services for participants. I used generic qualitative inquiry using thematic analysis to analyze data collected through semi-structured interviews. I coded and analyzed data to facilitate the identification of recurrent themes and linkages to aide in analyzing the research utilizing tenants of the Anderson (1967) model.

Definitions

Hemophilia

According to Castaman and Matino (2019), hemophilia is a rare X-linked bleeding disorder that affects the blood's ability to clot resulting from mutations in the gene's encoding coagulation factor VIII (FVIII; hemophilia A [HA]) and factor IX (FIX; hemophilia B [HB]) or a spontaneous mutation that occurs once in 100,00 cases. Hemophilia occurs when one has a deficiency of coagulation factor VIII (FVIII) in HA or factor IX (FIX) in HB (John et al., 2017).

According to Page (2019), hemophilia is an X-linked congenital bleeding disorder caused by a deficiency of coagulation factor VIII (FVIII) in HA or factor IX (FIX) in HB or a spontaneous mutation that occurs 1 in 100,00 cases.

Bleeding Disorders

According to the National Hemophilia Federation (NHF), bleeding disorders are a group of disorders that share the inability to form a proper blood clot. Sometimes the bleeding is spontaneous, without a known or identifiable cause but most bleeding disorders are inherited or acquired. The term bleeding disorder is often used synonymously instead of hemophilia.

Utilization

According to Teich et al. (2017), mental health utilization refers to one's usage of available services to prevent or manage mental health challenges. Several factors influence one's utilization of mental health services. For veterans, utilization of mental health services comes with a perception of risk to service continuation and possible rank promotions.

Preterm birth is an independent risk factor for postpartum mental healthcare utilization. An individual's utilization of these services relies on several factors: the availability and convenience of the services, the acknowledgement that there is a need for the service, and follow up from the service provider (Calthorpe, 2021).

Caregiver

According to Yeoman et al. (2017), caregiving can be divided into specific categories. Anticipatory caregiving is defined as a change in lifestyle and behaviours to accommodate a patient's future needs. Preventative caregiving involves actively and frequently monitoring a patient to improve their wellbeing and health. This type of caregiving involves taking the patient to doctors' appointments to learn ways to keep the

patient healthy, prepare for the various challenges facing the patient, keeping the patient familiar with their own healthcare needs and what to look out for, and making sure a patient's surroundings are safe by changing the physical household and lastly by asking a patient about their needs to mitigate symptoms (Bouldin et al., 2017).

Assumptions

The hemophilia community is a very complex subset of the population. Their medical needs are vast, often financially overwhelming, can be very painful, and require constant vigilance and treatment (Miravitlles et al., 2015). Because of these factors, caregivers often push patients' needs for mental health intervention to the back of the list of priorities. Caregivers often believe the needs of those they are caring for take precedence over their own needs. This belief usually prevents caregivers from seeking assistance for the overwhelming burden, sadness, and heartache that stems from watching your loved ones suffer the effects of the debilitating and incurable chronic disease.

These assumptions were considered necessary to provide a representation of the utilization of mental health services in this community. Hemophilia treatment centers (HTCs) all employ social workers, yet the use of these social workers in the role of mental health counseling has been underutilized. Instead, this critical member in the healthcare triad is often used to make connections to outside resources for financial support, arranging discharge plans, and routine follow up after yearly visits.

Scope and Delimitations

This study focuses on two aspects of the broader research problem namely, the perceptions of the caregivers of hemophiliacs and secondly the utilization of mental

health services for the hemophilia impacted caregiving community. According to Miravitlles et al. (2015), caregiving can be demanding physically, emotionally, and financially. This can lead to a high caregiver burden. Caregiver burden can occur due to a decrease in quality of life, which can significantly impact a caregivers' physical and mental health (Miravitlles et al., 2015).

This study was designed to understand caregivers' beliefs and experiences regarding their utilization of mental health services. According to Schwatz et al. (2017), as the role of caregiving can require constant vigilance and numerous changes to one's lifestyle understanding the utilization, or underutilization, of mental health services for caregivers will highlight the issue and contribute to the existing body of literature regarding improving the quality of life for those charged with caring for persons with a chronic diagnosis like hemophilia.

The boundaries of the study include only interviewing participants who initially filled out the demographic questionnaire as well as those who are actively providing care to a person diagnosed with hemophilia. This research excluded those who are not actively providing care to a person diagnosed with hemophilia to ensure direct and first-hand perceptions of the caregiver experience regarding mental health utilization. I issued the survey to participants who reside within the United States and did not target a particular state.

I used generic qualitative inquiry as the research design for this study, as it is the framework most closely related to the study topic, as it focuses on people's experiences, personal opinions, attitudes, beliefs, and the highlights about their thoughts and feelings,

according to Percy et al. (2015). Generic qualitative researchers seek to gather data that are inherently subjective in nature and seek to uncover the process in which a person understands their own experiences without outside influence and guidance.

I considered but did not choose ethnographic and narrative research methods for this study. Ethnographic research occurs when the researcher immerses themselves in a group or organization to understand the culture (Creswell, 2015). I do not want to bias the research with personal experiences due to having family members diagnosed with hemophilia. Narrative research allows the researcher to interpret participants' stories to understand how people make sense of their experiences and perceptions. I wanted the participants to be the sole provider of data without the data collector's interpretation. Therefore, I hope to be able to develop better service provisions of mental health services to caregivers of hemophiliacs based on the identified themes and interpretations of the participants who identified systemic and interpreted barriers of service delivery.

Finally, transferability is how the qualitative researcher demonstrates that the findings can be used in similar situations and with similar populations. Some ways to establish transferability include thick description and variation in participant selection. Thick description in relationship to transferability refers to the researcher's ability to provide a robust and detailed account of their experiences during data collection. It is typical for researchers to make connections to the cultural and social context involved in data collection. This includes speaking about where the interviews occurred and situations that may have affected data collection like the time of day the study occurred, which could influence the interview.

Limitations

Research studies often face multiple limitations. Some of these limitations include methodological limitations, participation to get a sufficient sample size, methods and instrument limitations and actual researcher limitations (Queiros, et al., 2017). Lack of participation from caregivers of hemophiliacs for group or individual interviews may be a possible barrier to the study's success.

Transferability is how the qualitative researcher demonstrates that the findings can be used in similar situations and with similar populations. As hemophilia is a unique disease, transferring perceptions of utilization of mental health to other chronic illnesses may not be possible. In order to minimize limitations with transferability, focus was placed on the aspect of caregiving to persons with chronic illnesses.

Dependability of the research assumes another researcher could repeat the original researcher's study and that the findings would be consistent. I ensured that data collection methods as well as conceptual frameworks were clearly delineated, therefore replication of study would be more accessible for future researchers.

Researcher bias may also be considered as a limitation. As I am a caregiver in this community, it was. very important to note my feelings and thoughts that occur while conducting the research. I noted personal biases and experiences that may hinder the research. I reviewed this reflective journal regularly to ensure I managed my own thoughts, feelings, and perceptions.

Finally, another limitation that arose related to hemophilia being genetic. Because of this, many participants were also carriers of the disease or sufferers of the disease

themselves, which may have influenced their responses based on the challenge of separation of roles (hemophiliac, carrier, caregiver). Having multiple roles can provide a skewed response that may encompass aspects of caregiving such as one who is receiving care or will be receiving care in the future. I reiterated the purpose of the questions as it relates to caregiver perception repeatedly to ensure the distinction of the role and purpose of this research study.

Significance

This study will address the issue of mental health service utilization for caregivers of persons with hemophilia. Dockery et al. (2015) stated informal caregiving has become a frequent occurrence in families. Because of this, understanding the utilization or underutilization of mental health services for caregivers within the hemophilia population will assist service providers and medical professionals with providing care to the entire family system. It is significant and vital to ensure caregivers' well-being as society moves to the philosophy of holistic healing where treating a multiplicity of illnesses is common practice.

The emphasis on family wellness including mental health service utilization lays the foundation for less caregiver stress and the ability to help families live as healthy lives as possible both mentally and physically while managing the chronic disease of hemophilia. Understanding the utilization, or underutilization, of mental health services for caregivers will illuminate the issue and contribute to the existing body of literature regarding improving the quality of life for those charged with caring for persons with a chronic diagnosis. Kinchen (2014) and Roymeke and Stummer (2015) asserted that

caregivers who can take care of their own needs and maintain a good quality of life can provide better care to those living with chronic diseases.

Summary

This chapter provided an overview of the research process from participant recruitment to data analysis. This study focused on the utilization of mental health services for caregivers of hemophiliacs. I addressed the rationale for utilizing qualitative research, emphasizing the importance of obtaining participants' subjective experiences as a valid point of study. This chapter detailed the background surrounding the study's subject matter with an emphasis on the purpose and necessity of the subject matter. I defined key terms and discussed the assumptions, scope, limitations, and delimitations as a roadmap for the study's relevancy. I also stated and justified the data-collection methods and conceptual frameworks.

This chapter presents a framework for Chapter 2, where an exhaustive literature review will provide further background of the utilization of mental health services for caregivers of hemophiliacs.

Chapter 2: Literature Review

Introduction

This study addressed the issue of mental health service utilization for caregivers of persons with hemophilia. Informal caregiving refers to the help and support family members and friends provide daily to individuals who are either temporarily or permanently unable to function independently (Eifert et al., 2015; Hepburn & Siegel, 2020). Dockery et al. (2015) stated informal caregiving is a frequent occurrence in families. The stress related to caring for a loved one can be extremely difficult and really challenging mentally for the entire family, especially for the caregiver.

Caregivers often underutilize mental health services to assist with the stress, anxiety, and sadness often associated with caring for someone with a chronic disease (Mosher et al., 2015). Understanding the overall utilization and the possible reasons for underutilization of mental health services for caregivers within the hemophilia population can ultimately assist providers of mental health services and medical professionals with providing care to the entire family system. Understanding caregivers' utilization or underutilization of mental health services contributes to the existing body of literature to improve the quality of life for those caring for persons with a chronic diagnosis.

My goal is to provide information on hemophilia including the symptomatology, statistical data surrounding this condition, and traditional demographics and prevalence associated with the disease, including the definition of caregivers, caregiver demographics, and caregiver models. I will expound on the significant aspects of caregiving complications including the financial, emotional, and psychological aspects

such as family stress and burden. I aim to present the services currently available for caregivers, especially those that are uniquely developed for caregivers of hemophiliacs.

A significant gap identified in this literature regards caregivers of hemophiliacs and their utilization of mental health services. I have been unable to find research that covers the topic of mental health service utilization in this community. This gap provides an opportunity to present relevant insights into these caregivers' unique experiences. I present information from various studies on the complications of caregiving, mental health service availability, and the utilization of such services as a foundation to present relevant insights for this study.

I sought insight regarding the perceptions and experiences of caregivers of hemophiliacs in relation to their utilization of mental health services. For this purpose, I used generic qualitative inquiry as the framework for this study. According to Percy et al. (2015), researchers use generic qualitative inquiry to understand people's experiences, personal opinions, attitudes, beliefs, and highlights about their thoughts and feelings. Generic qualitative research is often subjective in nature and seeks to uncover the process in which a person understands their own experiences without outside influence and guidance.

I did not use quantitative research due to the gap in the literature regarding the perceptions and experiences of caregivers of hemophiliacs in relation to their utilization of mental health services. The use of qualitative methods allowed for humanistic perspectives to take precedence and drive the research (McGarrigle, 2018). Encouraging participants to share their experiences allows for individual interpretations of life events

and circumstances. In this vain, generic qualitative research is fluid without constraint and researchers should be open to garner information in the participants' natural environments.

This chapter will provide a context for the literature review, including the literature review search strategy and conceptual framework research and justification. An exhaustive literature review will provide foundational research surrounding the utilization of mental health services in the hemophilia community. This chapter will end with a summation of the information set forth in the chapter and transition to the research design method and data analysis review in Chapter 3.

Literature Search Strategy

I utilized CINAHL, CINAHL & Medline (combination), ProQuest, PsychINFO, Sage Premier, SocINDEX, DOAJ, ScienceDirect, AARP State Data Center, and Google Scholar to gather relevant peer-reviewed research that is significant to my topic area. I utilized the following search terms to highlight certain articles and journals specific to my topic area: *caregiver, hemophilia, chronic disease, healthcare utilization, mental health services, caregiver burden, stress and coping, managing a chronic disease, informal caregivers, barriers to healthcare, resources for caregivers, COPD, asthma, autism, diabetes, cancer, high blood pressure*, and *Anderson's behavioral model of utilization*.

The literature review includes current literature and seminal research. I utilized literature between 2015 and 2021. I expanded the literature search to include other chronic diseases relating to caregiver burden, stress, and mental health service utilization due to the lack of mental health services research regarding caregivers of hemophiliacs.

Conceptual Framework

I adopted Andersen's (1968) behavioral model of utilization as the conceptual

framework in this study. This model includes the following three stages of utilization:

predisposing, enabling, and component-of-need phases (Andersen, 1968). These

components explain the widely differing use of medical care services within families.

Medical care usage takes place (a) when a family member is predisposed to receiving

medical care, (b) where conditions make health services available to the family, and (c)

where the family perceives a need for these services and responds to that need (Andersen,

1969). The most important tenant in this theory is the focus on belief systems and

attitudes in relation to the utilization of healthcare services (Andersen, 1995; Childers,

2019). This model has been augmented to reflect the need for public health responsibility

and the need for individuals to be personally responsible for global health outcomes

(Andersen & Newman, 2005).

The combination of these three essential factors mentioned above—predisposing,

enabling, and need factors—are considered when analyzing healthcare utilization. On an

individual level, predisposing factors refer to various characteristics such as age, marital

status, education, employment, social status, and overall health beliefs. A person's

attitudes and values associated with the delivery of healthcare services represent these

beliefs (Isaac et al., 2020). Enabling factors are the resources available to individuals so

they can seek and receive healthcare services.

These services are primarily individual and community resources such as health

insurance, income, and availability of healthcare services in urban and rural areas. Need

factors can be conceptualized based on the specific needs perceived by individuals or assumed by healthcare professionals (Childers, 2019). Need factors are the most essential predictors of the utilization of healthcare services (Childers, 2019). At the contextual level, there are specific societal and community-related factors beyond individuals' controls in terms of making healthcare decisions. Contextual factors are identified as environmental, macroeconomic, and policy factors (Childers, 2019). Environmental factors are commonly represented by employment rate, crime rate, and particular social norms associated with the delivery of healthcare services to a particular population or group (Isaac et al., 2020).

Macroeconomic factors relate to healthcare providers' availability, which affects individuals' decision-making processes with regard to their utilization of healthcare services. Included in this decision-making process is the influence of policy factors in relation to the development of health insurance programs and the services that correspond to their preferences and current social and financial circumstances (Shi & Singh, 2017; Tingey et al., 2020). The utmost objective of Andersen's (1968) behavioral model of utilization is to specify the conditions that may enhance or impede one's utilization of healthcare services. The real focus is on providing relevant measures of access to medical care (Isaac et al., 2020).

Analyzing all critical factors of service delivery as part of the comprehensive evaluation of an individuals' situational needs is important, especially prior to the occurrence of illness as a predictor of their utilization of healthcare services (Shi & Singh, 2017). As noted above, need factors are perceived as the most immediate cause of

health service utilization among diverse population groups (Shi & Singh, 2017). Healthcare utilization often relies not only on the availability of services, or a family who perceives the need for the services, but also on the incorporation of health services in a regular routine of healthcare delivery and utilization (Babitsch et al., 2015). Therefore, these services would become normalized as a holistic approach to service delivery. According to Issaac et al. (2020), caregivers of hemophiliacs who manage complex care needs may not view mental health counseling as a need that would take precedence over the day-to-day medical treatments and caregiving responsibilities in their daily lives. However, caregiver stress and burden may be viewed as an integral part of the caregiving experience if it is valued and implemented in medical practice and treatment regimens (Isaac et al., 2020).

There are noted limitations in the theory regarding environmental influences in relation to healthcare utilization such as accessibility, proximity to service providers, financial resources, and family dynamics (Joo, 2015; Kent, 2016; Potter, 2018). Although this limitation is remarkable, this model provides a valuable contribution toward understanding the attitudes, experiences, and identifying themes and patterns of use when it comes to the utilization and underutilization of mental health services for caregivers of hemophiliacs.

Hemophilia: Definitions, Statistics, and Historical Information

Definition and Statistics

Hemophilia is a life-threatening illness resulting from the blood's inability to form clots, which can increase the occurrence of life-threatening hemorrhaging (HFA,

2020). Hemophilia is a recessive disorder that occurs in 1:5,000 to 1:10,000 persons depending on the various types of hemophilia (Centers for Disease Control and Prevention, 2017). The actual number of individuals living with hemophilia in the United States is unknown. Fernández et al. (2015) utilized data from patients receiving federally funded hemophilia treatment between 2012 and 2018 and showed that approximately 33,000 males and 15,000 females were living with this diagnosis in the United States.

The yearly hemophilia survey of 2018 indicated that 187,183 people have hemophilia globally. Hemophilia is both physically and mentally challenging for the diagnosed hemophiliac as well as for their caregiver (Peng et al., 2017). The variability between HA and HB is only noticeable to the extent of the deficient element (Mazepa et al., 2016). Ten to 15% of people with hemophilia C (HC) exhibit hemorrhage symptoms without a family history, and many of those patients go undiagnosed by their physicians for multiple years before receiving an official diagnosis of HC (Mancuso & Cannavò, 2015).

Hemophiliacs tend to bleed excessively from even a slight injury. This hereditary factor relates to the lack of a coagulation protein in the blood, most often due to factor VII. Therefore, people with hemophilia are likely to experience unprompted hemorrhage. There are rare occasions when people acquire hemophilia at an advanced age in life. Most of these incidences are associated with the elderly population, the middle-aged, and sometimes young women who have recently given birth or those in advanced periods of their pregnancy (Bertamino et al., 2017).

Hemophilia is a common bleeding condition that affects people across all race and socioeconomic levels (Schulz & Eden, 2016). Hemophilia can be treated effectively and safely among most predominant monogenic conditions (Bertamino et al., 2017). However, there is no specific and definitive cure for hemophilia. In the absence of a cure, as part of major healthcare objectives, emphasis is placed on providing timely treatment, preventing and determining episodes of bleeding, and implementing all interventions that could avert complications from bleeding episodes (Castaman & Matino, 2019).

Symptomatology

When hemophilia is not managed properly at an early age, it can result in chronic illnesses and permanent disabilities due to excessive bleeding in the joints, complications from continuous infusions, and frequent but necessary surgical procedures that target mobility issues. According to Mustafa et al. (2016), signs and symptoms of hemophilia differ based on a variety of factors. Similarly, Mazepa et al. (2016) found the acuteness and danger of the bleeding are associated with a scarce amount of the clotting element.

A person with a mildly reduced level of clotting may only bleed when injured or after a surgical operation. Conversely, a person with severe clotting deficiency will have spontaneous bleeding, often in their joins and limbs. Bleeding episodes can go undetected for some time and often lead to extreme pain, cartilage deterioration, and ultimately, repeated surgical procedures to fuse bones due to mobility and pain issues. Thus, very young adolescents often experience multiple surgeries before reaching adulthood as these events of joint bleeds have no age limit. According to Khair and Chaplin (2016) and Jayakrishnan et al. (2019), hemophilia carriers often present a tendency for hemorrhages

and might require management with clotting-factor alteration as well when exposed to hemorrhagic trauma. This is significant due to the genetic component of hemophilia wherein the caregivers are often carriers themselves.

Hemophilia has always been considered a male disease, as few women, until recent years, were appropriately diagnosed. According to Sumheda et al. (2019), women are often misdiagnosed or labelled as carriers of the hemophiliac gene and are not given the same opportunity for treatment as they are deemed carriers only and not hemophiliacs themselves. According to Arya et al. (2019), women's symptoms should be thoroughly considered because, apart from the common bleeding symptoms associated with any of the rare bleeding disorders, female patients may experience excessive gynaecologic bleeding. This fact has caused years of misdiagnoses and has introduced a needed dismantling of the stereotype of hemophilia being a "male disease."

In its worst form, hemophiliacs develop inhibitors to treatment (Palla et al., 2015). Generally, those who develop inhibitors are treated in the same way as HA and HB patients are treated with noted differences in clotting elements. Meeks and Batsuli (2016) stated people with hemophilia can have a more improved quality of life than in previous years, although there are still incidences of medical complications. Some symptoms may seem very treatable, but the frequency of bleeding episodes for hemophiliacs, as well as the financial and emotional strain of constant pain, infusions, and fear of their futures, has long-lasting mental and physical effects.

Caregivers

Types of Caregiving

Caregiving can be divided into specific categories. Anticipatory caregiving is defined as a change in lifestyle and behaviours to accommodate a patient's future needs (Yeoman et al., 2017). Yeoman stated this type of caregiving can be mostly distant, and it involves making sure the patient is included in activities and outings, decisions regarding proximity, where to live in relation to the patient, and job choice and flexibility. The second category is called preventive caregiving, which involves actively and frequently monitoring a patient to improve their wellbeing and health. This type of caregiving involves taking the patient to doctors' appointments to learn ways to keep the patient healthy, prepare for the various facets of the ailments facing the patient, familiarizing the patient with their own healthcare needs and things to look out for, and making a patient's surrounding safer by changing the physical household or asking a patient about their needs to mitigate symptoms (Bouldin et al., 2017).

A third caregiving category is referred to as supervisory caregiving. This category involves actively engaging a patient and controlling and arranging their activities such as laying out tools to assist them with daily living activities (DLAs) and independent daily living activities (IDLAs) and offering verbal signals so they can be actively involved in their life to maintain a sense of independence (Ringer et al., 2017). Instrumental caregiving is the most serious form of caregiving, where the caregiver provides hands-on responsibilities, such as dressing, bathing, and feeding. This type of caregiving is at the core of the majority of studies on caregiving. The last category, protective caregiving, is

the most challenging and demanding for caregivers. This type of care involves protecting

a person who is receiving care from a facility or an outside entity from the effects of an

illness, mostly from harm to a patient's physical health and mental wellbeing (Yeoman et

al., 2017).

Traditionally, long-term caregivers of patients with chronic health conditions are

family members. These caregivers must often make serious healthcare decisions in the

absence of the patient's ability to do so themselves, acting as an intermediate between

their family member and the healthcare professionals (Hagedoorn et al., 2017). Nurses

commonly view family caregivers as partners of care, which forms a foundation to

enhance the efficiency of care provided to chronically ill patients with open dialogue and

mutual respect (Howrey, 2018). From this perspective, caregivers fulfil three main roles:

providing direct care to patients, forming a bond of cooperation with the healthcare

practitioners, and balancing their caregiving responsibilities with their own needs.

Kim et al. (2018) indicated the impact of chronic diseases can be lifelong and

increases the importance of informal caregiving. Therefore, the need to increase

awareness of caregiving is necessary. There is also the need to understand the specific

intricacies of caregiving. In fact, Kim et al. stressed the importance of certain

generational differences in the caregiving context, such as the challenges baby boomers

(people born between 1943–1968) may face as caregivers. These baby boomers find

themselves in the caregiving role, often without choice, trying to balance caregiving tasks

while maintaining personal o; bligations such as work and family. This situation often

leads to increased caregiver burden and also affects the baby-boomer caregivers who

have distinct characteristics pertaining to autonomy and independence. Kim et al. intimated that the factors of increasing burden for the caregiver are directly linked with the levels of family involvement with the caregiving responsibilities. Kim et al. emphasized that younger caregivers are more likely to prioritize their social roles rather than their caregiving roles, which can often put strain on other family members.

Besides the aging population, the rise in chronic diseases has also increased the need for caregivers (Mazepa et al., 2016; Mustafa et al., 2016). One in every five Americans is currently providing care or has provided care to a significant other or family member in the last 12 months (& (American Association of Retired Persons [AARP], 2020; National Alliance for Caregiving [NAC] & Ringer et al., 2017). These statistics further indicated that almost 53,000,000 people provided care in the past 2 years as opposed to the 44,000,000 estimated in 2015 (AARP, 2020 and NAC). This result shows that the prevalence in providing care has increased close to 20% in 2020 compared to the 16.6% recorded in 2015 (AARP, 2000 and NAC).

Complications Associated with Caregiving

Caregiver burden "refers to the physiological, mental, social, economic, and emotional strains that caregivers experience while providing continuous care to patients or family members" (Lee et al., 2016, p. 13). Becoming an informal caregiver can either be a choice or an obligation. Often, this decision is made without much input from the identified caregiver, often leading the caregiver to feel forced to care for their loved ones (Kim et al., 2018). In some families, the caregiving responsibility falls to one particular person and often forces them to step into this role without considering their existing

family dynamics, including their job, finances, health, childcare, and other responsibilities.

The caregiver role often impacts various areas of the caregiver's life, including personal responsibilities to work, family, and self. Caregiving can also cause a disruption to family life, family dynamics, and cohesion, as these caregivers encounter competing demands such as full-time jobs, childcare, as well as their chronically ill family members (Hou et al., 2016; Ketcher et al., 2020). Caregivers often find themselves in roles of managing multiple priorities for their patient or family member. Klassen et al. (2016) and Kinchen (2014) asserted that caregivers who can take care of their own needs and maintain a good quality of life can provide better care to those living with chronic diseases. Caregivers often view supportive resources as intrusive and unwarranted; therefore, it is important to garner input from caregivers when crafting specialized resources and patient support networks (Kriseman, 2015).

As illustrated by Pendergrass et al. (2018), the impact of caregiving can be psychologically substantial as caregivers' responsibilities vary based on the needs and complexities of each patient. Devlin et al. (2018) and Khanna et al. (2015) indicated that the negatives of providing care often outweigh the positives. This is often due to the overwhelming financial, psychological, and emotional needs required to be a caregiver. These complications are also compounded by the lack of family support and the physical impact on the caregiver themselves.

Physical Complications

Statistical reports indicate almost 40% of all caregivers claim that taking on the responsibility of caregiving is physically challenging (Chen, 2016; Khair & Chaplin, 2016). This statistic specifically addresses caregivers who perform ADL's and IADL's, which include bathing, transferring, dressing, lifting, as well as transporting and moving patients throughout the day. The complex medical requirements of caregiving increase over time and although an institutional setting may be more appropriate, family members are pressured to continue providing care (Geng et al., 2018). It also directly linked caregiving to caregiver health, stating that the stress and strain of informal caregiving duties caused rapid changes in caregivers' neurohormonal and inflammatory processes, which further increased the risk of morbidity and mortality among the caregivers themselves.

Another noted physical complication associated with caregiving is sleep disturbance. According to Lee et al. (2015), caregivers of advanced cancer patients frequently complained of sleep deprivation. As a result of persistent patterns of sleep disturbance, caregivers often found themselves drowsy while providing caregiving duties as well as lacking mental clarity and focus. These caregivers frequently reported that they were exhausted and interrupted by their loved ones at night, thereby causing experiences of insomnia over longer time periods. This research indicated some caregivers spend more than 16 hours a day on caregiving tasks, which leads to increased fatigue levels and correlates to the loss of regulation and balance of circadian rhythms for the caregiver themselves (Yiin et al., 2015).

Emotional/Mental Health Complications

Hou et al. (2016) and Lee et al. (2016) stated there are implications and correlations between caregivers' physical symptoms and their incidents of psychological distress. The complexities of the situation involve the mental distress that can come from making medical decisions for their loved ones. That enormous burden, as well as the reoccurrence of stressful events from day-to-day management of the family members' care needs, ultimately contributed to quality-of-life problems, complex physical, emotional, and mental consequences for the caregivers, changes in personality traits, and depression (Fu et al., 2018).

According to Gerain & Zech (2019), neuroticism has also been observed among informal caregivers. These scholars further asserted that certain personality traits linked with the stressors of caregiver burden led to neurotic behaviors. The lack of adequate coping mechanisms and mental health interventions also exacerbate this neuroticism. For many caregivers, it becomes impossible to maintain a sustained, happy, and positive outlook throughout the process of caregiving due to the myriad of emotions they experience while caregiving, including sadness, depression, stress, and anxiety (Nissim et al., 2016; Versey, 2017).

Geng et al. (2018) found a link between caregivers' quality of life and depression. They indicated that caregivers' experiences providing care to family members causes significant burden to the caregiver themselves. Constant day-to-day care was noted as providing repeated thoughts of mortality and caused a form of posttraumatic stress disorder (PTSD), in a sense of compounded trauma experiences. Most caregivers

demonstrate increased anxiety, which is linked to their fear of the unknown aspects of chronic health conditions (May et al., 2016).

The variability in caregivers' responsibilities and sometimes unstable psychosocial wellbeing often led to notable anxiety, depression, burden, and extremely low self-efficacy beliefs. This state of depression observed among these caregivers was severe and often based on the intensity of the caregiving responsibilities (Ketcher et al., 2020). Some caregivers even thought that addressing their self-care needs, including their own health and household responsibilities, was selfish and egocentric (Berube et al., 2016). Along with fear of deteriorating their relationships with their loved ones, these caregivers aimed to balance the need to relieve patients' suffering with the willingness to manage their own needs for control. This internal battle often resulted in feelings of helplessness, which often increased their depression and anxiety (Finucane et al., 2016).

Financial Complications

Nissim et al. (2016) and Finucane et al. (2016) indicated that family caregivers find themselves making hard decisions when it comes to money management and providing care to their loved ones. Oftentimes, they must take away from their own household expenses and duties. Both studies addressed the huge issue of insufficient financial resources, which adds to the stress and strain of families providing caregiver duties. Families do not often possess the financial resources necessary to provide adequate care to their loved ones, outside of insurance entitlements. As Nissim et al. presented, insurance companies often provide equipment for bedridden patients, such as

wheelchairs and hospital beds, but they do not provide the essential care items required for day-to-day patient assistance.

Caregivers experienced a significant financial burden over time in caring for patients with acute lymphoblastic leukemia (Kumari et al., 2019). This financial burden caused stress and anxiety, disruptions in normal family activities, and an adverse effect on financial well-being to the caretakers and care receivers' basic needs. Caregivers with lower social support and family involvement were more likely to experience increased financial burden as it rests solely with the primary caretaker.

Family Burden/Stress

Nissen et al. (2016) asserted that a significant correlation exists between poor family functioning, anxiety, and depression for caregivers. Lower levels of family cohesiveness were reported because of familial dysfunction, which impacted the caregiving process directly. Depressive symptoms were easily predicted due to the family's inability to work together to solve issues such as shared caregiving responsibilities, financial obligations, and respite care. Bioku et al. (2020) indicated that caregivers of adolescents with sickle cell disease experienced an additional burden of helping them negotiate self-identification. Often, these adolescents had a hard time developing a positive self-concept as their focus was primarily on maintaining their health condition. Helping them adjust to their disease was problematic to caregivers who were trying to manage the internalizing and externalizing behavior patterns they exhibited while trying to mature and gain independence.

This difficulty in transition often left the caregiver depressed. Depression also positively correlated to the frequency of hospital visits, additional financial burden on family caregivers, and pain experiences of the person they were caring for. Conversely, Brown et al. (2016) discussed the complications related to family caregiving for adults with sickle cell disease. These scholars indicated that while caregiving can sometimes be a source of joy for families, considering the aspect of togetherness and comradery it affords, it can also present chronic sorrow as sickle cell episodes can be painful and long lasting. The clinical variability of this disease, along with the daily disruptions experienced in family interactions and financial stress, ultimately increased caregivers' emotional distress (Brown et al.,).

Caregivers of patients with primary brain tumors focused on mediating the relationship between caregiving and managing burden and stress (Reblin et al., 2017). Reblin emphasized the changes in the caregiving role based on the patient's changing health condition. The caregiver's experience often became increasingly more difficult if the patient's needs continued to increase. I emphasized support in this study, which indicated that the level and type of support caregivers accessed influences the increase in care need and the caregiver's burden and stress. Caregivers' burden of care significantly decreased if they had access to more extensive social and psychological support (Friedman et al., 2018).

In another study by Carlsen et al. (2019), their findings indicated that not only did caregivers worry about the future of their children's health condition, but informal family caregivers frequently endorse negative feelings arising from children's chronic disease.

Along with encountering anxiety, strain, and guilt, these caregivers experienced a significant amount of anger and pessimism. In examining the level of caregiver burden and strain among caregivers of patients with inflammatory bowel disease, Zand et al. (2020) concluded that the high strain of this chronic disease substantially impacted caregivers' quality of life. The disease's unpredictable demands and its varied treatment options often led caregivers to feel powerless and unsure of their next steps, often focusing on their loved ones' future and longevity.

Caregivers of Hemophiliacs

The Hemophilia Federation of America (HFA) (2020) persistently emphasizes the need for well-focused, community-centered research on hemophilia patients and their caregivers. Caregivers of hemophiliacs are encouraged to involve themselves in ongoing research through the initiatives this organization promotes. The caregiving process for this chronic health condition is different from caring for individuals with other chronic diseases (Qian et al., 2019). Caregivers usually conduct day-to-day care, which includes infusion and pain management. Yet, the precise number of caregivers specific to hemophilia is unknown due to the field's research gap. Cutter et al. (2019) indicated that parents assume most of the caregiving responsibilities with hemophilia patients. These caregivers are often carriers of the hemophilia gene themselves and possessed first-hand knowledge of the struggles associated with managing the disease. These caregivers noted that the time commitment necessary for treatment emerged as the most significant issue that impacted their quality of life (Wiley et al., 2019).

Unique challenges included managing the fear associated with needles and the PTSD symptoms associated with repeated sticks, mainly with children suffering from the disease (Wiley et al., 2019). Some caregivers also expressed their constant stress, worry, and concern of medical complications such as increased risk of infection and multiple surgeries. Westesson et al. (2019) assessed caregiver burden among 102 caregivers of patients with hemophilia. The caregivers indicated a state of worry that was constant. Not only was worry prevalent but it was often paired with guilt and fear.

D'Angiolella et al. (2018) noted that worry and stress associated with managing a chronic disease such as hemophilia impacts the entire family structure. Other family members often reinforce generational traumas due to the long history of treatments because of the disease's genetic component. For caregivers, the constant need to manage pain and flares causes a continues cycle of stress and anxiety (Khair & Chaplin, 2016). In turn, caregivers' work-life balance significantly diminishes over time. Unique also to caregivers of this community is the fear that the prescribed treatment will lead to inhibitors (Okide et al., 2019). In this context, observing hemophiliacs' pain, fear, and insecurity during treatment tends to impact caregivers' long-term psychological wellbeing.

O'Mahony et al. (2018) noted that caregivers report high levels of physical and mental exhaustion ensuing through their attempts to infuse their loved ones. Also of note was the caregivers' personal and social lives. Caregivers indicated the challenges of spending time with significant others due to hemophilia treatment and finding a partner

who understands the chronic disease's specificity. Thus, some caregivers experience loneliness and social isolation (O'Mahony et al., 2018; Sidonio et al., 2017).

The impact on caregivers' productivity is substantial due to frequent absence from the workplace (O'Mahony et al., 2018). Some caregivers even reported problems with coworker perceptions, as this medical diagnosis is rare and unfamiliar to many. Another unique stressor for caregivers of hemophiliacs is the constant influx of new treatment options and the pressure to try these new medications from big pharmaceutical companies. Although there is a deep desire to improve the current treatment array for hemophiliacs, the patient risks are often great and can be life threatening (Stjernsward & Hansson, 2020). The constant worry about treatment options, joint and brain bleeds, possible surgeries, joint fusions, and inhibitor developments all increases the caregiver's physical and psychological pressures (Stjernsward & Hansson, 2020; Zhou et al., 2015).

Services for Caregivers

Since chronic diseases are ongoing and incurable, caregivers of patients with chronic health conditions are encouraged to access a wide range of resources to improve their physical, psychological, and mental health. According to Childers (2019), Gringeri et al. (2016), Kumar et al. (2016), Kumari et al. (2019), and McLaughlin et al. (2017), for families affected by hemophilia, the emphasis has historically been placed on managing pain and quality of life for the hemophiliac and has not addressed caretakers' physical, psychological, or emotional burdens. In recent years, resource development has included a variety of networking opportunities, healthcare alliances, support groups, and wellness programs designed specifically for caregivers.

The perceptions of stress, coping, and interventions shared by caregivers of chronically ill persons was paramount in the search for services. Caregivers often express frustration and depression. At times this motivates them to seek and receive resources and services to learn coping mechanisms and strategies to assist with overwhelming emotion (Waters et al., 2017).

The majority of these caregivers recognized the importance of addressing their stress levels and ultimately decreasing stress by exploring various self-management techniques and participating in meetings with other caregivers. In this way, these caregivers expressed that they hope to build a toolbox of interventions to reduce the stress and anxiety that comes from caregiving by exchanging relevant knowledge on the various diseases and sharing their experiences of being a caregiver.

Ketcher et al. (2020) emphasized the need to increase social support for caregivers of advanced cancer patients. These social supports included new methods for treatment options, informational knowledge gathering, advice on responding most effectively to their patients, and interventions to improve caregiving outcomes. These caregivers are encouraged and supported to make informed treatment decisions that also include input from the medical professional and loved one. This same study indicated the importance and need to improve the fundamental way caregivers are included in this care triad. This solidifies the triad and often makes caregiving a more dynamic, family centered care approach and less of a burden. These family centered approaches are unique and rely on the individualized strengths, supports, and inherent resources within the family system. Medical professionals are encouraged to convene a "family planning

meeting" where all persons are given the opportunity to present their strengths and ideas to develop a treatment plan. The primary caregiver directs the meeting along with the medical team and clearly delineates their support needs (Ketcher et al., 2020).

Kriseman (2015); Reblin et al. (2017), and Schwartz et al. (2019), concluded that the earlier supports are employed within the caregiver paradigm, the better the outcomes are for caregivers. Specifically, Reblin et al. indicated that supportive interventions substantially mediate the link between caregiver burden and psychological distress when social support is implemented at approximately the fourth month of care. The combination of family system and external resources played a significant role in determining caregivers' experiences. In some cases, although family support was present, some caregivers still experienced elevated stress due to the lack of external resources, which indicated a need for both resources to provide an optimal resource continuum. Even with the emphasis on internal and external resource necessities, Diallo et al. (2019) stressed the importance of mediating this link between informal and formal sources of support to decrease the stress and strain for family caregivers in navigating and organizing these support networks.

The current services array for caregivers of hemophiliacs focuses on addressing the unique challenges these individuals experience. Most of these services are provided by specific member organizations such as The Hemophilia Federation of America (HFA) , The National Hemophilia Federation (NHF), and local Hemophilia Treatment Centers (HTC's). These organizations provide family programming, advocacy, and research to support the needs of families and caregivers living with bleeding disorders.

Various online toolkits, quarterly webinars, and annual HFA member organization meetings address the needs of caregivers of hemophiliacs (HFA, 2020).

These organizations' utmost goal is to improve the connectedness of these individuals. Although these organizations provide extensive educational programming, they are just now addressing the area of mental health. These agencies' focus is mainly directed at discussions of new treatment options, new drug initiatives, managing pain, and social connectedness. In 2019, this community reported 11 suicides of those suffering with hemophilia related to their psychological diagnosis, stress, and mental health concerns (HFA, 2020). This statistic in this rare community expresses an example of the need for mental health awareness and utilization.

These 11 suicides are significant because the impact on the caregivers, who are more than likely hemophiliacs themselves, heightens the need for mental health services. To this end, the HFA, recently organized a mental health awareness campaign to help caregivers of hemophiliacs' access mental-health-specific services. Poti et al. (2019) referred to the importance of mental health services for improving caregiving experience as these improved experiences were directly related to the quality of mental health services provided to the caregiver. This knowledge allowed mental health providers to improve their service delivery and allocation of resources which ultimately enhanced the caregivers' experiences (Poti et al., 2019).

Introducing a multidisciplinary model of care is an important aspect of the mental health service provision for caregivers of hemophiliacs. In this multidisciplinary health model of care, the emphasis is on the importance of a team delivering specialized

treatment that aims to alleviate caregiver burden and stress (Yeung et al., 2016). From this perspective, the mental health support caregivers of hemophiliacs receive is quite enlarged, as caregiver mental health assistance emerged as a continued theme that different disciplines of healthcare practitioners widely utilized (Poti et al., 2019).

Utilization and Considerations for Service Delivery

The AARP (2020) produced a report detailing U.S. caregivers that stated their difficulty in accessing services had a lot to do with finding affordable services in their community. The report also indicated that caregivers in higher-intensity care situations, performing mostly all ADLs and IADLs, who frequently need help the most, are unable to receive support due to the necessary time and finances required to successfully complete these duties. This report further indicated that 20% of caregivers failed to receive any help or information pertinent to their caregiving experience due to the lack of transparency about their care needs, lack of knowledge about how to access services, and the time necessary to avail themselves of the support networks.

Ormel et al. (2017) indicated that having service options available to caregivers is highly recommended. Although options are recommended, access to these services is the key factor that affects utilization. This is further justified due to the ever-changing nature of caregivers' responsibilities, which prompts them to search for relevant and timely solutions, up-to-date health information, and healthcare models that could improve the health of their loved one and themselves. The caregiver becomes either unwilling to provide care or excessively stressed when this information is not readily available, therefore complicating their ability and willingness to access the available service array.

The most requested service for caregivers is respite care (Ormel et al., 2017). This resource provides a reprieve from daily responsibilities for short periods of time and relieves the caregiver of the continuous care demand. Unfortunately, arrangements must be made well in advance when accessing this service, and caregivers are often told the waiting list is vast or that these services are not available at all in their specific community. Arrangements for respite can be made through some private organizations, but this option is very costly and often increases the financial burden the caregiver is already experiencing (Johnson, 2019).

Hawken et al. (2018) conducted a study that addressed caregivers' needs for mental health therapy to assist with the burdens and stressors of the caregiving role. The caregivers of chronically ill individuals found that accessing such services was difficult, often leaving the caregivers to try and handle the physical and psychological pressures of caregiving on their own. The study also concluded that the failure to recognize the need for mental health therapy made the caregivers more vulnerable to caregiver burden and reduced their chances of developing effective and strategic coping skills, especially if the caregiver viewed their situation as manageable. These caregivers often never sought any type of service or considered mental health therapies as part of the available service array (Kriseman, 2015; Swartz & Collins, 2019).

Another major obstacle that arose from Swartz & Collins' (2019) study was the fact that "there has been a delay in translating the research into resources that are readily accessible to these caregivers" (p. 701); thus, the need for standardized best practices related to service development and delivery is critical in meeting caregivers' needs. Berry

et al. (2016) reported that caregivers of cancer patients accessed available services because the offerings were individualized and specifically designed to address caregivers' complex and expansive needs, including the use of behavioural counseling models that specifically addressed the caregivers' various mental health needs. This is relevant for caregivers of hemophilia patients as the genetic predisposition of haemophilia often means the caregivers quite possibly suffer with the disease themselves; therefore, "a positive and enabling policy context involving caregivers as decision makers is critical when supporting these families" (Davidson et al., 2018, p. 1). These policy implications provide an opportunity for a refined focus of supportive resources that are inclusive and meet the specialized needs of all caregivers.

Various scholars have suggested several ideas and models toward improving caregivers' experiences and mental healthcare utilization. Diallo et al. (2019) discussed the importance of a holistic approach to supportive service delivery where the emphasis is placed on pooling resources within the family structure and developing management techniques to assist with scheduling and organizing the patient's needs while incorporating built-in time for the caregiver. Whereas Kind (2018) suggests communication between different stakeholders in the caregiving context, particularly caregivers, patients, and healthcare professionals, is the essential way to enhance and create new and innovative support services.

Daaleman & Helton (2018) and Waters et al. (2017) asserted that the wide range of contributing factors involved in caregiver burden must be adequately explored to inform the development of more effective chronic care models that emphasize caregiver

needs, which would evolve into a clearer understanding of caregiving complexities. Baird (2018) discussed the consideration of chronic care models as a roadmap for service delivery. These models ensure caregivers have increased resources available to them as their caregiving needs escalate. Chronic care models also provided a means to a holistic approach to help caregivers manage their emotional well-being and overall quality of life (Baird). Overall, the researchers speak to the necessity for these caregivers to receive an opportunity to design and create client- and caregiver-friendly services that are well crafted, considering them the experts.

Caregivers of children with hemophilia most frequently utilize current mental health services compared to caregivers of adults with hemophilia (Berube et al., 2016). Caregivers have started recognizing the need to utilize current mental health services more frequently to become better providers of care to those diagnosed with hemophilia (Khair & Chaplin, 2016). As a result, caregivers of hemophiliacs emphasized the correlation between their mental health and ability to enhance their decision-making skills regarding the caregiving experience.

In this community, the focus on mental health mainly involves improving areas of education and has not focused solely on the mental health services that help the caregivers. This denotes an obvious need for education around the benefits of mental health services, a possible restructuring, and an adaptation of a holistic model of care where caregivers in this community feel empowered to seek mental health assistance. Nossair & Thornburg (2018) indicated that education in the hemophilia community enables caregivers to rethink and refine their caregiving experiences.

Mental-Health-Specific Services

According to the Anxiety and Depression Association of America (2020), the number of caregivers showing symptoms of depression is around 40%. Caregivers frequently feel trapped in their roles, feeling a wide range of mixed feelings such as frustration, resentment, anger, and even depression (Attridge, 2019). Caregivers often seek advice from family members about feelings of being overwhelmed and stressed. Caregivers often feel guilt, shame, and pressure to maintain a high level of caregiving responsibilities without family support and outlets to process their emotions. Therefore, seeking mental health services centered around feelings of isolation and powerlessness is a real necessity for some caregivers.

These services must also include the ability for caregivers to assess their capacity, set boundaries, evaluate their energy, and prepare to instill greater balance in their lives (Attridge, 2019). According to Ferrell and Wittenberg (2017) and Rosa et al. (2017), services should stress the importance of building resilience and coping skills as well as providing psychoeducational interventions, skills training, and therapeutic counseling that encourage mutual support and a strong sense of community. The resources should be well-structured to address the complex mental health needs that may arise from caregiving (Benton & Meyer, 2019; Hamovitch et al., 2019; & Hong & Harrington, 2016).

Catering to caregivers' mental health needs is a complex process that should be structured to avoid additional strain for caregivers. Caregiver burden decreased and caregivers' ability to implore coping strategies and feelings of enhanced self-efficacy

improved when caregivers had frequent access to interventions. Physicians, mental health professionals, and other family members should encourage caregivers to use these services as they provide a strategy for coping and a way to reduce burnout (Gerain & Zech, 2019; Hamovitch et al., 2019).

A positive aspect today is that caregivers have recognized the impact caregiving has had on their lives and have made themselves amenable to seeking professional help to address their symptoms of depression and burnout (Kriseman, 2015). Sullivan and Miller (2015) noted that these individuals have considered the importance of self-care and now take it more seriously despite fluctuations in caregivers' utilization of current mental health services.

Some caregivers define mental health improvement as living healthy lives and maintaining healthy social relationships. They often value those things more than addressing their mental health needs (Sullivan & Miller, 2015). Because of this, mental health providers must highlight the links between optimal health and the ability to be efficient caregivers. This holistic approach will ultimately improve caregivers' physical, psychological, and emotional states, decreasing caregiver burnout and aiding them in helping others. Sullivan and Miller, advise that caregivers select a mental health provider with extensive experience in understanding caregiving experiences from the perspective of chronic disease management. This selection, coupled with the caregivers' early access to these providers, related to successful outcomes in terms of caregivers improved mental health.

Summary and Conclusions

The hemophilia population is unique in its rarity of medical necessities as well as in its complex care needs. Hemophiliacs, as well as their caregivers, have lived with systemic issues and treatment disparities for many years, including access to mental health services. Because of this, and the fact that mental-health-services utilization has not been a systemic practice for their caregivers, the focus has solely been on medical treatments and the resulting health complications of the hemophiliac themselves.

According to Bouldin et al. (2017), the burden informal caretakers endure when taking care of individuals with chronic disease can be overwhelming mentally. As iterated in the above literature review, mental health utilization relies on varying factors, including the availability of services, families' perceptions of the service need, the type of service array delivery, families' values of the services, and healthcare professionals' abilities to view the families in holistic ways beyond medical care, but also considering the mental health needs that arise from taking care of individuals with chronic diseases. Even with the information on caregiver burden, medical professionals and policymakers are often unwilling to encourage and empower mental healthcare utilization (Attridge, 2019; Berry et al., 2016). In the hemophilia community, the grief and loss associated with the illness as well as generations of managing the effects of the disease, including chronic pain, joint replacements, and often drug dependence, have taken precedence over caregivers' needs for mental health services.

Multiple factors impact utilization, including the family's predisposition to receiving holistic health services, access to the services, and lastly, the family's belief

that the services are necessary (Andersen, 1968). Utilizing mental health supports has not been a priority in the hemophilia community (Assari et al., 2015). The current array of service options is not often specific to the needs of this population. Although most HTCs employ social workers, they are used in the capacity of case managers, often maneuvering health insurance claims and referrals for occupational and physical therapy. This is a vital missed opportunity to provide mental health services or to encourage the utilization of said services.

Although research exists on a variety of caregiver stress involving taking care of a person with chronic health concerns, I have not found literature that explicitly relates to the utilization of mental health services for caregivers of hemophiliacs. For this reason, a qualitative study that suggests an extensive exploration of participants' experiences in relation to their personal journey of being caregivers of hemophiliacs in the United States is warranted and will fill a gap in the literature and aide in developing services for these caregivers from a holistic perspective. The selection of a qualitative research methodology makes it possible to present an in-depth study of the research topic, as participants' distinct views and opinions can be considered from multiple perspectives (Creswell & Poth, 2017). Even though the findings generated through this type of methodology may not generalize to the wider population, the study can provide a thorough overview of the utilization of mental health services by caregivers of hemophiliacs in the United States.

Chapter 3 provides an overview of generic qualitative inquiry, which includes the method and steps involved in utilizing this method. Chapter 3 also presents the

opportunity for thematic analysis through this method and the relevance of coding to

facilitate data collection and analysis.

Chapter 3: Research Methods

Introduction

Purpose

The focus of this study is to assess the utilization of mental health services by caregivers of hemophiliacs. The utilization of mental health services in this community warrants exploration to determine the contributing factors; specifically, exploring how the beliefs, perceptions, and possible stigmas associated with seeking mental health services influence caregivers' utilization or underutilization in this community. The literature review, although deeply mined, did not specifically reveal the perceptions, beliefs, stigmas, or attitudes of caregivers of hemophiliacs around their mental health service utilization.

Chapter Overview

In this chapter, I will (a) identify qualitative research methodology that will establish caregivers' perceptions, experiences, and beliefs regarding mental health services and (b) seek understanding surrounding caregivers' utilization or underutilization of mental health services. As Roymeke and Stummer (2015) and Kinchen (2014) asserted, caregivers who can take care of their own needs and maintain a good quality of life can provide better care to those living with chronic illnesses. This study will include a presentation of the issue, how I recruited participants, conceptual framework, and ethical complications in research studies.

Generic qualitative inquiry is an appropriate research method for this study as I seek to understand caregivers' experiences and perceptions. According to Percy et al.

(2015), generic qualitative data collection seeks information from representative samples of people about real-world events and processes their experiences. The object is to get a broad range of opinions, ideas, and reflections from caregivers to hopefully inform mental health service delivery for the hemophilia community.

Research Design and Rationale

Research Question, Phenomenon, and Tradition

I sought insight regarding the perceptions and experiences of caregivers of hemophiliacs in relation to their mental health utilization. For this purpose, I used generic qualitative inquiry as the research design for this study. According to Percy et al. (2015), researchers are seeking to understand people's experiences, personal opinions, attitudes, beliefs, and highlights about their thoughts and feelings when using generic qualitative inquiry. Generic qualitative research is often subjective in nature and seeks to uncover the process in which a person understands their own experiences without outside influence and guidance.

I did not utilize quantitative research due to the gap in the literature regarding the experiences of hemophiliac caregivers in relation to their mental health services utilization. The use of qualitative methods will allow for humanistic perspectives to take precedence and drive the research (McGarrigle, 2018). Examining participants' experiences allows for individual interpretations of life events and circumstances. In this vain, generic qualitative research is fluid without constraint and researchers should be open to garner information in the participants' natural environments.

Rationale for the Chosen Tradition

According to Leme Fluery et al. (2018), Kegler et al. (2019), and Percy et al. (2015), qualitative inquiry allows for individualized knowledge and realities that are developed and personal to each person. Their realities belong to them and may not be shared by other individuals living in similar situations. This methodology must be coupled with a conceptual framework that helps connect the participants' beliefs and attitudes to possible motivators of their experiences.

I considered but did not choose to employ ethnographic and narrative research methods. Ethnographic research allows the researcher to immerse themselves in a group or organization to understand the culture (Gentles et al, 2016). I did not want to bias the research with personal experiences due to having family members diagnosed with hemophilia. Narrative research allows the researcher to interpret participants' stories to understand how people make sense of their experiences and perceptions. I wanted the participants to be the sole provider of data without the data collector's interpretation. Because of this, I will be able to develop better service provisions of mental health services to caregivers of hemophiliacs, to address, if identified, any systemic and interpreted barriers of service delivery.

I used surveys and semi structured interviews to obtain participants' information. The collection of information from a sample of individuals through their responses to questions is survey research (Kelley-Quon, 2018). Traditionally survey research focuses on obtaining demographic and personal information that aids in research studies. Surveys also help scholars conduct a preliminary screening to ascertain the viability of potential

participants. Interviews are a critical aspect of data collection and analysis, which aim to get a deeper understanding of social phenomena.

I chose to use semi structured interviews as opposed to structured interviews to allow for data collection rooted in open dialogue of thoughts and feelings that would allow me to analyze each participant's subjective experiences (Percy et al., 2015). I coded data to facilitate the identification of reoccurring themes and linkages. The conceptual framework utilizing the Andersen model(1967), provided a basis for analysis. This model asserts that there are three stages of utilization, which include the predisposing, enabling, and component-of-need phases. These components help explain the widely differing uses of medical care services within families. Usage takes place (a) when a family member is predisposed to receive medical care, (b) where conditions make health services available to the family, and (c) where the family perceives a need for these services and responds to that need (Andersen, 1968). The most important tenant in this theory is the focus on belief systems and attitudes in relation to the utilization of healthcare services (Andersen, 1995; Childers, 2019).

The Researcher's Role

My role in this study was as an observer participant. It is the understanding, through generic qualitative inquiry, that participants experience multiple realities. The researcher creates knowledge through subjective analysis of participants in a naturalistic setting. In the case of generic qualitative inquiry, this methodology embraces an aspect of research without limitations (Kennedy, 2016). As a qualitative researcher, I became an instrument used in the gathering of data. I established an atmosphere of trust to garner

participants' experiences. I aimed to build rapport with the participants in hopes of receiving truthful and purposeful information to provide meaningful data that would add to the body of literature surrounding caregivers' utilization of mental health services in the hemophilia community.

Qualitative research through interviews requires superior listening skills, observational skills to note nonverbal communication, and the ability to form a trusting relationship with participants (Cobern & Adams, 2020). I have personal connections to this community. I adopted a daughter with hemophilia. As a very vocal advocate for my daughter for many years within the hemophilia community, I was presented with an opportunity to become a curriculum developer and lecturer for the HFA.

Since my consultancy, I have traveled around to the 44 member organizations presenting lectures on various topics related to the community. Because of this opportunity, many participants over the last 5 years have heard me facilitate workshops and lectures. Although this familiarity will help build rapport with the participants, I am acutely aware of maintaining strict boundaries as it pertains to data collection and analysis. I made participants aware that their names were not included in data analysis; instead, I gave each participant a number for identification purposes.

Bias Management

I documented my feelings and thoughts that occur while conducting the research. I will note any personal biases and experiences that may hinder the research. I reviewed this reflective journal regularly to ensure I manage my own thoughts, feelings, and perceptions. I made the interview questions very clear. According to Eagle et al. (2019),

the researcher must know each interview question's intent so they can clearly present the question to the interviewee. With this knowledge, I was able to ask follow-up questions (if warranted).

Ethical Considerations

I avoided acquiescence bias. Acquiescence bias occurs when the interviewee provides answers to the interviewer that they think the interviewer wants to hear instead of their own perceptions and experiences. Ensuring that the interviewee understands how important they are to the study helps shift the perceived power from the researcher to the participant. The researcher must also provide feedback to responses not laced with nonverbal encouragement, but instead acknowledgements of participation. This helps reduce the perceived agreement or bias in favor of participants' responses (Oosterveld et al., 2019).

I kept copious notes of participants' responses during each interview while remaining engaged throughout the interview process. I ensured the open-ended questions were relevant and specific to garnering knowledge from the participant. I completed this process by conducting several reviews of the questions and practicing mock interviews. Lastly, I processed some data immediately after the interviews by noting reoccurring themes and responses that are significantly different from previous interviews.

Methodology

Participant Selection Logic

I interviewed caregivers of hemophiliacs who submit a demographic questionnaire. I only excluded those who are not actively providing care to a person

diagnosed with hemophilia to ensure I ascertain direct and first-hand perceptions of the

caregiver experience in relation to mental health utilization. I obtained a sample size of

20 people for this study. I encouraged a wide range of caregiver participation,

encompassing all demographics inclusive of age, sex, and race. I issued the survey to

participants who reside within the United States and did not expressly target any

particular state.

I included the following questions in the demographic survey:

1. Please provide your contact information.

____Email_____

____Phone_____

2. Are you currently a caregiver for someone diagnosed with hemophilia?

(Please Check) _____Yes or ____No

3. Have you ever been diagnosed as having a bleeding disorder?

(Please Check) _____Yes or ____No

4. What is your age? _____

5. What is your identified gender? _____

6. What state do you reside in? _____

7. Which of the following best represents your racial or ethnic heritage?

Choose all that apply:

__Non-Hispanic White or Euro-American

__Black, Afro-Caribbean, or African American

__Latino or Hispanic American

__East Asian or Asian American

__South Asian or Indian American

__Middle Eastern or Arab American

__Native American or Alaskan Native

__Other: _____

8. Would you be willing to participate in an interview regarding your caregiving

experiences? (Please Check) _____Yes or ____No

I used nonprobability sampling, specifically purposive sampling in this study. According to El-Masri (2017), nonprobability sampling involves collecting feedback from participants that is open and not a fixed-selection process. This method of sampling also creates an assumption when the research topic is not widely studied (El-Masri, 2017). This is especially relevant with the utilization of mental health services in the hemophilia community as the topic has not been widely researched. Nonprobability sampling aids in the immediate gathering of information that can promote further research. Purposive sampling allows the researcher to focus purely on the study's purpose.

The researcher must have a basic knowledge of the target audience. This knowledge allows the researcher to explain the study's purpose and procedures to the participants in great detail but remain objective in the data-collection process. It was my responsibility to be fully engaged with the participants while being open to opportunities to learn about new perspectives and personal areas of growth through the participants' experiences.

I contacted the HFA as well as the local Hemophilia Chapters in Maryland, the District of Columbia and Virginia to obtain permission to utilize their contact list serve to send emails requesting participation in the study and to ask permission to pass out flyers regarding participation in the study at their meetings, symposiums, and conferences. I detailed the study's purpose in an introductory email/letter/flyer to each potential participant. The letter/email/flyer included the link to complete the demographic survey. The email/letter/flyer included an explanation for the study's procedures and a statement indicating that the completion of the demographic survey and, if selected, the subsequent interviews are completely voluntary.

The letter/email/flyer addressed possible ethical considerations and indicated that ethical concerns will be discussed in detail and resources for assistance made available if they are selected for the interview process. Lastly, the email/letter included a statement indicating that completing the demographic survey does not guarantee an interview.

Demographic information is easily collected by utilizing questionnaires. The usage of the questionnaire allows for uniformity in general responses and provides a better understanding of each person in relation to the larger population. Questionnaires also allow a way to narrow down the research sample in cases of overwhelming participation. As participants return their completed questionnaires, I contacted those participants willing to be interviewed utilizing their preferred contact method as indicated on the questionnaire.

I handed out the informed consent letters or electronically delivered them to each participant. These letters of informed consent provided a further description of the

study's purpose and procedures, and a detailed list of possible ethical considerations and resources due to COVID-19 restrictions. I sent informed consent documents utilizing an electronic signature software, HelloSign, to three participants who participated through zoom, prior to the interviews. I did not collect any direct medical information from the caregivers or person to whom they are providing care. When similar themes emerge and no new thematic analysis can occur, the researcher should recognize this as the saturation point. I obtained a sample size of 20 people for this study and was able to reach a point of saturation.

Instrumentation

All information was self-reported by the participants. I conducted interviews using a basic standardized discussion guide, augmented by prompts for clarification. The interview process allowed for open dialogue between the interviewer and interviewee, which allows a platform to elicit the most authentic responses from the participants. According to Dai et al. (2019), informal interviews allow for conversational information gathering. These interviews allow the participant to provide a personal account of their experiences without influences. Semi-structured interviews should be broad in nature and allow the participants to provide a narrative of their own personal experiences. This form of interview allows for participants' perceptions and beliefs to be accurately represented; therefore, I utilized semi-structured, open-ended questions to guide the interview.

These general questions helped to discern the perceptions and experiences of caregivers of hemophiliacs concerning their utilization of mental health services. I asked the following open-ended questions to all participants:

1. Describe for me in your own words your caregiving experience.

2. What are some of the challenges you have had to manage providing care to your loved one with hemophilia?

3. How do you know when you are stressed or anxious?

4. How do you typically manage when you are experiencing stress or anxiety?

5. What are your thoughts about seeking counseling and mental health services?

6. What are some of the barriers you perceive about seeking mental health resources?

7. What role do you see a mental health professional playing in helping you manage your stress or anxiety due to caregiving?

8. What do you believe the primary role of the HTC social worker entails?

I alerted the participants that the interviews could be conducted in multiple ways, including in person, by phone, or through virtual platforms. I scheduled participants for interviews at their convenience utilizing their preferred interview method. I notified all participants that I would be taping the interviews. Taping allows for an accurate and clear documentation of the participants' responses and also provides the interviewer with a way to validate any notes taken during the interview process. I used inductive coding to transcribe and independently code the taped interviews. Throughout the interviews, I informed participants that they could stop the interview process at any time.

According to Kegler (2019), sample sizes should be large enough to ensure shared information is comprehensive in nature. With qualitative sample sizes, researchers should consider the quality of the information gathered and not just the quantity of participants

(Kegler, 2019). I offered a financial incentive of $25.00 gift cards as well as I collaborated with the local HTCs to assess their willingness to distribute information regarding the study to ensure I had the interest and participation in the study.

The interviews began with introductions and the reading of the informed consent documentation. Participants signed this document before the interview process began. I reiterated the study's purpose with the participants and, when warranted, thoroughly addressed questions. I gave each participant an opportunity to decline the interview process before I began asking questions. I gave each participant copies of the following documents: the study's description, the study's purpose and procedures, and a detailed list of possible ethical considerations and resources that will be available to them. All documents included my contact information.

I began by asking questions from the interview guide, keeping in mind that the dialogue should be open and driven by the participants' experiences and perceptions. After the interview was complete, a debriefing with each participant allowed them an opportunity to provide any feedback, concerns, or questions regarding the study. I informed the participants that the entire interview would be transcribed and sent to them to ensure accuracy of their responses.

Data-Analysis Plan

I utilized narrative analysis as the foundation of the coding process. Narrative analysis uses interviews, conversations, and life experiences as units of analysis. Initially, the development of the research question is necessary to garner the raw data (i.e., the questionnaire that ascertains the perceptions and experiences of the caregivers of

hemophiliacs). Organizing the data and coding helps extrapolate redundant information to narrow down the data to common themes.

I assigned each participant an identifying number after the interview to represent them in lieu of their name. A data chart represented these numbers and I recorded the transcribed information from participants' interviews. The process of coding involves assigning labels to recurring themes in participants' responses. According to Miles and Huberman (2020), researchers can use first-cycle coding to detect patterns and categories and develop a proposition or theory. Coding is not just foundational knowledge in preparation for the higher level of processing the data collected but instead coding itself represents a deep understanding and interpretation of the data, therefore an integral part of data analysis. I followed the process of coding data asserted by Yang Yang (2018).

Inductive coding allows the narrative or theory to emerge from the raw data (Huberman, et al., 2020). In Vivo Coding utilizes the participant's own spoken language to understand the intent and meaning of the data being collected. I read over all data collected, divided the information into segments, labeled the segments of information into codes, deduced overlapping and redundant codes, and collapsed the codes into themes. To explain further, I reviewed the audio and visual tapings of the participants' interviews. I also reviewed any written notes collected during the interview process.

I used In Vivo coding, which involves the use of words and phrases directly from the participants to formulate codes. This is an important method of coding for this study as it allows for specific vernacular and terminology specific to the researched population

(i.e., the hemophilia population). This acknowledgement helps prioritize and honor each participant's voice (Miles & Huberman, 2020).

I also used emotion coding to document the participants' life conditions and personal perspectives. I noted the emotions the participants express in quotation marks during the In Vivo coding process. According to Miles and Huberman (2020), value coding includes three distinct parts. These distinct parts are values, attitudes, and beliefs when brought together represent the participants. A value (V) is the importance we attribute to ourselves, another person, a thing, or an idea (Miles & Huberman, 2020). Attitude (A) is the way we think and feel about ourselves, another person, a thing, or an idea. A belief (B) is part of a system that includes values and attitudes, plus personal knowledge, experiences, opinions, prejudices, morals, and other interpretive perceptions of a social world (Miles & Huberman, 2020, p. 67).

I used value coding to ascertain the perceptions and experiences of the hemophilia population regarding their mental health utilization. This coding method is particularly relevant for the incorporation of the conceptual theory, Andersen's utilization model, which asserts that a family's perception of the necessity of services affects caregivers' overall mental healthcare utilization. I also evaluated initial coding for the possible need of sub coding. Researchers use sub coding when the initial coding is too broad and needs to be refined. The researcher must ensure that these codes follow a particular structure that relates to one another in a coherent way (Miles & Huberman, 2020). This process of heuristic discovery allows for careful analysis and familiarity of the data by the researcher (Miles & Huberman, 2020). I organized, analyzed, and found insights in the

narrative data. This allowed for the emergence of multiple themes, which helped identify what the participants were feeling and thinking about utilizing I used d Andersen's behavioral model of utilization as a basis for conceptual analysis. According to Miles and Huberman (2020), conceptual frameworks and research questions are the best defense against overload when it comes to data analysis. They assert that all data do not necessarily need to be coded, just the data driven by the research question and conceptual framework for the premise of the study. Andersen's behavioral model of utilization, according to Babitsch et al. (2015), asserts that healthcare utilization often relies not only on the availability of services, or a family who perceives the need for the services, but also on the incorporation of health services in a regular routine of healthcare delivery and utilization. These services would be more of an expectation and norm. For caregivers of hemophiliacs, managing stressors and mental health services may be considered additional services that are not more important than the day-to-day medical requirements and caregiving responsibilities of their daily lives. It is therefore critical that I understand the experiences and perceptions of the caregivers through data analysis as I look at how the identified themes may coincide with the theory.

Issues of Trustworthiness

According to Shenton (2015), establishing trustworthiness in qualitative research involves proof that the research findings are credible, transferable, confirmable, and dependable.

Credibility

Credibility refers to confidence in the study's findings. Researchers can use multiple techniques to establish credibility including triangulation, saturation, reflexivity, and peer review. Triangulation refers to the validation of data through the usage of multiple sources. Saturation is a point in the data-collection process when no new information is discovered. This redundancy indicates that the data collection can cease. Reflexivity refers to the examination of one's own beliefs and judgements during the research process (Raskind et al., 2019). As a researcher of qualitative inquiry, you must be open to one's own biases and assumptions while conducting the research. Peer review is the evaluation of work by one or more people with similar competencies as yourself. This method of credibility is a way to ensure accountability to the data-collection process. This method also allows for refinement of quality standards and data-collection methods (Raskind et al., 2019).

Transferability

Transferability is how the qualitative researcher demonstrates that the findings can be used in similar situations and with similar populations. Some ways to establish transferability include thick description and variation in participant selection. Thick description in relation to transferability refers to the researcher's ability to provide a robust and detailed account of their experiences during data collection. Researchers often make connections to the cultural and social context involved in data collection. This includes speaking about where the interviews occurred and situations that may have

affected their data collection, like the time of day the study took place, which could influence the interview.

Confirmability

Confirmability refers to the degree of neutrality in the study's findings. This means the researcher's bias, or any personal motivators did not influence participants' responses. The researcher must be able to provide a step-by-step accounting of the data-gathering and analysis process. This detailed account helps eliminate any chance that the research will be discounted as valid.

Dependability

The dependability of the research assumes another researcher could repeat the original researcher's study and that the findings would be consistent. For this to occur, a researcher must provide enough information for the study to be properly replicated. A way to ensure dependability in the qualitative research process is by using inquiry audits. These audits are conducted by outside persons who review and examine the research process and data analysis to ensure the findings are consistent and able to be repeated.

Ethical Procedures

Each participant received and went over a consent form before the interview process began. This form was signed, and I provided a copy to each participant. I explained and reviewed the study's purpose and ethical considerations. This process helped protect the participants and safeguarded them from unnecessary and unintended harm. A debriefing at the end of the interview allowed for the processing of any sensitive

feelings and emotions. Questions were welcomed and addressed before the participants left the interview session.

There is always a chance for ethical concerns when conducting participant interviews. Emotions, feelings, and unresolved sadness that have never been addressed in a therapeutic setting may arise for participants when discussing their mental health service usage. These emotions may be overwhelming and warrant immediate attention for those participants. To address this area of possible concern, a list of available referral resources, including therapists, crises phone lines, and resource material on grief, loss, depression, anxiety, and stress was readily available.

Participants may also have concerns regarding issues surrounding addiction. The hemophilia community often struggles with pain management and the unfortunate dependency on opioids. Resources for drug counseling, Al-Anon resources, rehabilitation centers, and the local HTCs were available to participants. Participants may be struggling with caregiver stress and burden. Resources specific to being a caregiver, caregiver stress, and caregiver support groups was also readily available.

The IRB's ethics review and approval are required before participant recruitment, data collection, or data analysis. The primary role of the IRB is to ensure the safety of human participants in research studies. In the case of my study, I contacted participants via email or flyer distribution, detailing the steps of the study. I encouraged participants to complete the demographic questionnaire, which included a question ascertaining their willingness to be formally interviewed. I emailed or hand delivered the informed consent document prior to the interview date. At the time of the interview, I read the informed

consent document with the participant and proceeded when the participant agreed to proceed with the interview process.

I notified participants that I would be collecting all data and that it would only be shared with the Dissertation Committee, myself, and possibly other designated University Staff. I continue to retain the interview transcripts and subsequent coded data on a password-protected thumb drive in a locked safe and will do so for a period of five-years. To ensure participants' privacy and confidentiality, I communicated that each person interviewed would be given an identifying number and that their names would be omitted and not included for the purposes of data collection and analysis. Participants also received a packet of information including an introductory letter reiterating the purpose of the study, my contact information, and a statement addressing ethical considerations including issues surrounding confidentiality.

Summary

This chapter provided an overview of the research process from participant recruitment to data analysis. This study focused on the utilization of mental health services for caregivers of hemophiliacs. I addressed the rationale for utilizing qualitative research, emphasizing the importance of obtaining participants' subjective experiences as a valid point of study. This chapter detailed the steps necessary to achieve a proper study that is credible, transferable, dependable, and meets confirmability.

I discussed the data-analysis process, including the conceptual framework of Andersen's model of utilization. I also addressed ethical standards and practices,

including the mitigation of researcher bias, participants' confidentiality, and data

processing and storage. Chapter 4 will present the study's results.

Chapter 4: Results

Introduction

I conducted a generic qualitative inquiry to understand caregivers' perceptions

and experiences with mental health service utilization in the hemophilia community. I

sought to deepen my understanding of the perceptions, lived experiences, and

understanding of mental utilization of mental health services through the caregiver lens.

The study consisted of 20 participants, all with experience as caregivers to someone

diagnosed with hemophilia. This study utilized a demographic questionnaire as well as a

general question guide to illicit discussion from participants.

Chapter 4 illustrates the results of my study. I will provide basic demographic

information including age, gender, identified residency, and racial/ethnic identification of

the participants as they relate to the study. I also provide tables and figures to show the

major categories that emerged from the participant interviews and how themes emerged. I

will discuss the strategies I used to ensure confirmability, dependability, credibility, and

transferability of my study. Lastly, I present the results of my study and a summary of the

findings based on the research question.

Setting

I received IRB approval (#04-18-22-0091192) on April 18, 2022. I began

recruitment on April 20, 2022. The HFA had their annual symposium in Texas from

April 20-23, 2022. I received permission to place the recruitment flyer (See Appendix C)

on the registration table where attendees received their conference folders and

information. I was able to recruit all 20 participants within this 4-day period utilizing the methods outlined in Chapter 3.

Seventeen participants were interviewed in person, and three elected to be interviewed on Zoom. The 17 participants were asked if they were willing to be audio recorded; all agreed. The three Zoom participants were given a choice to be onscreen or off screen while the interview was conducted, and they were also asked to consent to their interviews being recorded; all elected to be onscreen and agreed to be recorded.

Demographics

My participants were all current caretakers of someone with hemophilia. Out of the 20 participants interviewed, 11 were diagnosed with hemophilia themselves. There were both male and female participants, eight males and 12 females. The participants ranged in age from 18 to 70. There were five nationalities represented among the participants, and the participants resided in 12 different states.

Most of the participant's loved ones were receiving treatment from their local HTC. For the participants' loved ones who did not receive treatment from the local HTCs, many factors including distance to the HTCs, rural locals of the families and availability of hematologist were all contributing factors for them to receive medical care by a primary care physician or local hospital. All the participants discussed in lengthy detail, their lived experiences with caregiving and their perceptions and understanding of the utilization of mental health services in the hemophilia community.

Table 1

Demographics of Participants

Participant#	Sex	Age	Residency	Race/ethic identification
#001	F	43	FL	Non-Hispanic White or Euro-American
#002	M	35	AZ	Latino or Hispanic American
#003	F	46	CA	(Other) Hispanic & Native American
#004	F	57	GA	Black, Afro-Caribbean/African American
#005	F	37	GA	(Other) African
#006	F	18	FL	Non-Hispanic White or Euro-American
#007	F	30	WV	Non-Hispanic White or Euro-American
#008	M	33	TX	(Other) White & Hispanic American
#009	M	62	MO	Non-Hispanic White or Euro-American
#010	F	34	TX	Non-Hispanic White or Euro-American
#011	M	28	TX	Latino or Hispanic American
#012	M	32	VA	Non-Hispanic White or Euro-American
#013	F	58	DE	Non-Hispanic White or Euro-American
#014	M	33	ME	Black, Afro-Caribbean/African American
#015	F	68	MA	Non-Hispanic White or Euro-American
#016	F	67	GA	Black, Afro-Caribbean/African American
#017	F	58	TX	Non-Hispanic White or Euro-American
#018	M	70	GA	Black, Afro-Caribbean/African American
#019	F	27	MD	Black, Afro-Caribbean/African American
#020	M	43	TX	Non-Hispanic White or Euro-American

Data Collection

I received a total of 23 participant inquiries. Of those 23 inquiries, three individuals were not current caregivers of persons with hemophilia and were excluded from participation. Seventeen of the participants were given the Informed Consent and signed the document after reading it and being asked if they had any questions. A copy of the Informed Consent was emailed and read out loud to three participants over Zoom. All agreed verbally while recorded that they had no questions and agreed to proceed with the interview.

Generic qualitative inquiry is an appropriate framework for this study as I am seeking to understand caregivers' perceptions and experiences. I used semi structured interviews to garner verbal and nonverbal information. I noted facial expressions as well as emotional responses such as tearfulness, laughter, and visible frustrations during responses. The youngest participant (#006) was asked clarifying questions about her caregiver role. She was forthcoming about having hemophilia and providing care to her younger sister who had hemophilia because her mom was suffering from depression due to the sudden loss of her father to a heart attack last year; therefore, she was providing primary support and care.

Data Analysis

I used a combination of thematic and cultural narrative analysis. Narrative analysis uses interviews, conversations, and life experiences as units of analysis. Thematic narrative analysis focuses on themes that emerge during the process of gathering and analyzing the data that was collected (Huberman et al., 2020). According to

Huberman et al. (2020), as themes emerge, salient concepts within the data form the heart of the analysis. Cultural narrative analysis looks at how the data collected through stories and interviews reflect the values, beliefs, history and or current situations of a specific group. According to Creswell et al. (2018), cultural influences affect how people view and express their lived experiences. These lived experiences, once analyzed, help to represent the worldview of a particular group, in this case those affected by hemophilia.

Organizing and summarizing the data through the coding process is an essential step for research analysis. According to Huberman et al. (2020), coding triggers analytic thought and a way to formalize conclusions in a study. Coding helps to get rid of repeated information and helps to narrow down the data into common themes. I utilized inductive coding that allows the narrative or theory to emerge from the raw data (Huberman, et al., 2020). In Vivo Coding utilizes the participant's own spoken language to understand the intent and meaning of the data being collected.

According to Saldana (2016), a code is most often a word or short phrase that symbolically assigns a summative, singular, attribute for a portion of dialogue into visual data. First cycle coding is a way to initially summarize segments of data, whereas second cycle coding or pattern coding is a way of grouping those summaries into a smaller number of themes, concepts, or categories (Huberman et al., 2020; Saldana, 2016; Yin, 2018).

Each interview was transcribed into written text by using the MS Word function in the Microsoft platform. This was done by placing the mini recorder to the microphone on the computer. These transcribed interviews were reviewed twice for any errors in

translation. I used first cycle coding which required me to read the transcribed text of the interviews word for word. The data were grouped into larger buckets of similar concepts and then to smaller common themes. These common themes represented the codes, and this process was completed by hand.

Each participant was assigned a number as an identifier after the interview to represent them in lieu of their name. A data chart represents these numbers, and basic demographic information from each interviewee. All data were then stored on a password protected thumb drive. I completed several read throughs of the data. I created a document to capture the common phrases, words and themes. Some of the codes included mental health stigma, cultural issues, focus on physical health not mental, and lack of awareness. A line-by-line analysis and summation of commonalities developed into the chart below (see Table 2).

Table 2

Organization of Categories and Themes

Initial coding	Line by line	Summarized (make consistent)	Themes
Cultural barriers	Hispanic community stigma attached so barrier	Cultural barriers have prevented people seeking mental health services	Cultural sensitivity to the needs of the community. Breaking the old stigma of mental health making it "ok" culturally
Barriers Insurance company pay for mental health treatment versus medical (cap due to medication cost)	African American Community cultural barriers	Financial Constraints. Caps on co pays and insurance people perceive they are unable to afford mental health services	Financial constraints
Negativity towards mental health treatment (you are crazy)	We don't want to be considered crazy. That is the word people use when they are talking about mental health. Even the word therapy would be better	Negative stigma about seeking services being labeled "crazy" prevents people from seeking services	Demystifying mental health. Normalizing treatment
Stigma surrounding mental health from family. We don't discuss it because you look weak, and you have to be strong in this community	We were trained that what goes on in your family stays in the family. We need to present as strong. Our family has handled hemophilia for years without mental health intervention	Must remain strong because this community is resilient and strong and mental health makes you look weak	Mental health viewed as weakness. Cultural influences

Initial coding	Line by line	Summarized (make consistent)	Themes
People's perception of mental health not just talking about things but a "diagnosis"	We don't necessarily understand mental health services. Does it mean being labeled something and medication or just talking	Defining mental health to include therapeutic services. Clarifying the need for "treatment" versus talking with someone	Clarity in defining mental health services
Focus on physical health and not mental health	We really don't have the time to focus on anything but just making it with all the challenges we face with hemophilia	A choice must be made physical vs. mental	Guilt for seeking help because of the physical aspects of the chronic disease (no extra time so ease of service)
Lack of exposure nobody talks about mental just physical	I really don't know much about what services would be available. The HTC social worker does help with resources. They are really good at that	Lack of information. No discussion. Lack of access or ability to hear information regarding mental health (choice physical vs mental)	HTC to utilize social workers or a social worker trained in providing counseling services and not just service provision
A place for it but nobody focusing on it	I see it as worthwhile but we really don't hear anyone talk about it until this symposium	No information sharing	Value but no exposure

Initial Coding	Line by Line	Summarized (make consistent)	Themes
Kids need the mental health as well	What about the kids. They also get depressed and have self esteem issues. Sometimes the focus should be on their mental health. Some kids have PTSD from it. The constant needle sticks and the pain and bleeds, hospital stays. That is enough to cause mental health concerns	mental Health beneficial for everyone not just adults. Need for discussion early on in the process	PTSD aspect for those who are affected
Covid has had a positive impact on mental health. People are seeking treatment and help because of it	Due to covid more people had to face mental health challenges	Covid has opened the door for discussion	Exposure to Mental Health through other means such as COVID
You are not a good Christian if you seek mental health treatment. You are denying your faith, not believing in GOD if you seek mental health	You just need to pray, and it will get better. Christians don't to therapy.	Barriers: Religion; Culture; Financial concerns; stigma; family culture and dynamics,	Busting the barrier of religion and culture with exposure. Normalizing the mental health piece by placing value on the entire person the whole being who has a chronic disease

Initial Coding	Line by Line	Summarized (make consistent)	Themes
Family and friends not valuing mental health treatment because the medical is covered	You have treatment so get over it about needing therapy	Feelings: you should be thankful you have treatment; focus solely on physical aspects of disease; must present as strong and resilient in this community	No guilt or shame or association as a weakness because of seeking help
Mind/Body connection but we avoid that	We ignore that there is a mind/body connection and just try to focus on the physical	Lack of knowledge: Nobody talks about mental health so not aware of the resource in relationship to the chronic disease	Cant address physical chronic disease and leave out the mental
People are ashamed, Stigma associated with mental health	We just don't discuss within the family	Mental health stigma with cultural component	Removing stigma see above
Focus only on the treatment options.	We have so much to discuss regarding treatments new and old and nobody ever talks to us about mental health	Focus on physical not mental	The whole person Mind/Body Connection see above (value system)
Nobody talks about mental health until recently	We never really heard about mental health until this symposium.	Interest but no information	If information is offered or given not opposed to the services

Initial Coding	Line by Line	Summarized (make consistent)	Themes
Not sure I would use it due to how I was raised	Not sure I would use it as my we don't really talk about mental health. The men have the hemophilia and we don't talk about it	Cultural piece can be influenced by gender	Barriers of "how I was raised" and culture including gender Men don't talk
Men don't "do" mental health	In my men's group. We don't share feelings we just want to relax and fish and things like that nothing else	Gender roles and the acceptance of seeking help. The "role" doesn't allow for vulnerability or seeking help	Normalize for men taking care of their mental health
Valuable service. Very involved now run groups about PTSD in community	A pastor helped me and told me to get help I was in a dark place	When someone reached out he accepted help. Normalization is the key	If it is talked about more will come to value the importance of services
Newly talked about	I am so glad it is now being talked about	If it is talked about more people would be amenable to services	See above
Not always see value in mental health as it doesn't change the chronic disease.	I mean we can talk about it but it doesn't change my situation	The physical takes precedence over the mental. Not seen as valuable.	Reiterate the mind/body connection as valuable not just the chronic illness which is systemically practiced
We don't have time to focus on mental health	I am managing work, children, marriage, family issues. Don't really have the time to add to the plate if you know what I mean	Life is overwhelming and mental health seen as a chore or an added stressor	Valuing system. Mental Health matters

Initial Coding	Line by Line	Summarized (make consistent)	Themes
Multiple children often mean less time to focus on anything but the disease	Support is so very important when you have a lot of children and you really don't have extra time	Mental health is seen as time consuming. Nothing more to focus on because of being overwhelmed	If services were offered at the HTC or a collaboration with HTC and local therapist (telehealth) consumers may be interested
The HTC doesn't tell us about mental health	My HTC has never asked me "how I am feeling" just what services do I need	Mental health as part of the hemophilia appointment	Consistency regarding service delivery within HTC
Good nurses at HTC	We have a great nurse at the HTC but she doesn't do therapy or ask about how we are doing emotionally	(interviewee used nurse but we were referring to social worker at HTC) Service delivery not an issue but no information or discussion about mental health	Consistency with service delivery. Routine appointments should include questions about mental health
Bad HTC's not supportive	They are horrible at the HTC. Just feel like we are a number of the many hemophiliacs. I was new to the country and they treated me like I didn't deserve services	No consistency to help with mental health or to even inquire	Location matters. Some good HTC's some bad HTC's

Initial Coding	Line by Line	Summarized (make consistent)	Themes
Focus solely on disease not able to focus on anything else	We have good discussions about the physical parts of the disease but not the mental healthy aspect	See above	Must stress importance of receiving services to decrease the burden not adding to it with time and effort or financial burden
New focus on mental health at large symposiums	I haven't seen a focus on this until this symposium	More information needs to be provided	More exposure means normalization
Focus on mental health should be on local chapters	At these big events it is one thing but maybe if mental health was discussed at the local chapters, people would be more open to talk about it because they are with people they know and feel comfortable with.	Not just at national events but the discussion regarding mental health should be throughout the local member organizations as well	46 member organizations need focus on mental health and service provision and connections within their community.

Results/Thematic Analyses

The following themes emerged during data analysis.

Figure 1

Cultural Impact/Stigma of Mental Health Services Interviewee Comments
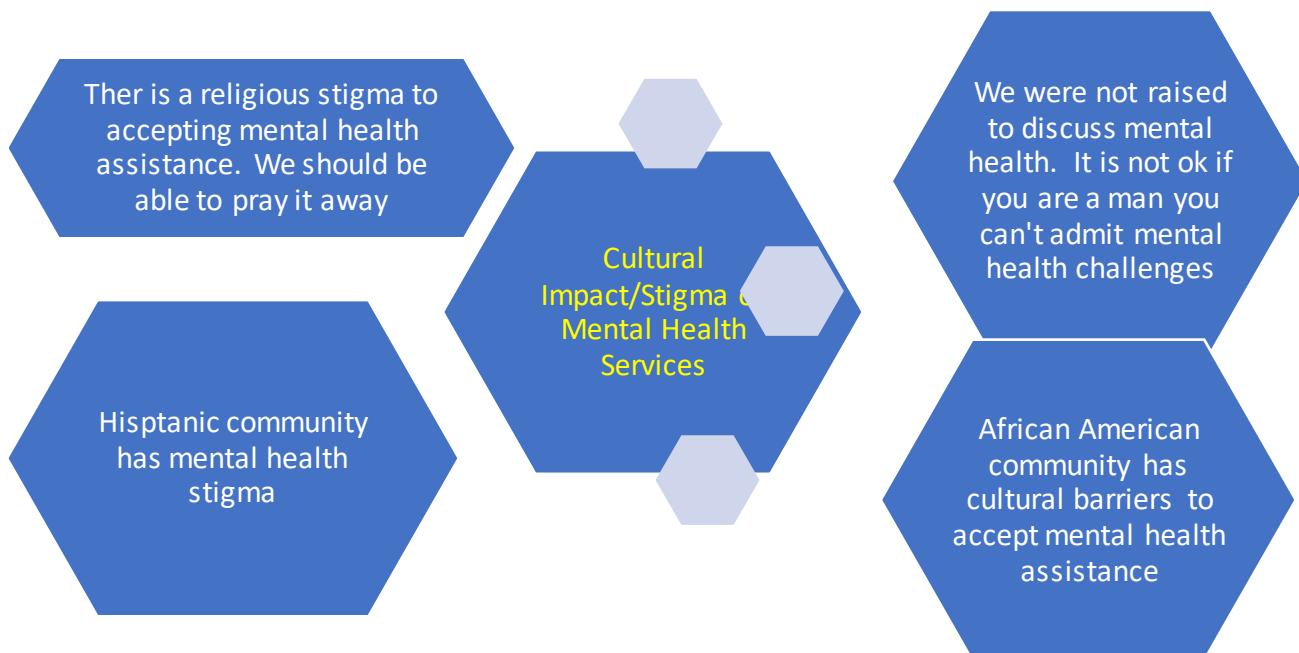
This theme emerged as participants discussed the cultural stigmas in their families

regarding mental health and mental health services. The participants expressed that

expressing a mental health challenge is met with "your just sad" 3 Cultural

Impact/Stigma of Mental Health Services or "we don't have time for that psychobabble".

Participants were raised in an atmosphere of denial of mental health or categorization of

it as a "weakness". Seeking help outside of the family structure is not acceptable in any

circumstance. Participants #002, #003 and #011 all mentioned that they would bring

shame to their families if they sought mental health treatment in any form. They stated

that even the discussion is taboo in their community and highly frowned upon.

Figure 2

Normalizing Mental Health Services in the Hemophilia Community (National Impact)
Interviewee Comments

We don't want to be considered "crazy"

You are seen as weak when you say you need mental health services

Normalizing Mental Health Services in the Hemophilia Community National Impact

People dont understand what mental health is. Is it just talking or are you being diagnosed?

It is important but nobody is talking about it. The first we heard about it in this community was at this symposium
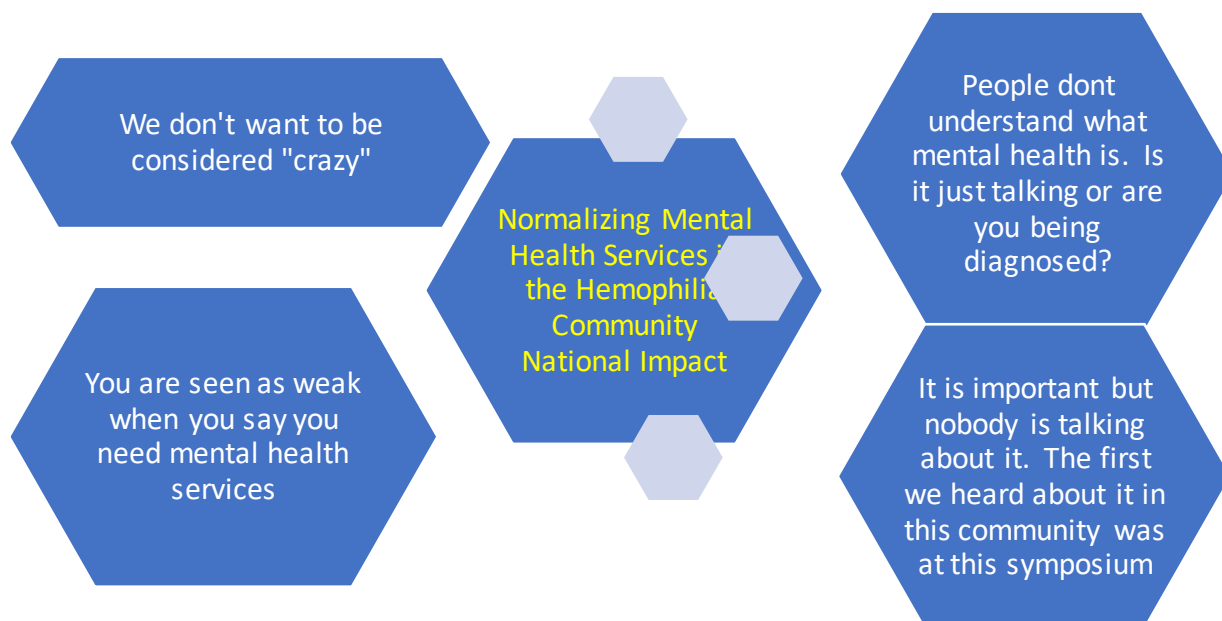
Caregivers expressed that mental health was not talked about in the community until recently. Participant #001, #004, #006, #008, #014, #017, #019, #020 all stated that "this symposium is the first time I have seen workshops on mental health". Participant #003 shared that "most of the focus is always on coping with the disease, new treatment options and new research on the various components of the factor deficiencies." Participant #012 shared that "nobody discussed the mental health aspect of living with a chronic illness until we lost 4 people to suicide in this community". Participants #002, #009, #014, #015, #020, all specifically mentioned that HTCs do not discuss mental health services or provide therapeutic intervention during visits. Focus remains on disease, treatment options, and pain management. No focus on whole person (mental, emotional, and physical).

Figure 3

Inconsistencies in HTC Service Delivery Interviewee Comments
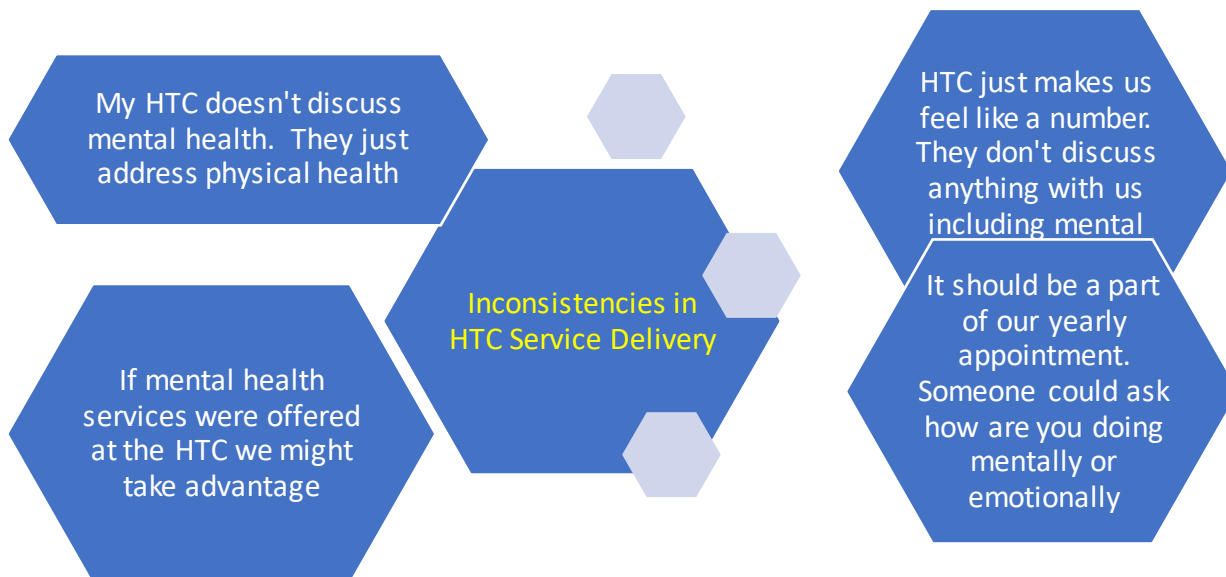
Participants' experiences were often based on the HTC's they were assigned to

for treatment. Participant #018 stated that" if the HTC discussed things such as emotional

support or traumas associated with caregiving, maybe I would think about seeking mental

health treatment." Participants all shared varied responses that emphasized no

consistency from HTC to HTC or state to state. Participants #001, #002, #006, #009, #

013 #015, #016, #019 shared that they have never been asked about how they were

feeling emotionally. Participants #010 and #011 stated that the HTC social worker has

asked how they were doing and how they were feeling in general but has not asked them

anything about their caregiver roles or support or the need for therapy services.

Participant #011 added that the social workers always ask about resources we need,

practically things like food or if we are struggling with bills, they give referrals for the

national organizations like HFA or Colbourn Foundation. Participant #006 and #005 stated that nobody really discusses how you feel about caregiving or having an illness and how that "affects your mind." Participant #001 stated that the stress level from caregiving is so difficult to manage along with the other pressures you face like work or school, and finances. "Stress causes all kinds of physical problems and I have high blood pressure because of it. I don't sleep well either."

Figure 4

Clarity of Role of HTC Social Worker Interviewee Comments
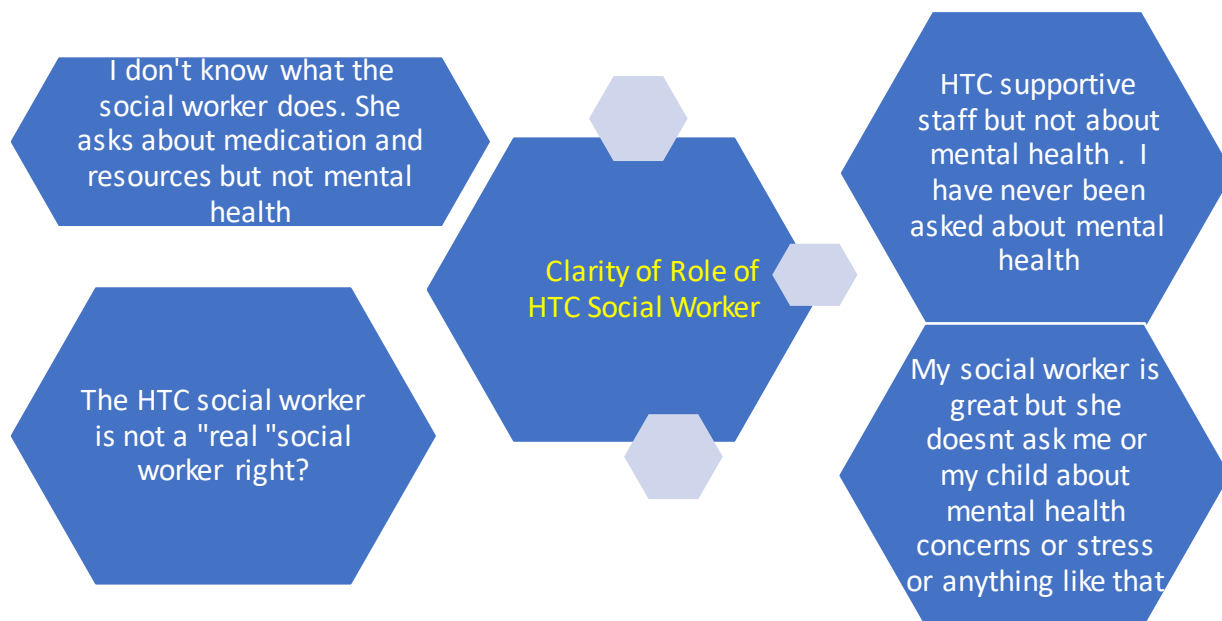
Participants shared that although social workers are part of the Hemophilia Team

at most HTC's, they saw them as purveyors of resource referrals. They shared

conversations with social workers about delivery of medication or new treatment options.

They discussed kids programming such as camp or academic scholarship opportunities.

They also shared programs for financial assistance for families or families struggling with

the cost of medication. Participants #010 and #011 did share that they were asked in

general "how they were feeling" or "if they were overwhelmed". Despite the answer,

mental health intervention was not the focus but more so a "here is a resource that may

help" that did not include a therapist or a mental health specialist. Participants, #013 and

#017 commented that they never see the social worker when they go for their

appointments, even though it is a part of the regularly scheduled yearly hematology

examination. #013 and #017 mainly received treatment outside of an HTC due to the distance of the HTC. Both did attempt to go once a year but for the most part saw a local Hematologist in their local areas. Participants in general were not clear about the role of the social worker but generally most did not believe they could sit and talk with them about feelings of emotional instability, stress, anger, depression, or sadness. The participants did indicate that they were comfortable asking about resources.

Figure 5

Member organizations emphasis on mental health (Local Impact) Interviewee Comments
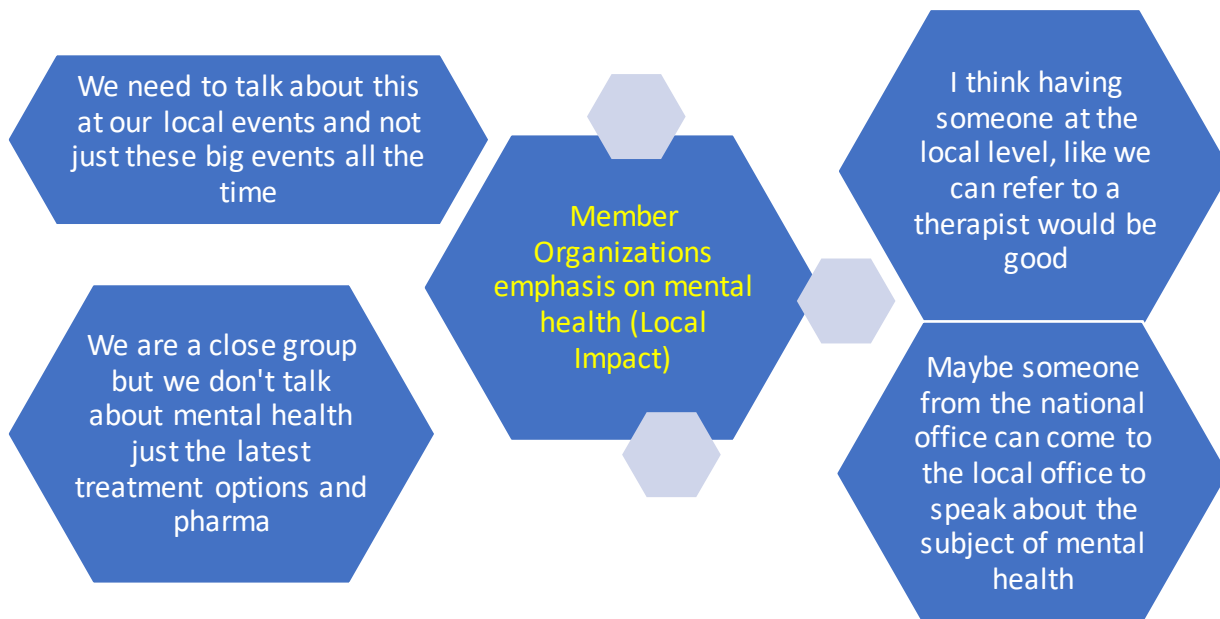
On a local level, some participants commented that their local member

organizations were very open to discussing mental health therefore they felt very

comfortable about seeking mental health treatment. Participant #003 shared that in the

local organization, they are open and have great discussions about taking care of your

mental health. They also provide resources that have a therapist you can talk to.

Participants #009 and #012 discussed that after the death, to suicide of one of their

members, their local organization had a therapist come speak to them about grief and

loss. Participants #001 stated that they often feel like they are the only one experiencing

depression or anger and sadness, so they don't really feel comfortable discussing needing

help through therapy or speaking with someone at the local member organization.

Participants #002 and #015, stated that their local organizations programming is mainly

for kids. Participant #015 added, "I think kids should be encouraged to seek mental health treatment as well as the caregivers and adults suffering with the disease because they lose so much. Things they can't do like their peers, constantly being hospitalized and infusing all the time. That can cause stress as well, needle sticks every day or every other day. That's overwhelming because it is for the rest of their lives."

Figure 6

Guilt and shame of seeking services because of "strength messaging"/Resiliency of community (Past generations had it worse so stop complaining/weak).
Interviewee Comments

Participants #002, #007, #008, #011#018 and #020 all shared that it is difficult to ask for help because all we ever hear is about how strong we are in this community. We hear about the atrocities that those with hemophilia went through in the past and how "good we have it now". Participants #012 shared that you feel guilty even mentioning how hard it is to be a caregiver and how emotionally drained and sad you get sometime because people encourage you to be resilient and we have to be strong to not let the disease stop us from living a life as normal as possible. Participant #018 stated that. "For a man it is difficult to even discuss needing help. You just hear all the horror stories of the past and how many people were lost in the Hemophilia Holocaust and you remember how many of your friends are dead to this disease then you see the older ones, like

myself, walking around limping and struggling with pain and then you think I can't complain, I can't feel sad, I can't let the disease get the best of me because they didn't so you just suffer in silence and swallow that pain. You don't seek help for it". Participant #001 stated that "you feel guilty as a caretaker because you see your kids just moving through the infusions every day, they suffer the bleeds and still smile and not complain plus you feel guilty that you were the carrier or part of the genetic reason they have the disease so even if you are feeling overwhelmed, you don't get help because you have to be strong or appear strong for them." Participant #067 stated that "all you ever hear is how amazingly strong the members of this community are, so you feel ashamed if you are at your breaking point. You instead just move on to the next step and the next infusion or the next surgery. You just don't have time to focus in on mental health."

Figure 7

Ease of service delivery Interviewee Comments
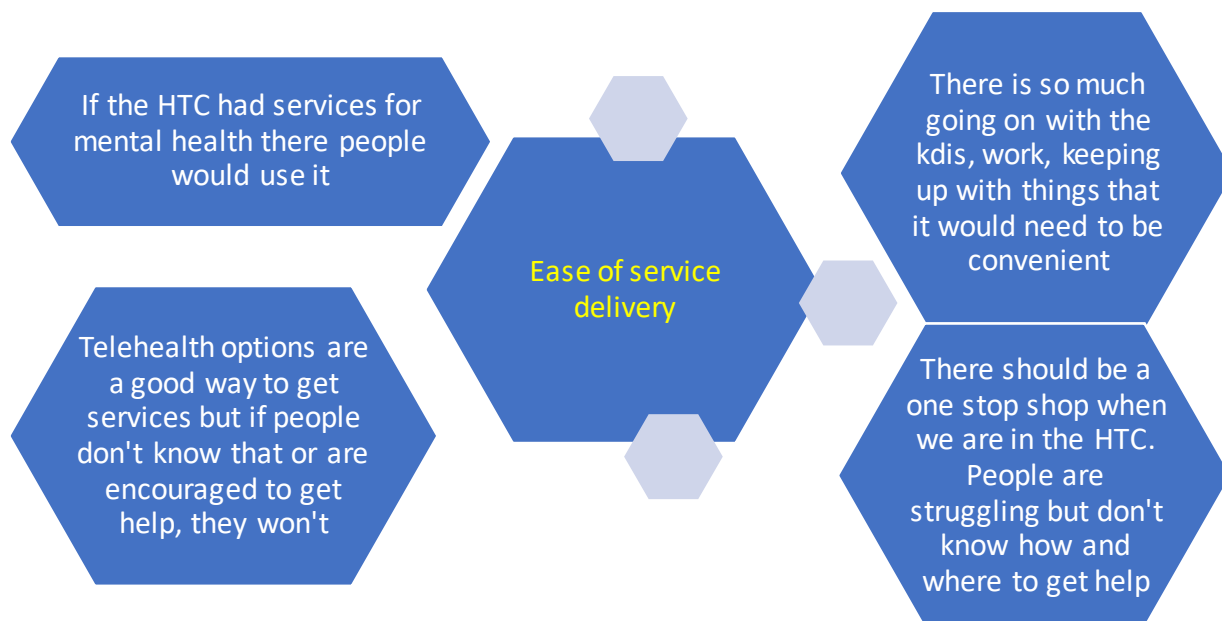
Participants #009 and #020 shared that if "the HTC social workers could ask about our mental health during a visit, we may be open to receive services." The participants in general shared that they would speak to someone in the office about how caregiving affects them if it was offered during their examinations. Participants #017 and #006 shared that if the social workers provided a short session to discuss feelings, they would be open to it as long as it didn't require another visit. Participant #005 stated that she could have used a social worker when she found out her son was a hemophiliac. She was new in the country, and she didn't really understand the doctors coming at her and that she was so stressed and "if there was someone there to help her navigate and process her feelings and emotions, she wouldn't have had to go back to her country to get help". Participants, #014, #017, #019 stated that the social workers are there so they should be clear about their role and provide mental health support. Participant #011 stated that "it may be easier to get help in an environment like the HTC because nobody is in the room with you during

appointments and because it is such a stigma in my culture, I would feel more comfortable

sharing in that private environment."

Evidence of Trustworthiness

As stated throughout Chapter 3, it was crucial to maintain an ethical and trustworthy research study through the data collection and coding process. According to Shenton (2015), establishing trustworthiness in qualitative research involves proof that the research findings are credible, transferable, confirmable, and dependable. Trustworthiness, often called the "rigor" of the study refers to the degree of confidence in the data, interpretation of the data and the methods used to analyze the data to reach a conclusion or recommendation (Connelly, 2017). To ensure trustworthiness throughout my study, I conducted my research using the procedures listed below.

Credibility

I used three strategies to ensure credibility. Saturation is a point in the data-collection process when no new information is discovered (Raskind et al., 2019). This redundancy indicates that the data collection can cease. I continued to interview participants to garner new responses. As the response because similar, I ceased recruitment of new participants. Reflexivity refers to the examination of one's own beliefs and judgements during the research process (Raskind et al., 2019).

As a researcher of qualitative inquiry, you must be open to one's own biases and assumptions while conducting the research. I recorded my thoughts and feelings throughout the interview process to review any evident biases and assumptions. Lastly, I utilized member checking to ensure credibility. Member checking is a technique used to establish credibility but utilizing the participants to validate information (Ravitch & Carl, 2016; Raskind et al., 2019).

Transcripts of the recorded interviews were forwarded to all participants to garner clarity and to ensure that the information documented was accurate to the best of their recollection. 11 of the 20 participants responded to the emailed transcript and indicated that the information was accurate. Of the 11 participants, two provided clarity or further explanation of their recorded interviews.

Transferability

Transferability refers to the extent to which findings are useful to persons in other settings (Polit &n Beck, 2014). According to Connelly, (2016), researchers can support the study's transferability with detailed descriptions of the context, location, and people studied. I used thick description and variation in participant selection to account for transferability in my study. Thick description in relation to transferability refers to the researcher's ability to provide a robust and detailed account of their experiences during data collection. This research was collected at a national symposium for the bleeding disorder community. Participants were interviewed in various "quiet" places in the hotel where the conference was being held.

The participants made the initial contact with me by phone, and I would meet them at a time convenient to them. Participants came from various states covering the East, West, South and North of the country and had varied in nationalities. Both men and woman participated, and ages varied from 18, the youngest participant, to 70 our oldest participant. Some interviews were held in the morning, some in the afternoon and some in the evening.

Dependability

Dependability is a way to ensure that future researchers can repeat this study. It is important that the data over time remains stable, i.e. dependable (Polit & Beck, 2014). I have maintained all pertinent information that led to my study from beginning to data collection. This includes how the participants would be recruited, screening tools and questionnaires. I have recorded all interviews and ensured confidentiality of information. I have kept records on all data collected in transcript form.

I have coded sheets and document how the research led to specific themes. I kept records of my experience throughout the data collection process and all findings. I consulted with my chair and committee members as needed, to review my research design and data sources and theme development. It is important to maintain an audit trail of process logs of things that happened during the study (Connelly, 2016).

Confirmability

Confirmability refers to the degree of neutrality in the study's findings. This means the researcher's bias, or any personal motivators did not influence participants' responses. Amankwaa, (2016), assets that confirmability is the neutrality or the extent that the results are consistent and can be repeated. I used reflexivity to ensure conformability. I utilized coded data to ensure that the participants response drove the research and to ensure that I was able to go beyond personal beliefs, positionality, and assumptions during data analysis. I kept a detailed journal of my personal views and wrote down my thoughts and feelings during the process of data collection. I monitored my preconceived ideas and ensured that I was not influencing any of the study analysis.

Summary

Chapter 4 detailed the data collection and the process for analysis. I described, in this chapter, the settings, demographics, the process for getting participants, how the data was collected and the analysis of the data. The data was collected and analyzed using thematic and cultural analysis. According to Ravitch & Carl, (2016), common concepts in data devise themes. The thematic analysis resulted in the following key themed areas-Cultural Impact/Stigma of Mental Health Services**;** Normalizing Mental Health Services in the Hemophilia Community (National Impact); Inconsistencies in HTC Service Delivery**;** Clarity of Role of HTC Social Worker**;** Member organizations emphasis on mental health (Local Impact); Guilt and shame of seeking services because of "strength messaging"/Resiliency of community (Past generations had it worse so stop complaining/weak); and Ease of service delivery. These themes represented the lived experiences of those interviewed. The first cycle and second cycle coding methods helped to narrow down the data into these themes. The themes that emerged from this coding process were detailed and evidence of trustworthiness was established.

Chapter 5 will provide a review of the study purpose, discussion of the data collected and recommendations and implications for service for the hemophilia community. I will incorporate my literature review from Chapter two and discuss, in detail, the relevance of my theoretical framework to my research analysis. Lastly, Chapter 5 will include the limitations of the study, recommendations for additional research possibilities regarding my subject matter and the implications for positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This generic qualitive inquiry study was conducted to get an understanding of the utilization of mental health services for caregivers of hemophiliacs. Generic qualitative inquiry seeks information from representative samples of people about real world events and processes their experiences (Percy et al., 2015). Qualitative interviews of caregivers were, therefore, essential to determining current and past experiences and solution-focused needs of the community. By explaining the lived experiences, the research could point to the gaps in services and resources. The study findings revealed seven themes: Cultural Impact/Stigma of Mental Health Services; Normalizing Mental Health Services in the Hemophilia Community (National Impact); Inconsistencies in HTC Service Delivery; Clarity of the Role of the HTC Social Worker; Member Organizations Emphasis on Mental Health (Local Impact); Guilt and Shame of Seeking Services because of "Strength Messaging"/Resiliency of Community (Past Generations had it Worse so Stop Complaining/Showing Weakness); and Ease of Service Delivery.

In Chapter 5, I provide a summary of key findings. I will also explain the interpretation of the findings, and the conceptual framework relevance in explaining the data. I will also explain implications for service delivery to meet the needs of caregivers of those with hemophilia. Lastly, I will clarify the limitations of the study, recommendations for further research, and the potential impact on social change.

Interpretation of the Findings

This study used a generic qualitative inquiry design, as I was seeking to understand caregivers' perceptions and experiences with caregiving for hemophiliacs. This study design allowed for exploration of the factors that contribute to the utilization of mental health services in this community. Using semi-structured interviews, I gathered valuable insight from participants that addressed systemic and cultural views regarding mental health and the hemophilia community. The collected data were analyzed using a thematic and cultural analysis. Themes and categories were devised based on the saturation of the data point. The study findings revealed seven themes: Cultural Impact/Stigma of Mental Health Services; Normalizing Mental Health Services in the Hemophilia Community (National Impact); Inconsistencies in HTC Service Delivery; Clarity of the Role of the HTC Social Worker; Member Organizations Emphasis on Mental Health (Local Impact); Guilt and Shame of Seeking Services because of "Strength Messaging"/Resiliency of Community (Past Generations had it Worse so Stop Complaining/Showing Weakness); and Ease of Service Delivery.

Cultural Impact//Stigma of Mental Health Services

The first theme, Cultural Impact/Stigma on Mental Health Services, is supported by Abdullah and Brown (2019), who asserted that public and self-stigma operate based on the idea that cultural influences, rather than race and ethnicity, influence people's stigmatizing beliefs, attitudes, and actions. There may be several features of cultural influences that impact public and self-mental illness stigma, including culture-specific beliefs regarding the etiology of mental illness, culture-specific stigmatizing beliefs about

mental illness, historical injustices and mistreatment by the health care system and government, and cultural norms, values, and socialization.

Hinshaw (2007) and the U.S. Department of Health & Human Services (1999) asserted that mental illness stigma, the devaluing, disgracing, and disfavoring by the public of individuals with mental illnesses, is a huge challenge for progress in the area of mental health and illness. According to the Surgeon General's report on mental health (U.S. Department of Health and Human Services, 2019), belief systems including cultural expectations affect the ability to share information about mental health. This report also asserts that the inability to share information ultimately affects the opportunity for service delivery. Andersen's (1969) behavioral model of utilization asserts that families must perceive a need for services and have the desire to respond to that need being met. The most important tenant to this point is that the belief systems and attitude in relationship to the utilization of healthcare services must be aligned before the follow through on seeking the services (Andersen, 1995; Childers, 2019).

Normalizing Mental Health Services (National Impact) and Member Organizations Emphasis on Mental Health (Local Impact)

The second and third themes, Normalizing Mental Health Services in the Hemophilia Community (National Impact) and Member Organizations Emphasis on Mental Health (Local Impact), are jointly explained by Andersen (1995) and Babitsch et al. (2015), who assert that there is a "need" phase in the utilization of medical services where the family perceives a need for services and therefore responds to that need. Secondly, Andersen asserts that utilization happens when conditions make the healthcare

service available to the family; therefore, healthcare utilization not only depends on the availability of the services, a family perceiving a need for the service but also the incorporation and normalization of the health services in a regular routine of healthcare delivery.

Those interviewed shared that the mention of mental health services is neither spoken on the local nor national level. The participants indicated that the focus has remained on the management of chronic disease without mentioning the emotional toll of managing hemophilia. It was shared that there are extreme variations when it comes to the way their local chapters discuss mental health. Some indicated that the programming is not at all related to emotional issues surrounding hemophilia, whereas some chapters discuss the emotional side of hemophilia and have resources to assist their membership.

If the national organizations emphasized the importance of mental health and provided education and programming to the local organizations, it would help to normalize mental health as an integral part of the hemophilia treatment plan. It is also important that the larger hemophilia community address the issue of mental health with a unified message including pharmaceutical companies, who have a huge impact on their consumer base and have the largest platform to reach all persons receiving medication management for their hemophilia.

Inconsistencies in HTC Service Delivery

The fourth theme was Inconsistencies in HTC Service Delivery. According to Andersen (1995), utilization of medical services (mental health services) takes place where a family is predisposed to receive medical care and under conditions that make

health services available to the family. Participants shared a wide variety of responses when it comes to HTCs. Most participants were never asked about their mental health or the possible need for therapeutic services or the ability to speak to someone about the emotional side of caring for someone with a chronic disease. The hyperfocus on the medical treatment does not include the holistic approach of the mind/body connection and the stress, depression, and anxiety that often comes from managing and taking care of someone with hemophilia.

Overlooking this aspect of "total" care speaks to the lack of consistent policy and processes for routine and emergent hemophilia visits. According to Anderson (1995), if mental health services were a routine part of the comprehensive care at HTCs and were readily available, increased utilization may occur. Participants also shared that if mental health services were offered as a collaborative part of the HTC visit, it would help to normalize it as acceptable. This would also encourage families to view mental health as a part of routine health care. If a caregiver was asked about their mental health or their overall well-being, they would not face the stigma of "seeking out the treatment on their own" but instead having access because it is "just a part of the normal visit and asked to every patient.".

Clarity of the Role of the HTC Social Worker

The fifth theme that emerged was Clarity of the role of the HTC social worker. According to Andersen's (1995) behavioral model of utilization, usage of health care services takes place where the family is predisposed to receive medical care and conditions make health services available to the family and lastly the family perceives a

need for these services and responds to that need. Most if not all the HTCs where hemophilia treatment occurs employ social workers. The role of the social workers seems to be ambiguous. Participants shared that most of the social workers discussed resources with them readily but did not ask questions regarding their stress level, anxiety levels or mental health status during their visit.

Participants also shared that they did not feel that the HTC's social workers were there for emotional support; but that their role was simply referrals. Most of the social workers are clinical social workers and have the ability to provide brief therapy and/or referrals to therapeutic resources. If their role was clearly defined by policy and practices within the HTC, social workers may be able to normalize the integration of mental health services into the regular routine of health treatment by asking questions related to mental health. This may provide an atmosphere where patients feel comfortable asking for help or ask for a referral to speak with someone.

Guilt and Shame of Seeking Services Because of "Strength Messaging/Resiliency of Community"

The sixth theme that emerged from participants is Guilt and Shame of Seeking Services because of "Strength Messaging"/Resiliency of Community. According to Andersen (1995), a family must perceive a need for services and be willing to respond to that need. Participants felt very strongly that this was one of the biggest barriers to utilization of mental health services. The community has a history of suffering, due to the hemophilia holocaust, grief, loss pain management and physical disabilities. They have rallied a spirit of resilience and due to new treatment options have lived full lives. The

ideal of resiliency has been a widespread taught message, to those currently diagnosed. Often the focus has been centered on managing the new and emerging therapies and the physical complications of managing the disease.

Participants shared that focusing on mental health has never been acceptable within their families. As the disease is generational and older sufferers have had to endure such hardships losing so many to death, managing deformities in joints, and pain, talking about mental and emotional challenges, stress, anxiety, depression has not been valued by most families. According to Andersen's (1995) behavioral model of utilization, families would need to perceive mental health as an important part of managing the disease. Caregivers are often "projecting" being strong for those who are managing the disease and often don't want to admit the stress and strain that comes along with caregiving.

Ease of Service Delivery

The last theme that emerged is Ease of Service Delivery. According to Andersen (1995), a family would be more likely to utilize services if the services take place where medical care occurs, and the health services are available to the families. The integration of mental health services at an HTC appointment would allow families to have the opportunity to address the emotional side of managing the chronic disease of hemophilia. Participants shared that if they had the opportunity to speak with a social worker about the challenges of caregiving while at an appointment, they would avail themselves of the service. It would also be an important change in the routine process of medical

intervention at HTCs if the social work role was to provide short-term support or referral services for mental health concerns.

Limitations of the Study

Research studies often face multiple limitations. Some of these limitations include methodological limitations, methods and instrument limitations and actual researcher limitations (Queiros et al., 2017). My study has limitations to be considered. The participants interviewed were all attending a national conference for families affected by hemophilia. These families were actively seeking education in reference to hemophilia therefore they could be perceived as the most empowered group of caregivers who were interviewed. This fact could be considered exclusionary and not a holistic representation of all hemophilia caregivers.

The interviews took place in a controlled setting of a conference, which restricted the organic nature of gathering participants in a random and generalized way. Although participants did not have to participate in the research study, and there was no active solicitation of participants besides flyers at the reception booth, caregivers of hemophiliacs outside of the conference were not interviewed; therefore, a broader perspective of diversity and experiences might have been omitted.

Another limitation of the study is that because hemophilia is in most cases genetically inherited, some of the caregivers may have also been diagnosed with hemophilia themselves. Because of this fact, it may be difficult to separate roles (hemophiliac, carrier, caregiver). Having multiple roles can provide a skewed response that may encompass aspects of caregiving such as one who is receiving care or will be

receiving care in the future. Based on this fact, I sought to ascertain the perceptions of the caregivers and mental health utilization were emphasized throughout the interview process.

Transferability is how the qualitative researcher demonstrates that the findings can be used in similar situations and with similar populations. As hemophiliacs are unique thereby their caregiving unique, transferring perceptions of utilization of mental health to other chronic illnesses may not be possible. In order to minimize limitations with transferability, focus was placed on the aspect of caregiving to persons with chronic illnesses.

As semi structured interviews were used as a data collection method, I may have missed data that could be collected in a focus group setting that may have revealed different perspectives influenced by group dynamics. Semi structured interviews may also lead to research bias. This limitation may come by my interview style and technique, or my personal perspective and lived experiences about the study topic. As I am a caregiver in this community, I was able to take thorough notes throughout the interview process that highlighted any personal feelings and thoughts that occurred while conducting the research. I utilized reflective journaling regularly to ensure I managed my own thoughts, feelings, and perceptions.

Another limitation of the study is that I was the sole researcher, and I was accountable for the entire project including the research design, data collection, analysis, and interpretation of the data. This allows for the potential of researcher bias. To accommodate that possibility, I relied on the tenants of trustworthiness throughout the

research process. I utilized reflective journaling to document thoughts and feelings to ensure that I was not influencing or adding to the participants responses.

Recommendations

Based on the findings of my study, and after these findings were examined using the theoretical perspective and my literature review, the following recommendations are being made for future research. There should be research on the impact of normalization of mental health for caregivers as a regular part of treatment in the hemophilia community. Participants revealed that ease of service and access to services is important. Researching a more holistic medical modality that includes a mental health discussion or screening as part of a regular routine doctor's visit at the local HTC or primary care office, could affect the utilization of mental health services within the community. Lastly, removing the shame of caregiver burnout at a routine office visit may affect the utilization of mental health services.

Normalizing the mental health discussion could also lead to research surrounding cultural and ethnic stigmas regarding mental health. Participants responses revealed evidence of closed family systems that did not discuss mental health based on cultural norms and stigmas. Focus remained centered on the physical impact of having hemophilia and the need to provide the caregiver role out of love for family without discussing the emotional impact of caregiving. As access to discuss the mental health, outside of family constraints and boundaries occur the opportunity to breakdown generational belief systems and value systems surrounding mental health may empower a broader thinking regarding utilization of mental health services.

Based on the literature review and the theoretical perspective, future research could investigate the impact of defining the role of the HTC staff, namely HTC social workers in the discussion surrounding mental health for caregivers. The current study showed that the role of the HTC social worker was unclear and ambiguous. Often HTC social workers were viewed as resource connectors and not clinical, licensed professionals who could provide screenings and/or interventions regarding mental health. The current study also showed that the level of involvement of the HTC social workers was not consistent from place to place and that the way they interact with patients and families being seen in the clinics was not uniformed. Research on defining standardized roles of the HTC social worker and standardizing practices for mental health interventions at HTC visits, could affect the utilization of mental health services in this community.

Lastly, research on the effects of standardizing policies and practices defining what is covered and included in routine medical visits for hemophiliacs and their families would be beneficial to hopefully remove the demographic and geographic barriers to receiving mental health care. Participants shared various inconsistencies in mental health service discussions, referrals, and interventions based on geographical location and overall demographics. Researching and updating practices for medical professionals in the hemophilia community could greatly impact utilization for caregivers.

Implications

The results of this study will affect social change on an individual, familial, organizational, and political level. Individually breaking down the stigma of mental health for caregivers of hemophiliacs can empower them to seek therapeutic services and

decrease feelings of guilt and shame in reference to needing help. Normalizing the mental impact providing care to someone with a lifelong chronic disease decreases feelings of isolation, helplessness, built up frustration and resentfulness. It also individually makes it alright to prioritize one's own mental health and taking care of self while also taking care of our loved ones.

The familial impact of this study addresses the issue of stigmatization of mental health based on cultural beliefs and attitudes. By normalizing this conversation in a non-threatening way such as at a routine HTC visit, families may not feel the pressure of breaking stereotypes and stigma within family structures but instead open a dialogue outside of the HTC visit as families may feel more open to bring up mental health in preparation for the visit or after the visit for follow up.

Organizationally, mental health can become part of a regular holistic approach to working with families affected by hemophilia. If the organizations on a local and national level that service the hemophilia community continue to emphasis the mind/body connection and build educational programming that emphasizes mental health, the medical community may be more inclined to see the value of including mental health as a routine part of care. Organizational change within the local and national level can set precedence for role model organizations that affectively address mental health within their communities evidenced by overall participation in community activities and volunteerism as well as an increase in overall mental wellness.

Societal, political, and policy change can establish macro practices for service delivery in the hemophilia community. Policies that dictate standardized practices for

hemophilia visits at HTC's will help decrease vacillating practices from practitioner to practitioner. Policy changes will assist with normalization of treating families as a holistic family system managing chronic disease by ensuring that access and ease of service delivery, outlined in the theoretical concept of this study, is addressed.

Conclusions

The current study explored the perceptions and lived experiences of caregivers in reference to utilization of mental health services. The study revealed that there are many barriers to accessing mental health services in the community for caregivers. Caregivers have been underutilizing mental health interventions based on multiple factors including cultural stigma, the need for mental health to be normalized in the community, and resiliency messaging.

There has been a hyperfocus placed on past traumas in this community which has built resilient families that are taught to be strong, address the medical management of the disease and ignore the emotional impact of managing a chronic illness. This normalization of mental health, especially caregiver stressors, helps to break down cultural beliefs, stereotypes, and attitudes as mental health becomes part of regular conversations. A unified effort from the local and national hemophilia community to continue to work towards the inclusion of mental health as a normal and routine part of managing the disease will hopefully impact the hemophilia community. It is hoped that caregivers will no longer have to deny the challenges of being caretakers for someone with a chronic disease but instead feel empowered to seek help to process the emotions that come from their caregiving role.

As the topic of mental health is newly introduced to this community, HTC's play a huge part in service delivery and exposure. On a macro level, service provision needs to be uniformed. Participants shared a lack of standardization of practices during routine visits regarding the interaction with social workers. According to Andersen (1995) utilization of health services takes place where a family receives their medical care, where conditions make health services available to the family and the family themselves perceive a need for the service. HTC's need to establish a platform of holistic care for the families they service by including mental health discussions, assessment, intervention, and referrals, especially utilizing the clinical social work staff.

Organizations that serve this population should educate and open a dialogue with their families that addresses the bio psychosocial effects of managing a chronic illness. The emphasis on family wellness including mental health service utilization lays the foundation for less caregiver stress and the ability to help families live as healthy lives as possible both mentally and physically while managing the chronic disease of hemophilia. Participants voiced a strong desire to utilize mental health services; but a great resistance to the stigma that comes along with it. As a community that has been rocked by tragedy, grief, and loss, the courage it will take to change the mindset of the overall community including those with cultural and ethnic barriers will be a great one, but this research emphasizes that the focus of mental health and caregiver wellness is a worthwhile investment.

References

American Association of Retired Persons Research Report. (2015). Caregiving in the

    U.S. https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-

    states-2015-report-revised.pdf

American Association of Retired Persons Research Report. (2020). Caregiving in the

    U.S. https://www.caregiving.org/wp-

    content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf

Akgul, N., & Ozdemir, L. (2015). Caregiver burden among primary caregivers of patients

    undergoing peripheral blood stem cell transplantation: A cross-sectional study.

    European Journal of Oncology Nursing, *18*(4), 372–377.

    https://doi.org/10.1016/j.ejon.2014.03.013

Andersen, R. (1995). Revisiting the behavioral model and access to medical care: Does it

    matter? *Journal of Health and Social Behavior, 36*(1), 1–10.

Andersen, R. & Newman, J. (2005). Societal and individual determinants of medical care

    utilization in the United States. *Journal of Population Health and Health Policy*,

    51(1), 95–124. https://doi.org/10.1111/j.1468-0009.2005.00428.x

Anderson, R. (1968). A behavioral model of families' use of health services. *Social

    Science Research Review*, *44*(25), xi–111.

Anderson, R. (1969). *A decade of health services. Social survey trends in use and

    expenditure*. Chicago Press.

Anxiety and Depression Association of America. (2020). *Caregiver mental health*.

    https://adaa.org/finding-help/caregivers

Arya, S., Wilton, P., Page, D., Boma-Fischer, L., Floros, G., Dainty, K. N., Winikoff, R., & Sholzberg, M. (2019) Healthcare provider perspectives on inequities in access to care for patients with inherited bleeding disorders. *PLoS One*, *15*(2), e0229099. https://doi.org/10.1371%2Fjournal.pone.0229099

Assari, S., Burgard, S., & Zivin, K. (2015). Long-term reciprocal associations between depressive symptoms and number of chronic medical conditions: Longitudinal support for Black-White health paradox. *Journal of Racial and Ethnic Health Disparities*, *2*(4), 589–597. https://doi.org/10.1007/s40615-015-0116-9

Attridge, M. (2019). A global perspective on promoting workplace mental health and the role of employee assistance programs. *American Journal of Health Promotion, 33*(4), 622–629. https://doi.org/10.1177%2F0890117119838101c

Babitsch, B., Gohl, D., & Von Lengerke, T. (2015). Re-revisiting Anderson's behavioral model of health services use: A systematic review of studies from 1998–2011. *Psycho-Social Medicine*, *9*, 200–212.

Baird, L. M. (2018). Conceptualization of the chronic care model: Implications for home care case manager practice. *Home Healthcare Now, 36*(6), 379–385. https://doi.org/10.1097/nhh.0000000000000699

Baur, N., & Hering, L. (2017). Combining ethnography and surveys mixed methods research designs beyond combining qualitative interviews with quantitative surveys. *Kolner Magazine of Sociology and Social Psychology, 69*, 387–414.

Benton, D., & Meyer, K. (2019). Healthcare providers can help to connect family caregivers to resources and supports. *Journal of the American Society on Aging, 3*, 43–47.

Berry, L. L., Dalwadi, S. M., & Jacobson, J. O. (2016). Supporting the supporters: What family caregivers need to care for a loved one with cancer. *American Society of Clinical Oncology, 13*(1), 35–42. https://doi.org/10.1200/jop.2016.017913

Bertamino, M., Riccardi, F., Banov, L., Svahn, J., & Molinari, A. C. (2017). Hemophilia care in the pediatric age. *Journal of Clinical Medicine*, *6*(5), 1–13. https://doi.org/10.3390%2Fjcm6050054

Berube, S., Mouillard, F., Amesse, C., & Sultan, S. (2016). Motivational techniques to improve self-care in hemophilia: The need to support autonomy in children. *BMC Pediatrics, 16*, 1–7. https://doi.org/10.1186/s12887-016-0542-9

Bioku, A. A., Ohaeri, J. U., Oluwaniyi, S. O., Olagunju, T. O., Chaimowitz, G. A., & Olagunju, A. T. (2020). Emotional distress among parent caregivers of adolescents with sickle cell disease: Association with patients and caregivers' variables. *Journal of Health Psychology,* 1–10. https://doi.org/10.1177/1359105320935986

Bouldin, E., Trivedi, R. B., Reiber, G. E., Rosland, A. M., Silverman, J. B., Krieger, J., & Nelson, K. M. (2017). Associations between having an informal caregiver, social support, and self-care among low-income adults with poorly controlled diabetes. *Chronic Illness, 13(4),* 239–250. https://doi.org/10.1177/1742395317690032

Bradley, E., McGraw, S., Curry, L., Buckser, A., King, K., Kasi, S., & Andersen, R. (2018). Expanding the Anderson model: The role of psychosocial factors in long-term care use. *Health Services Research*, *19*, 105–113. doi.org/10.1111/1475-6773.01053

Brown, S. E., Weisberg, D. F., & Sledge, W. H. (2016). Family caregiving for adults with sickle cell disease and extremely high hospital use. *Journal of Health Psychology*, *21*(12), 2893–2902. https://doi.org/10.1177%2F1359105315588215

Calthorpe, L., Baer, R., Chambers, B., Steurer, M., Shannon, M., Oltman, S., Karvonen, K., Rogers, E., Rand, L., Jelliffe-Pawlowski, L., & Pantell, M., (2021). The association between preterm birth and postpartum mental health care utilization among California birthing people. *American Journal of Obstetrics & Gynecology*, *104*(9), 1702–1709. https://doi.org/10.1016/j.ajogmf.2021.100380

Carlsen, K., Phan, B. L., Pittman, N., Benkov, K., Dubinsky, M. C., & Keefer, L. (2019). Coping among parents of teens with inflammatory bowel disease. *Gastroenterology Nursing, 42*(4), 342–350. https://doi.org/10.1097/sga.0000000000000374

Castaman, G., & Matino, D. (2019). Hemophilia A and B: Molecular and clinical similarities and differences. *Haematologica, 104*(9), 1702–1709.

Center for Disease Control and Prevention. (n.d.). *Diagnosis of hemophilia*. cdc.gov/ncbddd/hemophilia/diagnosis.html

Centers for Disease Control and Prevention. (2017a). *Data & statistics on hemophilia.*

https://www.cdc.gov/ncbddd/hemophilia/data.html#:~:text=In%20the%20United

%20States&text=Hemophilia%20A%20affects%201%20in,United%20States%20

is%20not%20known

Centers for Disease Control and Prevention. (2017b). www.cdc.gov

Chen, S. L. (2016). Economic costs of hemophilia and the impact of prophylactic

treatment on patient management. *The American Journal of Managed Care*,

22(5), S126–S133.

Childers, K. M. (2019). Synthesis of the literature: Variables influencing caregiver use or

non-use of supportive services. *SAGE Open Nursing, 5*, 1–12.

https://doi.org/10.1177/2377960819838411

Cobern, W. W., & Adams, B. A. J. (2020). *When interviewing: How many is enough?*

(EJ1249979). ERIC. https://files.eric.ed.gov/fulltext/EJ1249979.pdf

Creswell, J. W., & Poth, C. N. (2017). *Qualitative inquiry and research design: Choosing

among five approaches*. Sage Publications.

Cutter, S., Guelcher, C., Hunter, S., Rotellini, D., Dunn, S., & Cooper, D. L. (2019). Mild

severe hemophilia B impacts relationships of US adults and children with

hemophilia B and their families: Results from the B-HERO-S study. *Patient

Related Outcome Measures, 10*, 257–266.

https://dx.doi.org/10.2147%2FPROM.S214188

D'Angiolella, L. S., Cortesi, P. A., Rocino, A., Coppola, A., Hassan, H. J., Giampaolo, A., Solimeno, L. P., Lafranconi, A., Micale, M., Mangano, S., Crotti, G., Pagliarin, F., Cesana, G., & Mantovani, L. G. (2018). The socioeconomic burden of patients affected by hemophilia with inhibitors. *European Journal of Haematology, 101*, 435–456. https://doi.org/10.1111/ejh.13108

Daaleman, T. P., & Helton, M. R. (Eds.) (2018). *Chronic illness care: Principles and practice*. Springer.

Dai, N. T., Free, C., & Gendron, Y. (2019). Interview-based research in accounting 2000–2014: Informal norms, translation and vibrancy. *Management Accounting Research*, *42*, 26–38. https://doi.org/10.1016/j.mar.2018.06.002

Davidson, P. M., Abshire, M. A., Paull, G., & Szanton, S. L. (2018). Family caregivers: Important but often poorly understood. *Journal of Clinical Nursing*, *27*(23–24), 4242–4244. https://doi.org/10.1111/jocn.14654

Devlin, N., Shah, K., Feng, Y., Mulhern, B., & Van Hout, B. (2018). Valuing health-related quality of life: An Eq-5D-5L value set for England. *Health Economics*, *27*(1), 7–22. https://doi.org/10.1002/hec.3564

Diallo, A., Vang, C., Cuevas, S., & Vemu, S. M. (2019). Caregiving and stress: Family systems resources and external resources. *Journal of Rehabilitation, 85*(4), 4–13.

Dockery, L., Jeffery, D., Schauman, O., Williams, P., Farrelly, S., Bonnington, O., Gabbidon, J., Lassman, F., Szmukler, G., Thornicroft, G., Clement, S., & MIRIAD Study Group. (2015). Stigma-and non-stigma-related treatment barriers to mental healthcare reported by service users and caregivers. *Psychiatry Research*, *228*(3), 612–619. https://doi.org/10.1016/j.psychres.2015.05.044

Eagle, D. E., Hybels, C. F., & Proeschold-Bell, R. J. (2019). Perceived social support, received social support, and depression among clergy. *Journal of Social & Personal Relationships*, *36*(7), 2055–2073. https://doi.org/10.1177%2F0265407518776134

Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: A literature review. *American Journal of Health Education, 46*, 357–367. https://doi.org/10.1080/19325037.2015.1099482

El-Masri, M. M. (2017). Non-probability sampling. *The Canadian Nurse*, *113*(3), 17.

Fernández, R. M., Peciña, A., Sánchez, B., Lozano-Arana, M. D., García-Lozano, J. C., Pérez-Garrido, R., Nuñez, R., Borrego, S., & Antiñolo, G. (2015). Experience of preimplantation genetic diagnosis for hemophilia at the University Hospital Virgen Del Rocio in Spain: Technical and clinical overview. *BioMed Research International*, 1–8. https://doi.org/10.1155/2015/406096

Ferrell, B., & Wittenberg, E. (2017). A review of family caregiving intervention trials in oncology. *A Cancer Journal for Clinicians, 67*, 318–325. https://doi.org/10.3322/caac.21396

Finucane, A. M., Lugton, J., Kennedy, C., & Spiller, J. A. (2016). The experiences of

    caregivers of patients with delirium, and their role in its management in palliative

    care settings: An integrative literature review. *Psycho-Oncology, 26*(3), 291–300.

    https://doi.org/10.1002/pon.4140

Friedman, E. M., Trail, T. E., Vaughan, C. A., & Tanielian, T. (2018). Online peer

    support groups for family caregivers: Are they reaching the caregivers with the

    greatest needs? *Journal of the American Medical Informatics Association, 25*(9),

    1130–1136. https://doi.org/10.1093/jamia/ocy086

Fu, F., Chen, Y. Y., Li, Q., & Zhu, F. (2018). Varieties of home among family caregivers

    of patients with lymphoma. *Qualitative Health Research, 28*(13), 2048–2058.

    https://doi.org/10.1177%2F1049732318779051

Geng, H. M., Chuang, D. M., Yang, F., Yang, Y., Liu, W. M., Liu, L. H., & Tian, H. M.

    (2018). Prevalence and determinants of depression in caregivers of cancer

    patients: A systematic review and meta-analysis. *Medicine, 97,* 1–8.

    https://doi.org/10.1097/md.0000000000011863

Gerain, P., & Zech, E. (2019). Informal caregiver burnout? Development of a theoretical

    framework to understand the impact of caregiving. *Frontiers in Psychology, 10,*

    1–13. https://doi.org/10.3389/fpsyg.2019.01748

Gringeri, A., Berntorp, E., Von Mackensen, S., Eichler, H., Holstein, K., Khair, K., &

    Schramm, W. (2016). How health-related quality of life (Hrqol) in hemophilia

    patients can be affected by already a single bleed: OR03. *Hemophilia*, *14*.

Hagedoorn, E. I., Paans, W., Jaarsma, T., Keers, J. C., van der Schans, C., & Luttik, M. L. (2017). Aspects of family caregiving as addressed in planned discussions between nurses, patients with chronic diseases and family caregivers: A qualitative content analysis. *BMC Nursing, 16,* 1–10. https://doi.org/10.1186/s12912-017-0231-5

Hamovitch, E., Acri, M., & Gopalan, G. (2019). Relationships between the working alliance, engagement in services, and barriers to treatment for female caregivers with depression. *Child Welfare, 97*(3), 23–40.

Hawken, T., Turner-Cobb, J., & Barnett, J. (2018). Coping and adjustment in caregivers: A systematic review. *Health Psychology Open,* 1–10. https://dx.doi.org/10.1177%2F2055102918810659

Hemophilia Federation of America. (2020). *About HFA research*. https://www.hemophiliafed.org/for-patient-families/participate-in-research/about-hfa-research/

Hemophilia Federation of America. (n.d.). www.hemophiliaFed.org

Hepburn, K., & Siegel, E. O. (2020). New directions to advance family caregiving research. *The Gerontological Society of America, 60*, S1–S4. https://doi.org/10.1093/geront/gnz182

Hermans, C., Jennings, I., Dolan, G., Windyga, J., Lobet, S., Rodriguez-Merchan, E., Dario Di Minno, M. N., Jiménez-Yuste, V., & O'Mahony, B. (2015). Managing hemophilia for life 5th hemophilia global summit. *European Journal of Hematology*, *95*(78), 1–25. doi.org/10.1111/ejh.1261

Hong, M., & Harrington, D. (2016). The effects of caregiving resources on perceived health among caregivers. *Health & Social Work, 41*(3), 155–163. https://dx.doi.org/10.1093%2Fhsw%2Fhlw025

Hou, W. K., Lau, K. M., Ng, S. M., Lee, T. M., Cheung, H. Y., Shum, T. C., & Cheng, A. C. (2016). Psychological detachment and savoring in adaptation to cancer caregiving. *Psycho-Oncology, 25,* 839–847. https://doi.org/10.1002/pon.4019

Howrey, M. M. (2018). Health sciences library outreach to family caregivers: A call to service. *Journal of the Medical Library Association*, *106*(2), 251–258. https://doi.org/10.5195/jmla.2018.390

Isaac, C. A., Mota, N., Medved, M., Katz, L. Y., Elias, B., Mignone, J., Munro, G., & Sareen, J. (2020). Conceptualizations of help-seeking for mental health concerns in First Nations communities in Canada: A comparison of fit with the Andersen behavioural model. *Transcultural Psychiatry*, *57*(2), 346–362. https://doi.org/10.1177/1363461520906978

Javalkar, K., Rak, E., Phillips, A., Haberman, C., Ferris, M., & Van Tilburg, M. (2017). Predictors of caregiver burden among mothers of children with chronic conditions. *Children (Basel)*, *4*(5), 39–42. https://dx.doi.org/10.3390%2Fchildren4050039

Jayakrishnan, T., Shah, D., & Mewawalla, P. (2019). Hemophilia C: A case report with updates on diagnosis and management of a rare bleeding disorder. *Journal of Hematology*, *8*(3), 144–147. https://dx.doi.org/10.14740%2Fjh522

John, M. J., Kakkar, N., Matthew, A., Phillip, C. C., Tanuja, T., Kaur, R., Singh, J., & Dunkley, S. (2017). Hemophilia treatment center: A stratification model for developing countries: A pilot study from India. *Journal of Health and Research*, *4*(4), 253–258. http://dx.doi.org/10.4103/cjhr.cjhr_39_17

Johnson, C. N.tr (2019). *Getting through the dark days of caregiving*. Xlibris.

Joo, H., Fang, J., Losby, J., & Wang, G. (2015). Cost of informal caregiving for patients with heart failure. *American Heart Journal, 169*(1), 142–148. https://doi.org/10.1016/j.ahj.2014.10.010

Kegler, M. C., Raskind, I. G., Comeau, D. L., Griffith, D. M., Cooper, H. L. F., & Shelton, R. C. (2019). Study design and use of inquiry frameworks in qualitative research published in Health Education & Behavior. *Health Education & Behavior*, *46*(1), 24–31. https://doi.org/10.1177/1090198118795018

Kelley-Quon, L. I. (2018). Surveys: Merging qualitative and quantitative research methods. *Seminars in Pediatric Surgery*, *27*(6), 361–366. https://doi.org/10.1053/j.sempedsurg.2018.10.007

Kennedy, D. M. (2016). Is it any clearer? Generic qualitative inquiry and the VSAIEEDC model of data analysis. *Qualitative Report*, *21*(8), 1369–1379. https://doi.org/10.46743/2160-3715/2016.2444

Kent, E., Rowland, J., Northhouse, L., Litzelman, K., Chou, W., Shelburne, N., Timura, C., O'Mara, A., & Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, *122*, 1987–1995. https://doi.org/10.1002/cncr.29939

Keshavjee, S., Weiser, S., & Kleinman, A. (2017). Medicine betrayed: Hemophilia

    patients and HIV in the US. *Social Science & Medicine*, *53*(8), 1081–1094.

    doi.org/10.1016/S0277-9536(00)00403-2

Ketcher, D., Otto, A. K., & Reblin, M. (2020). Caregivers of patients with brain

    metastates: A description of caregiving responsibilities and psychosocial well-

    being. *Journal of Neuroscience Nursing, 52(3),* 112–116.

    https://doi.org/10.1097/jnn.0000000000000500

Khair, K., & Chaplin, S. (2016). The impact on parents of having a child with

    haemophilia. *The Journal of Haemophilia Practice*, *3*(2), 1–11.

    https://doi.org/10.17225/jhp00075

Khanna, A., Prabhakaran, A., Patel, P., Ganjiwale, J., & Nimbalkar, S. (2015). Social,

    psychological and financial burden on caregivers of children with chronic illness:

    A cross-sectional study. *The Indian Journal of Pediatrics*, *82*(11), 1006–1011.

    https://doi.org/10.1007/s12098-015-1762-y

Kim, H., Lee, S., Cheon, J., Hong, S., & Chang, M. (2018). A comparative study to

    identify factors of caregiver burden between baby boomers and post baby

    boomers: A secondary analysis of a US online caregiver survey. *BMC Public

    Health*, *18*, 1–9. https://doi.org/10.1186/s12889-018-5488-4

Kinchen, E. (2014). Development of a quantitative measure of holistic nursing care.

    Journal of Holistic Nursing, *33*(3), 238–246. doi.org/10.1177/0898010114563312

Kind, V. (2018). *The caregiver's path to compassionate decision making: Making

    choices for those who can't*. Education and Mediation, Inc.

Kirp, D. (2016). Look back in anger: Hemophilia and AIDS activism in the international tainted-blood crisis. *Journal of Comparative Policy Analysis: Research and Practice*, *1*(2), 177–202. https://doi.org/10.1080/13876989908412623

Klassen, A., Gulati, S., Granek, L., Rosenberg-Yunger, Z., Watt, L., & Sung, L. (2016). Understanding the health impact of caregiving: A qualitative study of immigrant parents and single parents of children with cancer. *Quality of Life Research*, *21*(9), 1595–1605. https://doi.org/10.1007/s11136-011-0072-8

Kriseman, N. L. (2015). *The mindful caregiver: Finding ease in the caregiving journey*. Rowman & Littlefield Publishers.

Kumar, S., Mishra, S., Panwar, A., Bhagchandani, D., Aneja, G., Verma, N., & Kumar, P. (2016). Clinical profile of hemophilia patients and assessment of their quality of life in Western Uttar Pradesh, India: An observational study. *Medical Journal DY Patil University*, *9*, 320–324.

Kumari, R., Kohli, A., Malhotra, P., Grover, S., & Khadwal, A. (2019). Burden of caregiving and its impact in the patients of acute lymphoblastic leukaemia. *Industrial Psychiatry Journal, 27*(2), 249–258. https://dx.doi.org/10.4103%2Fipj.ipj_75_18

Lee, K. C., Yiin, J. J., & Chao, Y. F. (2016). Development of an experience-based caregiver burden scale in advanced cancer. *Cancer Nursing*, *39*(1), 12–19. https://doi.org/10.1097/ncc.0000000000000230

Lee, K. C., Yiin, J. J., Lin, P. C., & Lu, S. H. (2015). Sleep disturbances and related factors among family caregivers of patients with advanced cancer. *Psycho-Oncology, 24*, 1632–1638. https://doi.org/10.1002/pon.3816

Leme Fleury, M. T., Marchiori Pacheco, L., Ribeiro Fernandes, K., & Leão, P. (2018). Qualitative inquiry and research design: Choosing among five approaches. *Revista de Administração de Empresas*, *58*(1), 101. https://doi.org/10.1177%2F1524839915580941

Mancuso, M. E., & Cannavò, A. (2015). Immune tolerance induction in hemophilia. *Clinical Investigation, 5*(3), 321–335. https://doi.org/10.1016/j.blre.2018.02.003

May, C. R., Cummings, A., Myall, M., Harvey, J., Pope, C., Griffiths, P., Roderick, P., Arber, M., Boehmer, K., Mair, F. S., & Richardson, A. (2016). Experiences of long-term life-limiting conditions among patients and carers: What can we learn from a meta-review of systematic reviews of qualitative studies of chronic heart failure, chronic obstructive pulmonary disease and chronic kidney disease? *BMJ Open*, *6*, 1–15. https://doi.org/10.1136/bmjopen-2016-011694

Mazepa, M. A., Monahan, P. E., Baker, J. R., Riske, B. K., & Soucie, J. M. (2016). Men with severe hemophilia in the United States: Birth cohort analysis of a large national database. *Blood, The Journal of the American Society of Hematology*, *127*(24), 3073–3081.

McGarrigle, J. G. (2018). Getting in tune through arts-based narrative inquiry. *Iris Educational Studies*, *37*(2), 275–293. https://doi.org/10.1080/03323315.2018.1465837

McLaughlin, J., Munn, J., Anderson, T., Lambing, A., Tortella, B., & Witkop, M. (2017). Predictors of quality of life among adolescents and young adults with a bleeding disorder. *Health & Quality of Life Outcomes*, 151–159. doi.org/10.1186/s12955-017-0643-7

Meeks, S. L., & Batsuli, G. (2016). Hemophilia and inhibitors: Current treatment options and potential new therapeutic approaches. *Hematology*, *2016*(1), 657–662.

Miravitlles, M., Pena-Longobardo, L., Oliva-Moreno, J., & Hidalgo-Vega, A. (2015). Caregivers' burden in patients with COPD. *International Journal of Chronic Obstructive Pulmonary Disease*, *10*, 347–356. https://doi.org/10.2147/COPD.S76091\

Mosher, C., Given, B., & Ostroff, J. (2015). Barriers to mental health services use among distressed family caregivers of lung cancer patients. *European Journal of Cancer Care*, *24*(1), 50–59. https://doi.org/10.1111/ecc.12203

Mustafa, M., Moktar, A., Hayati, F., Illzam, E., Azizan, N., & Sharifa, A. (2016). Hemophilia a genetic disorder: Diagnosis, treatment and prognosis. *IOSR Journal of Dental and Medical Sciences, 15*(10), 85–89.

National Alliance for Caregiving & American Association of Retired Persons. (2020). *Caregiving in the U.S.* https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf

Nissen, K. G., Trevino, K., Lange, T., & Prigerson, H. G. (2016). Family relationships and psychosocial dysfunction among family caregivers of patients with advanced cancer. *Journal of Pain and Symptom Management, 52*(6), 841–849. https://doi.org/10.1016/j.jpainsymman.2016.07.006

Nissim, R., Hales, S., Zimmermann, C., Deckert, A., Edwards, B., & Rodin, G. (2017). Supporting family caregivers of advanced cancer patients: A focus group study. *Interdisciplinary Journal of Applied Family Studies*, *66*(5), 867–879. https://doi.org/10.1111/fare.12291

Nossair, F., & Thornburg, C. D. (2018). The role of patient and healthcare professionals in the era of new hemophilia treatments in developed and developing countries. *Therapeutic Advances in Hematology, 9*(8), 239–249. https://dx.doi.org/10.1177%2F2040620718784830

O'Mahony, B., Dolan, G., Nugent, D., & Goodman, C. (2018). Patient-centered value framework for haemophilia. *Haemophilia*, *24*(6), 873–879. https://doi.org/10.1111/hae.13456

Okide, C. C., Eseadi, C., Koledoye, U. L., Mbagwu, F., Ekwealor, N. E., Okeke, N. M., Osilike, C., & Okeke, P. M. (2019). Challenges facing community-dwelling adults with hemophilia: Implications for community-based adult education and nursing. *Journal of International Medical Research, 48*(1), 1–11. https://doi.org/10.1177/0300060519862101

Oksuz, E., Baris, N., Arslan, F., & Ates, M. (2017). Psychiatric symptom levels and burden care of caregivers of patients receiving chemotherapy. *Journal of Anatolian Investigation*, *7*(1), 34–40.

Oosterveld, P., Vorst, H. C. M., & Smits, N. (2019). Methods for questionnaire design: A taxonomy linking procedures to test goals. *Quality of Life Research*, *28*(9), 2501–2512. https://doi.org/10.1007/s11136-019-02209-6

Ormel, I., Law, S., Abbott, C., Yaffe, M., & Saint-Cyr, M. (2017). When one is sick and two need help: Caregivers' perspectives on the negative consequences of caring. *Patient Experience Journal, 4*(1), 66–78. https://doi.org/10.35680/2372-0247.1179

Page, D. (2019). Comprehensive care for hemophilia and other inherited bleeding disorders. *Transfusion and Apheresis Science*, *58*(5), 565–568. https://doi.org/10.1016/j.transci.2019.08.005

Palla, R., Peyvandi, F., & Shapiro, A. D. (2015). Rare bleeding disorders: Diagnosis and treatment. *Blood*, *125*(13), 2052–2061. https://doi.org/10.1182/blood-2014-08-532820

Pendergrass, J. C., Targum, S. D., & Harrison, J. E. (2018). Cognitive impairment associated with cancer: A brief review. *Innovations in Clinical Neuroscience*, *15*, 36–44.

Peng, J., Yang, H., Fu, G., Zhao, X., Li, X., & Chen, F. (2017). A study of the stressors and coping behaviors of parents of Chinese hemophilic children. *Journal of Child Health Care*, *21*(2), 212–221. https://doi.org/10.1177/1367493517705736

Percy, W., Kostere, K., & Kostere, S. (2015). Generic qualitative research in psychology. *The Qualitative Report*, *20*(2), 76–85. https://doi.org/10.46743/2160-3715/2015.2097

Phillips, K., Morrison, K., Anderson, R., & Aday, L. (2018). Understanding the context of healthcare utilization: Assessing environmental and provider-related variables in the behavioral model of utilization. *Health Services Research*, *33*(1), 571–596.

Ploeg, J., Biehler, L., Willison, K., Hutchison, B., & Blythe, J. (2016). Perceived support needs of family caregivers and implications for a telephone support service. *Canadian Journal of Nursing Research*, *33*(2), 43–61.

Poti, S., Palareti, L., Cassis, F. R., & Brondi, S. (2019). Health care professionals dealing with hemophilia: Insights from the international qualitative study of the HERO initiative. *Journal of Multidisciplinary Healthcare*, *12*, 361–375. https://doi.org/10.2147/jmdh.s201759

Potter, A. (2018). Factors associated with caregivers' use of support services and caregivers' nonuse of services sought. *Journal of Aging & Social Policy*, *30*(2), 155–172. https://doi.org/10.1080/08959420.2017.1414539

Qian, W., Lam, T. T., Lam, H. H., Li, C. K., & Cheung, Y. T. (2019). Telehealth interventions for improving self-management in patients with hemophilia: Scoping review of clinical studies. *Journal of Medical Internet Research*, *21*(7), 1–15. https://doi.org/10.2196/12340

Queiros, A., Faria, D., & Almeida, F. (2017). Strengths and Limitations of Qualitative and Quantitative Research Methods. *European Journal of Education Studies, 3(9), 19-38.*

Raskind, I. G., Shelton, R. C., Comeau, D. L., Cooper, H. L. F., Griffith, D. M., & Kegler, M. C. (2019). A review of qualitative data analysis practices in health education and health behavior research. *Health Education & Behavior*, *46*(1), 32–39. https://doi.org/10.1177/1090198118795019

Reblin, M., Small, B., Jim, H., Weimer, J., & Sherwood, P. (2017). Mediating burden and stress over time: Caregivers of patients with primary brain tumor. *Psycho-Oncology*, *27*, 607–612. https://doi.org/10.1002/pon.4527

Ringer, T., Hazzan, A. A., Agarwal, A., Mutsaers, A., & Papaioannou, A. (2017). Relationship between family caregiver burden and physical frailty in older adults without dementia: A systematic review. *Systematic Reviews*, *6*(1), 1–12. https://dx.doi.org/10.1186%2Fs13643-017-0447-1

Rosa, F., Bagnasco, A., Aleo, G., Kendall, S., & Sasso, L. (2017). Resilience as a concept for understanding family caregiving of adults with chronic obstructive pulmonary disease (COPD): An integrative review. *Nursing Open, 4*, 61–75. https://dx.doi.org/10.1002%2Fnop2.63

Schulz, R., & Eden, J. (2016). Older adults who need caregiving and the family caregivers who help them. In *Families Caring for an aging America*. https://www.ncbi.nlm.nih.gov/books/NBK396397/

Schwartz, C. E., Zhang, J., & Su, J. (2019). Longitudinal validity of the hemophilia caregiver impact measure. *Quality of Life Research*, 1–10. https://doi.org/10.1007/s11136-019-02168-y

Schwartz, C., Powell, V., & Eldar-Lissai, A. (2017). Measuring hemophilia caregiver burden: Validation of the hemophilia caregiver impact measure. *Quality of Life Research*, *26*, 2551–2562. https://doi.org/10.1007/s11136-017-1572-y

Shenton, A. K. (2015). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63–75. http://dx.doi.org/10.3233/EFI-2004-22201

Shi, L., & Singh, D. A. (2017). *Delivering health care in America: A systems approach*. Jones & Bartlett Learning.

Shidhaye, R., Shrivastava, S., Murhar, V., Samudre, S., Ahuja, S., & Ramaswamy, R. (2015). Development and piloting of a plan for integrating mental health in primary care in Sehore District, Madhya Pradesh, India. *British Journal of Psychiatry*, *16*(1), 42–52. https://doi.org/10.1192/bjp.bp.114.153700

Sidonio, R., Holot, N., & Cooper, D. L. (2017). Evaluating the psychosocial impact of hemophilia B: The bridging hemophilia B experiences, results and opportunities into solutions (B-HERO-S) study. *European Journal of Haematology*, *98*, 3–4. https://doi.org/10.1111/ejh.12853

Srivastava, G., Tripathi, R., Tiwari, S., Singh, B., & Tripathi, S. (2016). Caregiver burden and quality of life of key caregivers of patients with dementia. *Indian Journal of Psychological Medicine*, *38*(2), 133–136. https://doi.org/10.4103/0253-7176.178779

Stjernsward, S., & Hansson, L. (2020). A qualitative study of caregivers' experiences, motivation and challenges using a web-based mindfulness intervention. *Community Mental Health Journal*, *56*, 416–425. https://dx.doi.org/10.1007%2Fs10597-019-00477-7

Sullivan, A. B., & Miller, D. (2015). Who is taking care of the caregiver? *Journal of Patient Experience*, *2*(1), 7–12. https://dx.doi.org/10.1177%2F237437431500200103

Sumedha, A., Wilton, P., Page, D., Boma-Fischer, L., Floros, G., Winikoff, R., Teitel, J., Dainty, K., & Sholzberg, M. (2019). "Everything was blood when it comes to me." Understanding the lived experiences of women with inherited bleeding disorders. *Journal of Thrombosis and Haemostasis*, *151*(20), 67–75. https://doi.org/10.1111/jth.15102

Swartz, K., & Collins, L. G. (2019). Caregiver care. *American Family Physician, 99*(11), 699–706.

Teich, J., Ali, M., & Ryan, M. (2017). Utilization of mental health services by veterans living in rural areas. *Journal of Rural Health*, *33*(3), 235–339. https://doi.org/10.1111/jrh.12221

Tingey, J. L., Lum, J., Morean, W., Franklin, R., & Bentley, J. A. (2020). Healthcare coverage and utilization among caregivers in the United States: Findings from the 2015 Behavioral Risk Factor Surveillance System. *Rehabilitation Psychology, 65*(1), 63–71. https://doi.org/10.1037/rep0000307

U. S. Department of Health and Human Services: Center for Disease Control and Prevention. (n.d.). *Hemophilia Facts*. www.cdc.gov/ncbddd/hemophilia

Versey, H. S. (2017). Caregiving and women's health: Toward an intersectional approach. *Women's Health Issues*, *27*, 117–120. https://doi.org/10.1016/j.whi.2017.01.009

Waters, D. M., Olson, A. M., Foushee, N., Shelef, D. Q., Stewart, L., Yadav, K., Horn, I. B., Streisand, R., Rand, C., & Teach, S. J. (2017). Perceptions of stress, coping, and intervention preferences among caregivers of disadvantaged children with asthma. *Journal of Child and Family Studies*, *26*, 1622–1634. https://doi.org/10.1007/s10826-017-0670-3

Weinbaum, R. K., & Onwuegbuzie, A. J. (2016). Getting more out of your interview data: Toward a framework for debriefing the transcriber of interviews. *Journal of Educational Issues*, *2*(1), 248–264. https://doi.org/10.5296/jei.v2i1.9216

Wesstesson, L. M., Sparud-Lundin, C., Baghaei, F., Khair, K., von Mackensen, S., Mora, M. A., & Wallengren, C. (2019). Burden on parents of children with haemophilia: The impact of sociodemographic and child's medical condition. *Journal of Clinical Nursing*, *28*, 4077–4086. https://doi.org/10.1111/jocn.15003

Wiley, R. E., Khoury, C. P., Snihur, A. W., Williams, M., Page, D., Graham, N., Laudenbach, L., Milne-Wren, C., & Stoffman, J. M. (2019). From the voices of people with haemophilia A and their caregivers: Challenges with current treatment, their impact on quality of life and desired improvements in future therapies. *Haemophilia*, *25*, 433–440. https://doi.org/10.1111/hae.13754

Yang Yang, Pankow, J., Swan, H., Willett, J., Mitchell, S. G., Rudes, D. S., & Knight, K. (2018). Preparing for analysis: A practical guide for a critical step for procedural rigor in large-scale multisite qualitative research studies. *Quality & Quantity*, *52*(2), 815–828. https://doi.org/10.1007/s11135-017-0490-y

Yeoman, G., Furlong, P., Seres, M., Binder, H., Chung, H., Garzya, V., & Jones, R. R. (2017). Defining patient centricity with patients for patients and caregivers: A collaborative endeavour. *BMJ Innovations*, *3*(2), 76–83.

Yeung, C. H., Santesso, N., Pai, M., Kessler, C., Key, N. S., Makris, M., Navarro-Ruan, T., Soucie, J. M., Schunemann, H. J., & Iorio, A. (2016). Care models in the management of haemophilia: A systematic review. *Haemophilia*, *22*(3), 3–40. https://dx.doi.org/10.1111%2Fhae.13000

Yiin, J. J., Lee, K. C., Lu, S. H., & Chao, Y. F. (2015). The burden of caregiving and sleep disturbance among family caregivers of advanced cancer patients. *Cancer Nursing*, *38*(4), E10–E18. https://doi.org/10.1097/ncc.0000000000000166

Zand, A., Kim, B. J., van Deen, W. K., Stokes, Z., Platt, A., O'Hara, S., Khong, H., &

    Hommes, D. W. (2020). The effects of inflammatory bowel disease on caregivers:

    Significant burden and loss of productivity. *BMC Health Services Research*, *20*,

    1–10. https://dx.doi.org/10.1186%2Fs12913-020-05425-w

Zhou, Z. Y., Koerper, M. A., Johnson, K. A., Riske, B., Baker, J. R., Ullman, M., Curtis,

    R. G., Poon, J. L., Lou, M., & Nichol, M. B. (2015). Burden of illness: Direct and

    indirect costs among persons with hemophilia A in the United States. *Journal of*

    Medical Economics, *18*(6), 457–69.

    https://doi.org/10.3111/13696998.2015.1016228

Appendix A: Participant Interview Questions

I will ask the following open-ended questions to all participants:

1.   Describe for me in your own words your caregiving experience.

2.   What are some of the challenges you have had to manage providing care to your

loved one with hemophilia?

3.   How do you know when you are stressed or anxious?

4.   How do you typically manage when you are experiencing stress or anxiety?

5.   What are your thoughts about seeking counseling and mental health services?

6.   What are some of the barriers you perceive about seeking mental health

resources?

7.   What role do you see a mental health professional playing in helping you manage

your stress or anxiety due to caregiving?

8.   What do you believe the primary role of the HTC social worker entails?

Appendix B: Recruitment Flyer

;
Mental health is important to everyone; especially those with a chronic medical diagnosis
Are you a caretaker for someone with Hemophilia?

PARTICIPANTS NEEDED
To be interviewed for a study on mental health utilization in the Hemophilia Community

If you or someone you know:
- ➢ **Is a caretaker for someone with Hemophilia**
- ➢ **Is willing to be interviewed and recorded for no more than 90 minutes.**
- ➢ **Is not suicidal, depressed, being treated for PTSD or have active substance abuse.**

I am doing research for my doctoral program at Walden University. The purpose of the research is to listen and learn about your lived experiences as a caretaker in the Hemophilia Community.

Participants will be given a $25 Gift Card for Participating in the Study
Interviews can be conducted in person (if local) and virtually based on CDC recommendations.

Please contact me today:
Ph.D Candidate
Walden University
Email Address:

Appendix C: Participant Selection Demographic Questionnaire

Interview Questions for: Caretakers of Hemophiliacs: 60 -90 min

1.   Please provide your contact information.

____Email_____

____Phone_____

2.   Are you currently a caregiver for someone diagnosed with hemophilia?

(Please Check) _____Yes or ____No

3.   Have you ever been diagnosed as having a bleeding disorder?

(Please Check) _____Yes or ____No

4.   What is your age? _____

5.   What is your identified gender? _____

6.   What state do you reside in? _____

7.   Which of the following best represents your racial or ethnic heritage?

Choose all that apply:

__Non-Hispanic White or Euro-American

__Black, Afro-Caribbean, or African American

__Latino or Hispanic American

__East Asian or Asian American

__South Asian or Indian American

__Middle Eastern or Arab American

__Native American or Alaskan Native

__Other: _____

8.   Would you be willing to participate in an interview regarding your caregiving experiences? (Please Check) _____Yes or ____No