CAREGIVER AND PROFESSIONAL EXPERIENCES WITH SOCIAL-EMOTIONAL LEARNING IN THE CLASSROOM FOR YOUNG CHILDREN WITH INHERITED BLEEDING DISORDERS: A PHENOMENOLOGICAL STUDY

by

Christy L. Miller

Liberty University

A Dissertation Presented in Partial Fulfillment
Of the Requirements for the Degree
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APPROVED BY:

Dr. Rachel N. Hernandez, Ed.D, Committee Chair

Dr. Lisa Stone, Ed.D, Committee Member

Abstract

The purpose of this transcendental phenomenology is to explore caregivers’ and professionals’ experiences of supporting young children’s social-emotional learning in the classroom and its impact on early education in Western Pennsylvania. The theory guiding this study is Bowlby’s theory on attachment as it focuses on how positive interactions with caregivers boost the psychological health and feelings of security that lead to expansion of positive social-emotional relationships with others. This qualitative research design was completed by interviewing eight caregivers and three professionals of young children with inherited bleeding disorders who are members of the local chapter of the Hemophilia Federation of America as well as document analysis and focus groups. Purposive sampling was utilized for this study design due to the nature of the research being conducted, specifically homogenous sampling due to seeking the experiences of specific groups of people. Constant comparison was utilized throughout the process to aid data collection. Thematic synthesis and member checking then occured to create common themes and assist in developing a hypothesis around social-emotional learning for young children with inherited bleeding disorders

Keywords: social-emotional learning, inherited bleeding disorders, medically complex, early childhood

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List of Abbreviations

American Academy of Pediatrics (AAP)

Collaborative on Social-Emotional Learning (CASEL)

Hemophilia Growth and Development Study (HGDS)

Hemophilia Treatment Center (HTC)

Hemophilia Experiences, Results, and Opportunities study (HERO)

Individuals with Disabilities Act (IDEA)

National Center on Pyramid Model Innovations (NCPMI)

Positive behavior interventions and supports (PBIS)

Von Willebrand disease (vWD)

CHAPTER ONE: INTRODUCTION

Overview

Young children with inherited bleeding disorders are a rare and complex group. This group has virtually no research base behind them due to the rare nature of inherited bleeding disorders. The range of bleeding disorders can be mild to severe, resulting in a diagnosis that may indicate anything from prophylactic treatment multiple times weekly to only treatment after trauma (Palla et al., 2015, Saes et al., 2020). Social-emotional development is considered critical in early childhood development and education (Cosso et al., 2021; Cressey, 2019), however, young children with inherited bleeding disorders may regularly experience events that would negatively impact their social-emotional development and education especially for children on the more severe end of the range of inherited bleeding disorders. The purpose of this phenomenological study was to explore the caregiver and professional experiences of what is needed to support these children in the classroom and how this may impact early learning. This chapter will describe the problem in detail, including the background, historical, social and theoretical contexts. It will further discuss the importance of the problem, purpose, and significance of the study. Research questions and definitions will be outlined in order to introduce the idea for this research.

Background

Social-emotional development is arguably one of the most important aspects of early childhood development and education, with the potential to impact everything from academics to mortality (Cressey, 2019; Hammer et al., 2018; Kern & Friedman, 2008). Cressey (2019) called social emotional learning the cornerstone of all other learning. For young children with inherited bleeding disorders, social-emotional development could be impacted by a variety of factors including trauma experienced during medical procedures and exposure to adverse childhood events (ACES) (Becker-Blease, 2017; Bethell et al., 2017; Matlin et al., 2019; Spehr et al., 2019). Young children with inherited bleeding disorders may experience routine medical procedures at a higher frequency than typical children, including regular blood draws, intravenous line placements administered by their parents, and more frequent hospitalizations (Saes et al., 2020). These could all lead to concerns with trauma, mistrust of the caregiver, and long-term impacts to social-emotional development and education (Becker-Blease, 2017; Bethell et al., 2017; Matlin et al., 2019; Spehr et al., 2019).

Historical Context

There are limited studies on young children with inherited bleeding disorders, and of the research that has been conducted, the focus has been on the impacts to the family (DeKoven et al., 2014; Khair & Pelentsov, 2019). Further, much of the available research is outdated. The only available research regarding social-emotional development and those living with bleeding disorders evaluates the impact for adults and was published in 2014 (Cassis et al., 2014). There is no documented research on how inherited bleeding disorders impact the education of young children, particularly regarding their social-emotional development which makes it difficult to establish historical context for this issue. While there is no historical information regarding children with inherited bleeding disorders and their social-emotional development specifically, one can examine related themes to establish some context for the importance of this matter.

There is some research available on the social-emotional development and impacts on the education of young children who are medically complex, which is a category that young children with inherited bleeding disorders fit (Clancy et al., 2020; Hammer et al., 2018; Kem & Friedman, 2008; Taft et al., 2020). However, these other disorders, such as congenital heart disease and gastroparesis, have little in common with inherited bleeding disorders, so it is unclear how much of this research can really be generalized to the population of young children with inherited bleeding disorders (Clancy et al., 2020; Taft et al., 2020). Additionally, this information is not necessarily historical in nature again due to the limited research available on this subject. This research does show that children who are medically complex, a category which young children with inherited bleeding disorders fall into, are at an elevated risk of developing concerns with social-emotional development that would impact their education. This includes concerns with behavior, academic achievement, and mortality (Clancy et al., 2020; Hammer et al., 2018; Kem & Friedman, 2008).

In terms of social-emotional development and its impact on education, one can look back to the 1960's and the Yale Child Study Lab when James Comer pioneered research there that examined the importance of social-emotional learning in school settings. Linking the importance of home and school learning together laid the groundwork to boost the importance of social-emotional learning in schools in an effort to increase academic achievement (Comer, 1988). In his research, not only did academic achievement increase dramatically, but truancy rates dropped significantly as well as behavior problems within the schools that were examined (Comer, 1988). He further discussed the importance of being flexible when considering individual student needs as well as the critical need for family involvement to ensure success. From there, the Collaborative on Social-Emotional Learning (CASEL) was developed in 1994 to help drive further research and support for schools as they began to implement social-emotional learning more purposefully into their programs and continues to do so to this day on a global level (Collaborative on Social-Emotional Learning, 2021).

As a result of this early study, a focus on social-emotional development began to take hold. Recognizing the need to improve outcomes for children with behavioral disorders through the use of effective behavior interventions, some schools sought out a framework to help support them in implementing such learning (California PBIS, 2016). Positive behavior interventions and supports (PBIS) began as a framework to support social-emotional development in the 1980's and has expanded through the years from supporting just children with behavior difficulties to generalizing across school-age programs down through early education programs (Sugai & Simonsen, 2012). When the Individuals With Disabilities Act (IDEA) was renewed in 1997, the importance of social-emotional development was highlighted by funding being granted to specifically address the social-emotional needs of students through a national PBIS Center (California PBIS, 2016; Sugai & Simonsen, 2012).

Social Context

Concerns with social-emotional development may affect the education of young children, including those with inherited bleeding disorders (Hemmeter et al., 2020). Additionally, it affects those providing care for young children with inherited bleeding disorders such as parents, grandparents, the medical community, early intervention services if the child is receiving such services, and enrollment in early education programs such as daycare, Early Head Start, and preschools (Khair & Pelentsov, 2019). In order to better understand the problem, there needs to be a larger research base to draw from, which does not currently exist for young children with inherited bleeding disorders. Indeed, there is some research regarding caregiver challenges, such as Mooney-Doyle and Lindley's recent 2020 work that sought to describe characteristics of the family and child when medical complexity is involved or Khair and Pelentsov's (2019) work that addressed supportive care needs for the family of a child with an inherited bleeding disorder. However, these studies as well as all others do not show specific characteristics for the vulnerable group of young children with inherited bleeding disorders.

Young children with inherited bleeding disorders should be integrated into every environment that children without inherited bleeding disorders are. Limitations with supports for children with inherited bleeding disorders have impacted this (Khair & Pelentsov, 2019). The creation of inclusive educational environments for all children ensures better quality education for all children (Bui et al., 2010; You et al., 2019). Further, a sense of belonging and respect is fostered through including diverse groupings of children in early childhood education programs.

Bick and Nelson (2016) found that early-life adverse events changes brain structure and how the brain functions. Young children with inherited bleeding disorders are often exposed to these adverse events through the course of their treatment. Identifying and preventing concerns with social-emotional development at a young age would lead to better long-term outcomes overall for young children with inherited bleeding disorders as it would for all early learners (Bui et al., 2010; Hemmeter et al., 2020; Khair & Pelentsov, 2019).

This study seeks to expand the knowledge base beyond simply the parent perspective regarding family support and pair data with theory to further the understanding of how caregiver perceptions regarding social-emotional development may impact education for young children with inherited bleeding disorders. Additionally, this study could help open the door to future research regarding young children and inherited bleeding disorders as well as young medically complex children by establishing the need for further research. A thorough understanding of family experiences and perspectives regarding their experiences of raising children with inherited bleeding disorders will help lay the groundwork for designing effective systems and policies to support children as they transition through early education programs.

Theoretical Context

Bowlby initially discussed his theory on attachment in 1944, and from there, attachment theory has grown over the years. The formation of early relationships is considered the "predominant organizing force of infant and young child social development" (Zeanah, 2019, p. 96). These early interactions with caregivers initially center on survival, but also lay the groundwork for more complex social-emotional development as children grow (Bowlby, 1944; Zeanah, 2019). The positive interactions with caregivers boost psychological health and feelings of security that lead to expansion of positive social-emotional relationships with others (Crittenden, 2017; Zeanah, 2019). The caregiver is seen as a "secure base" (Zeanah, 2019, p. 105) that allows the child to safely explore their environment in order to learn and grow, later expanding their relationships to other adults and peers. Children who develop secure and close attachments to their caregivers have greater social-emotional competence later in life (Zeanah, 2019). Those who develop other attachment patterns, such as a disorganized attachment pattern described by Main and Solomon (1986) may grow to be more controlling, exhibiting more problem behaviors throughout childhood, and eventually low self-esteem and poor academic achievement (Solomon et al., 2017; Zeanah, 2019). These relationships can be established with both the primary caregivers as well as early education providers with whom the child spends a good deal of time.

There are four stages of attachment that impact early childhood social-emotional development and focus on the development of essential early social-emotional skills. These include the pre-attachment phase, the "attachment in making" phase, the "clear cut" attachment phase, and the formation of reciprocal relationships (Ainsworth et al., 1978; Bowlby, 1969; Zeanah, 2019). While the first three phases progress rapidly during the first year of life, the fourth phase develops over the course of the remainder of the early childhood years. At the earliest stage, children learn to see their caregivers as the safe base described by Bowlby, but in young children with inherited bleeding disorders, they may view their caregiver as someone who is not safe due to that being the person who causes pain with treatments or being continually present during painful procedures, impacting their ability to trust and form close, secure attachments with their caregivers.

When examining other texts for the theoretical perspective as it relates to children with inherited bleeding disorders or other medical complexity and educational supports overall, nearly all focus on the care coordination aspect of living with an inherited bleeding disorder. A few studies examine the caregiver perspective. An analysis of education supports, specifically around social-emotional learning, was nearly non-existent. Khair and Pelentsov (2019) discuss the theory around the emotional and psychological impacts of supporting children with inherited bleeding disorders. Another supporting theory is that of person-centered planning (Fetting et al., 2021) which outlines the importance of aligning teacher beliefs on social-emotional development with caregiver beliefs and experiences to improve program quality. The experiences of families who have a child with an inherited bleeding disorder are going to vary greatly from a family without such complexity, making this an important consideration when examining the theoretical context of this issue.

The integration of cognitive, behavioral, and emotional regulation processes that bind the theory of social-emotional learning together have been studied extensively over the past few decades. Research has promoted the benefits of social-emotional learning on overall health, long-term academic achievement, and mental health (Brackett et al., 2019; Darling-Hammond & Cook-Harvey, 2018; Hemmeter et al., 2020). However, the research has not yet consistently delved into the realm of these supports and theories for children who are medically complex or have rare diseases such as inherited bleeding disorders.

Families of children with inherited bleeding disorders as well as families who have children with medical complexity are in a unique and privileged place due to the advances in medical technology that allow these children to be treated outside of a hospital setting, even at home, for conditions that previously they were unable to obtain such care for (D’Aprano et al., 2019; Van Orne, 2022). When polled about needed supports, caregivers have reported needing primarily medical supports. However, these studies have not shared the importance of social-emotional learning and impacts on long-term education. Instead, they have asked questions about care coordination without examining the education element, leaving a gap in the research, thusly further impacting the theoretical context due to lack of knowledge (Khair & Pelentsov, 2019; Taft et al., 2020; Van Orne, 2022). This study seeks to gain understanding of what types of supports caregivers perceive as helpful while they navigate both the bleeding diagnosis and supporting their child’s development, including enrollment in early education programs.

Problem Statement

The problem is that social-emotional learning and the overall education of young children with inherited bleeding disorders is impacted by many of the routine procedures that must be done as a result of having an inherited bleeding disorder (DeKoven et al., 2014; Khair & Pelentsov, 2019; Taft et al., 2020). Medical trauma is documented to cause concerns with post-traumatic stress though specific effects have all been theorized and not proven. This trauma could lead to long-term impacts on social-emotional development, which is a crucial piece of early childhood development and has impact on early childhood education (Taft et al., 2020).

There is a lack of current research available on young children with inherited bleeding disorders and their social-emotional development, leading to impacts on education. The closest research available states the impacts to family life when a child is diagnosed with an inherited bleeding disorder (DeKoven et al., 2014; Khair & Pelentsov, 2019). One study addressed the social impacts for adults living with hemophilia, but "the current evidence delineating the effects of haemophilia on interpersonal relationships is sparse and largely outdated" (Cassis et al, 2014, pp. 287-288). This issue is complex as people living with inherited bleeding disorders are a rare group, meaning less than 200,000 people in the United States are living with the individual disorders ranging from mild platelet dysfunction to severe hemophilia A with inhibitors (National Organization of Rare Diseases, 2019). While few people are impacted by inherited bleeding disorders, they live with impacts across all domains of their lives (Saes et al., 2020). The wide range of inherited bleeding disorders makes this group a difficult one to study (Khair & Pelentsov, 2019; Palla et al., 2015; Saes et al. 2020) in any area, including social-emotional development due to the nature of varying impacts depending on severity of disease.

Purpose Statement

The purpose of this transcendental phenomenology was to explore the caregivers' and professionals' experiences of supporting young children's social-emotional learning in the classroom and its impact on early education in Western Pennsylvania. Social-emotional learning is generally defined as developing and maintaining positive, meaningful relationships with caregivers and peers, how students learn to regulate emotions, communicate with others, employ compassion and empathy, recognize their own needs and the needs of others, and make positive decisions. The theory guiding this study is Bowlby's (1944) attachment theory as it examines both relationships and typical social-emotional development for young children as well as what happens when this typical development is interrupted for a variety of reasons.

Significance of the Study

This study is significant in that there is no available research on the social-emotional development of young children with inherited bleeding disorders, yet there are children living all over the United States with a variety of inherited bleeding disorders.

Theoretical Perspective

The population of young children with inherited bleeding disorders anecdotally can have impacts to their education due to lack of access to early education programs. Due to the range of bleeding disorders in the population, an exact number of young children living with inherited bleeding disorders has not been determined. The adult population living with a form of hemophilia is estimated around thirty-three thousand people in the United States, while another type of inherited bleeding disorder, von Willebrand Disease, is estimated to affect one in every one hundred people (National Hemophilia Foundation, 2021). Pelentsov et al. (2016) noted that social-emotional needs were not addressed adequately for children who are medically complex.

Looking at potential risk factors for attachment is necessary for understanding relationships (Bowlby, 1969). Manifestations of risk factors in early development can impact social-emotional learning for an extended time resulting in the need for clinical strategies to be implemented in order to address concerns (Zeanah, 2019). The parent-child relationship is particularly impacted when there is trauma exposure. Medical trauma at an early age can result in the child perceiving that the parent "is the agent of the traumatic event" or "the parent willfully failed to protect" (Zeanah, 2019, p. 491). This is particularly relevant when the parent is the one who has to administer the treatments. Attachment is essential for mental health per Bowlby (1969) and impacts to this attachment can negatively impact the social-emotional development of the child (Zeanah, 2019).

Concerns with post-traumatic stress from repeated exposure to unpleasant and traumatic medical procedures is minimally documented but due to lack of research rather than lack of experience (Taft et al., 2020; Zeanah, 2019). Placement of an intravenous line, sometimes by the parent, blurs the lines between separation of medical procedures in the healthcare setting versus medical procedures at home, thus potentially leading to concerns with increased stress. Young children who experience such stress are at higher risk of poor outcomes regarding social-emotional learning due to these factors as a result of having undeveloped skills in the areas of emotional regulation. They are experiencing rapid brain development that can impact the development of these skills. Children also expect their primary caregiver to be their safe base-someone who is able to protect them from emotional and physical harm, but again, when the caregiver is the one administering some of these painful procedures, the lines are blurred and can lead to increased stress (Zeanah, 2019).

Empirical Perspective

Many children with inherited bleeding disorders are followed by hemophilia treatment centers who provide a comprehensive care model that focuses not just on the medical aspects of having such a disorder, but also the social, educational, and environmental aspects (Khair & Pelentsov, 2019; Kuehn, 2013; Matlin et al., 2019). This study is needed due to the current lack of available research for children with inherited bleeding disorders and impacts on early education. Adding to the knowledge base for the comprehensive care model (Page, 2020) as well as early intervention and early education programs in assisting to recognize the difficulties that some children with inherited bleeding disorders may face will be one important result of this research. This study will be conducted with seven to ten families of young children with inherited bleeding disorders participating in a comprehensive care model of care and two to four early education professionals. This will result in recognizing areas for improvement in the comprehensive care model and in early education.

Practical Perspective

Parents of young children living with inherited bleeding disorders may feel isolated as their children are sometimes excluded from activities due to their diagnosis. Daycares and early learning programs who are privately funded may resist caring for children with such complexity or parents may not be comfortable sending their child to daycare as a result of their diagnosis. Public preschool programs that are required to provide accommodations are not available universally across the United States. Some activities, such as gymnastics or contact sports, are not permitted for children with inherited bleeding disorders due to the risk of bleeding, thus increasing isolation. Concerns with emotional distress have been described by caregivers of young children with inherited bleeding disorders, particularly being fearful that their child is not going to have the opportunity to develop like other children (An, 2016; DeKoven et al., 2014). By recognizing these concerns and weaving them into the comprehensive care model with a focus on the social-emotional learning of young children with inherited bleeding disorders, caregiver stress would be reduced and potential delays in development avoided. We know that social-emotional learning is critical to overall development and education (Cressey, 2019; Hammer et al., 2018; Kern & Friedman, 2008). Erikson (1964) discusses the importance of play on social-emotional learning. Through play, children learn to explore their world, including the big emotions and events that may happen to them. They can then try out different scenarios to enact change in their world. When young children have inherited bleeding disorders, their reality is often markedly different than the typical childhood experience. Instead of attending daycare or play groups, they may be limited in their activities. Caregivers sometimes limit activities for fear of injury while others are unable to participate due to programs fearing liability. This study will be able to look at some of these themes and both caregiver and early education professional perceptions of their impact.

Research Questions

When considering the questions to be addressed by this study, the main focus is established to be on social-emotional learning, a crucial piece to early childhood education. A review of data collected during the study was able to establish whether young children with inherited bleeding disorders are likely to have any delays in their social-emotional learning, crucial for all other development. The research is clearly lacking in all areas regarding children with inherited bleeding disorders, however, some of the available research does address the impacts to family life, especially given DeKoven et al.'s (2014) as well as Pelentsov et al.'s (2016) research. The medical and education professionals supporting these young children with inherited bleeding disorders have developed what they call a comprehensive care model, but with a lack of research guiding any recommendations that could be made, the supports may not be as robust as they could be. Therefore, a central research question and two sub questions were developed based on this information.

Central Research Question

How do caregivers and early education professionals describe their experiences of supporting social-emotional learning and education of young children with inherited bleeding disorders?

Sub-Question One

How do caregivers describe their experiences of providing and receiving social-emotional and educational support for young children with inherited bleeding disorders?

Sub-Question Two

How do early education professionals describe their experiences of providing and receiving social-emotional and educational support for young children with inherited bleeding disorders?

Sub-Question Three

How do caregivers describe their experiences with supports that are provided to enroll their child in early childhood education programs?

Definitions

1. *Adverse childhood experiences (ACES)*- events that impact a child as they grow, often causing trauma or other impacts to development with lifelong implications for health and mental health (Bethell et al., 2017; Matlin et al., 2019).
2. *Attachment*- close and secure relationships formed with caregivers (Zeanah, 2019).
3. *Comprehensive care model*- medical care that focuses on a spectrum of needs for the patient including medical, social, educational, environmental, historical, etc. (DeKoven et al., 2014).
4. *Early childhood education*- formal education that occurs between birth and age five, typically in a daycare, Early Head Start, Head Start, Pre-K Counts, or private preschool classroom (National Association for the Education of Young Children, 2021).
5. *Early intervention*- special education services provided to young children ages birth-five through an individualized plan that address concerns with cognitive, social-emotional, communication, motor, and/or adaptive skills (National Association for the Education of Young Children, 2021).

6. *Inherited bleeding disorder*- a congenital disorder leading to increased bleeding risk. These can include hemophilia, von Willebrand disease, or platelet function disorders (Khair & Pelentsov, 2019).
7. *Positive behavior interventions and supports*- a framework that supports social-emotional learning through the use of tiered systems of support (Sugai & Sorensen, 2012).
8. *Social-emotional learning*- the ability to develop close and secure relationships with adults and peers while regulating emotions (Hammer et al., 2018).
9. *Trauma*- negative events that impact a child's learning (Matlin et al., 2019)

Summary

The lack of research regarding young children with inherited bleeding disorders and social-emotional learning is quite concerning given the important nature of social-emotional learning across the lifespan, including early education through early intervention and preschool programs. These children are at increased risk for concerns with attachment and trauma as a result of frequent routine but necessary medical procedures (DeKoven et al., 2014; Khair & Pelentsov, 2019), thus impacting their social-emotional learning which could lead to concerns with behavior, academics, and mortality (Kern & Friedman, 2008). By working with families and comprehensive care teams to identify concerns for young children with inherited bleeding disorders, the researcher aims to establish a base for understanding parental perception of social-emotional learning and the education of young children. This study explored the caregiver and early education professional experiences of supporting young learners in their social-emotional learning and the impacts on early childhood education in Western Pennsylvania.

CHAPTER TWO: LITERATURE REVIEW

Overview

Through a thorough and systematic review of the literature, concerns regarding social-emotional learning and children with bleeding disorders were evaluated so that the available research could be synthesized and presented in this chapter. First, theories related to social-emotional learning and attachment are discussed. Available literature about social-emotional learning and medically complex children is discussed to lend information on the importance of social-emotional learning in young children and impacts on medically complex children. This will result in the identified gap in the research regarding caregiver concerns regarding the education of their young children with bleeding disorders, resulting in the need for additional research on this topic.

Theoretical Framework

Social emotional theories can be traced all the way back to Plato (Gutek, 2021), however, a more modern approach is taken through two theories supporting the research presented here. Bowlby's attachment theory and Erickson's theory of psychosocial development both heavily influence understanding of social emotional learning in young children. Other theories including Bandura, Vygotsky, and Piaget were considered for their work on social emotional learning, however, Bowlby and Erickson provide additional insight that may be helpful when considering the additional needs and experiences of children who are medically complex.

Theory of Psychosocial Development

Erikson first discussed the theory of psychosocial development in 1950, shortly after Bowlby began working on his attachment theory (Maree, 2021; Erikson, 1950; Bowlby 1944). The two theories are closely aligned in that both look at the developing child and how typical social-emotional development occurs as well as what can impact it. Due to this close alignment and the relative importance when considering social-emotional learning, it is crucial to acknowledge and understand the role of both in this context. Trust versus mistrust is the first step in Erikson’s theory. This is the theory that children should be exposed to safe and secure experiences as babies and toddlers in order to develop sufficient trust in their caregivers that will allow them to move through the other stages of psychosocial development (Maree, 2021; Erikson 1950).

The trust vs. mistrust stage described by Erikson (1950) typically lasts from birth through eighteen months, when children move from simply seeking care and affection to develop their social-emotional foundations to the autonomy stage. Children begin to develop their sense of independence in this second stage, which lasts until about age three (Maree, 2021). The third early childhood stage of psychosocial development outlined by Erikson (1950) is the initiative vs. guilt stage, which lasts until about age five. In this stage, children begin to exert control over their environment, sometimes leading to disapproval from adults and thus guilt or shame (Maree, 2021). During each of these stages, children develop new social-emotional skills crucial for learning. However, children who are medically complex may have these stages interrupted and thus impacts to their social-emotional learning based on their medical needs and experiences (Page, 2020).

Attachment Theory

The theory of attachment is closely aligned with social-emotional learning as children must develop close and secure relationships with caregivers so that they can develop essential social skills (Zeanah, 2017). These attachments begin in the earliest stages of infancy and continue to develop as the infant does. When an infant or child experiences perceived threats including challenging situations, it enables the child to seek out a person to provide care or a sense of security while developing more coping skills to be able to manage these situations more effectively in the future. Bowlby was the first researcher on attachment theory, with Ainsworth conducting further research on the subject and later in life working with Bowlby on this theory (Ainsworth, 1978; Bowlby, 1944; Crittenden, 2017). Infants seeking out attachment from their primary caregivers is an important indicator of infant mental health, especially when faced with difficult, threatening, or uncomfortable situations (Crittenden, 2017; Solomon et al., 2017). Similar to Erikson's theory of psychosocial development, children develop attachment to their primary caregivers in the early years and disruptions to this can lead to impacts on social-emotional learning (Ainsworth, 1978; Bowlby, 1944; Crittenden, 2017).

Three types of attachment styles exist per Bowlby (1944): secure, insecure-anxious, and insecure-avoidant. Children who fall under secure attachment feel free to explore their world confidently as a result of the consistent, loving responses received by their caregivers. When children do not or cannot have their emotional needs met by their caregivers consistently, they may develop insecure-anxious or insecure-avoidant attachment styles. This impacts their confidence when exploring their environment, impacting their ability to learn social-emotional and cognitive skills effectively (Bowlby, 1944; Crittenden, 2017; Lai & Carr, 2018).

For children without medical complexity, attachment comes easily from the nurturing and care they receive from their caregivers in their natural environment, which is typically a safe haven (Solomon et al., 2017). In fact, this is not the primary driving force for attachment as Crittenden (2017) describes that the environment is less impactful for children than the loss of a primary caregiver. Medically, this can be further reinforced by the increases in cortisol production in young children seen with maternal separation (Zeanah, 2019). In contrast, children with medical complexity often face life-altering challenges, including separation from their primary caregiver during medical procedures or as a result of false allegations of child abuse (Bressan et al., 2020; Collins et al., 2017; Kuehn, 2013) which can impact their ability to form safe and secure attachments, thus leading to concerns with mistrust (Ainsworth, 1978; Bowlby, 1944; Crittenden, 2017). Adshead and Guthrie (2015) offer the most current information available regarding attachment and children who are medically complex, sharing how attachment is impacted as a result of being medically complex and leading to other concerns including relationships with their caregivers, perceived stress, and influence the effectiveness of interventions related to the disease.

Related Literature

A synthesis of literature related to young children with inherited bleeding disorders and social-emotional learning is presented in this section. Developing an understanding of the shared experiences surrounding social-emotional learning for young children with inherited bleeding disorders is a topic that has not yet been explored in the literature so relevant themes are discussed here.

Social-emotional Learning

Social-emotional learning in young children is one of the most important areas of child learning (Cressey, 2019; Dusenbury & Weissberg, 2017; Hemmeter et al., 2016; Zeanah, 2017). Concerns about social-emotional learning impact the education of all young children (Hemmeter, 2020; Rausch et al., 2021). In the busy day-to-day grind, it can be easy to forget how vital social emotional learning is to the success of children including creating a positive environment in the home leading to a safe space for all. Social emotional learning is the cornerstone of all other learning, therefore it is critical that it is addressed for children who are most at risk for concerns regarding their social-emotional learning (Cressey, 2019; Rausch et al., 2021).

Strong social-emotional skills result in resiliency and self-regulation, both crucial skills as children grow through childhood and into adults (Duesenbury & Weissburg, 2017; Rademacher & Koglin, 2018). By promoting social-emotional competence, challenging behaviors can be reduced that impact overall learning and academic achievement (Hemmeter et al., 2016; Rademacher & Koglin, 2018). Attachment and psychosocial development are both important parts of social-emotional learning (Ainsworth, 1978; Bowlby, 1944; Erikson, 1950).

Early Childhood Social-emotional Learning

Social emotional learning in early childhood through the elementary years lays the groundwork for future success both in real world application of social skills and in academic achievement. Early childhood education programs can offer instruction in social emotional skills at a key time in children's development. The Center for Social-Emotional Learning (CASEL) and the National Center for Pyramid Model Innovations (NCPMI) outline several strategies critical to social emotional learning including self-awareness, self-management, social awareness, relationship skills, and responsible decision making (Dusenbury & Weissberg, 2017; National Center for Pyramid Model Innovations, 2022). These are skills identified that impact the abilities of children to engage with their environment and with others so that they are able to learn effectively and regulate their behavior. Explicit teaching of social skills at an early age shows promise for long term benefit for students (Casica and Barr, 2016; Szegedi-Hallgató, 2017).

Social-emotional learning in early childhood is a core skill that is necessary for children to thrive throughout their lives (National Center for Pyramid Model Innovations, 2022, Szegedi-

Hallgató, 2017). Beginning in infancy, children learn how to regulate their behavior in response to environmental triggers and continue to develop their ability to refine these processes of regulation dramatically over the next two years (Dale et al., 2011). These skills are refined during a critical period of overall development and lead to establishing skills needed to function in the classroom and beyond. Skills include effective communication, sustaining attention to play and academic activities, the ability to follow directions, conflict resolution, and impulse control.

For any education program to be sustainable, it must include elements of social-emotional learning. Children who are socially and emotionally well can engage in play and learning opportunities with their peers. Children who are social and emotionally well-adjusted have lower rates of mental health concerns and suspension and expulsion from school. Higher rates of academic performance are documented in children who have been exposed to regular social emotional instruction (DePaoli, Atwell, & Bridgeland, 2019). Research is beginning to suggest that early social emotional learning can even have impacts on long term mental health and mortality (Jones, Barnes, Bailey, & Doolittle, 2017). Social emotional learning in early childhood lays the groundwork for future success both in real world application of social skills and in academic achievement.

Social-emotional skills are also tied to achieving other developmental milestones including cognitive, physical, and adaptive milestones (Cosso et al., 2021; Cressey, 2019; Shire & Chang, 2021). Without strong social-emotional skills, taught through systemic learning opportunities in early childhood, no other meaningful learning can take place. Children who cannot count are less of a concern in the classroom than the child who is running out the door or screaming over the teacher. Using a framework that supports the development of crucial social-emotional skills that can prevent challenging behaviors, such as Pyramid Model practices, can improve childrens' ability to learn and be successful in the classroom and at home (Hemmeter et al., 2021; Rausch et al., 2021; Shire & Chang, 2021). Biological and environmental risk factors can impact learning as they can negatively affect neurodevelopmental processes. These critical processes that support maturing neurons and their ability to develop connections include myelination, neurogenesis, and synaptogenesis which assist in the brain being able to quickly and effectively transmit information (Ocansey et al., 2019; Zeanah, 2019). This allows children to learn the skill and then be able to recall the information and generalize it to other social situations.

Early childhood education professionals should be prepared to support the learning of all children in an inclusive and diverse manner that reflects their different cultural, educational, behavioral, and medical needs. The promotion of social-emotional learning is effective in addressing children's learningal and behavioral needs. Executive function is improved with systematic teaching of social-emotional skills in early childhood, which can be provided in a variety of settings including home, daycare, Early Head Start, Head Start, or other high quality education programs (Hemmeter et al., 2021). Researchers have found that social-emotional learning is linked to improved early literacy and numeracy skills (Clayton et al., 2021; Cosso et al., 2021; Dusenbury & Weissberg, 2017). High-quality early education programs such as early intervention programs, Early Head Start, Head Start, Pre-K Counts, and others have positive impacts on children's long-term educational and mental-health outcomes (Fetting et al., 2022; Phillips et al., 2017; Vandell et al., 2020). The benefits of these early education programs are even more pronounced for children with disabilities, such as those with inherited bleeding disorders (Cash et al., 2019; Conger et al., 2019, Fetting et al., 2022).

A key way that early childhood learning programs can promote social-emotional learning for all children is through the implementation of Pyramid Model practices with fidelity. Through this tiered model, eighty percent of all children- including those with inherited bleeding disorders- can have their social-emotional learning needs met (Hemmeter et al., 2020; National Center for Pyramid Model Innovations, 2022). Promoting inclusion for all children, the Pyramid Model focuses on helping teachers and caregivers provide high quality environments supported by nurturing and responsive relationships between children, families, and early childhood professionals. This comprehensive model is especially important for children with inherited bleeding disorders or other medical complexity. Teams that work together have higher rates of success in all areas, but especially in supporting social-emotional learning for these young children. If additional supports are needed, the higher tiers of the pyramid can provide this assistance through targeted social-emotional supports and intensive intervention. The explicit instruction that is provided at these higher tiers can help children learn self-regulation, problem-solving skills, give more targeted support for relationship building, and direct instruction on emotional literacy. When children are able to self-regulate their behavior through the use of positive guidance, their social skills increase, impacting their ability to engage in daily routines and learn effectively (Crawford & Weber, 2014).

Positive social-emotional skill learning can result in a reduction in behaviors identified as problem behaviors as well as a reduction in off-task behavior in the classroom. Explicitly teaching these foundational social emotional skills is necessary starting at a young age to support children in healthy relationships at home and at school (Hemmeter et al., 2016; National Center for Pyramid Model Innovations, 2022; Zeanah, 2017). However, these skills could be more difficult for children who have experienced trauma and other adverse childhood experiences.

Using Pyramid Model practices or other social-emotional learning opportunities can help facilitate the important relationship building skills needed to promote skill development for these at-risk children. Through guiding teachers to foster nurturing relationships with students, establishing predictable schedules and routines, and intentionally teaching crucial social-emotional skills, children who have experienced trauma can thrive in the educational environment (Hemmeter et al., 2021; National Child Traumatic Stress Network, 2017). If they need a higher level of support, this can be provided when following Pyramid Model practices through the intensive intervention tier, where highly individualized interventions can be provided to specifically target skills, with assessment built in to measure progress (Hemmeter et al., 2021; National Center for Pyramid Model Innovations, 2022; Zeanah, 2017).

Teaching critical social emotional skills for children, including medically complex children living with inherited bleeding disorders, may look different as well as need to be more intensive in nature than for children who do not live with medical complexity or inherited bleeding disorders due to concerns with psychosocial development and attachment (Ainsworth, 1978; Bowlby, 1944; Crittenden, 2017). In order for young children with inherited bleeding disorders to be full members of the educational community in which they participate, schools need to consider the full spectrum of needs and considerations for inclusive participation. Schools implementing systemic frameworks that promote social-emotional learning, such as positive behavior interventions and supports (PBIS) and Pyramid Model practices provide additional support to children with varying needs due to the tiered systems of support that are identified and implemented. This systematic method of teaching and reinforcing social emotional skills also incorporates a trauma-informed lens that promotes family involvement (Hemmeter et al., 2016; National Center for Pyramid Model Innovations, 2022).

Family engagement plays a huge part in social-emotional learning and school success. A key predictor in child learning, families who participate in meaningful engagement and relationship building activities in the home setting help their children learn key skills that translate to higher levels of academic achievement (Rey-Guerro et al., 2021). This starts in infancy with infants developing strong attachment with their primary caregivers. This important indicator of infant mental health can be impacted by difficulties forming attachments with primary caregivers (Crittenden, 2017; Solomon et al., 2017). Children who develop attachment to their primary caregivers in the early years have fewer difficulties in this area and improve social-emotional learning (Ainsworth, 1978; Bowlby, 1944; Crittenden, 2017).

In the early years when mother-child interactions lay the groundwork for beginning key social-emotional competencies, mothers may be impacted by their own mental health concerns. These can then result in poor bonding and sensitivity to their children's needs, impacting their social-emotional learning long-term (Behrendt et al., 2019). Supporting family engagement, including being sensitive of mental health concerns and providing the needed supports for families is crucial in order to support the social-emotional learning of young children. This family engagement is supported when implementing frameworks like Pyramid Model practices and PBIS (Hemmeter et al., 2021).

Adverse Childhood Experiences

Children who have been exposed to adverse childhood experiences (ACES) are at higher risk for long-term impacts to their physical health and mental health, as well as at higher risk for substance abuse (Matlin et al., 2019; Spehr et al., 2019). ACES cover a wide range of factors ranging from physical, emotional, or sexual abuse to being exposed to traumatic events (Spehr et al., 2019). Research states that these risk factors pose threats to typical learning. Further, when children are exposed to more than one adversity, the effects may accumulate and threaten a child's well-being and increase the risks to overall development. One protective factor that can assist in mitigating concerns for children with multiple risk factors is caregiver-child interactions (Behrendt et al., 2019; Cosso et al., 2021). Other protective factors include nutrition, the opportunity to be enrolled in a high-quality learning environment, and financial stability (Fetting et al., 2022; Spehr et al., 2019).

These ACES can significantly impact all areas of learning, but especially social-emotional learning by disrupting the typical psychosocial stages and forming close and secure attachments with caregivers. These impacts to social-emotional learning can be huge for young children, setting the stage for long-term concerns with resiliency and self-regulation (Cosso et al., 2021; Rademacher & Koglin, 2018). The ability of caregivers for children with inherited bleeding disorders to mitigate these concerns alone can be a challenge, and so bringing in other team members, such as those on the comprehensive care team (Page, 2020) for the child can be helpful in attempting to mitigate some of the concerns with social-emotional learning and reduction of traumatic experiences for these children. This is done through identifying supports in the home and community, including early education programs, that can successfully assist in addressing concerns that caregivers face when considering enrolling their young child with an inherited bleeding disorder in an early education program.

Researchers have found that children who are social and emotionally well-adjusted have lower rates of mental health concerns and suspension and expulsion from school (Jones, Barnes, Bailey, & Doolittle, 2017). Black boys, who have higher rates of some inherited bleeding disorders like sickle cell anemia and disorders of platelet number or function (Liu et al., 2019), have higher rates of facing lifelong consequences due to exclusionary discipline practices that start even in early childhood including less education as a result of increased suspension and expulsion, which leads to less job opportunity and a much higher potential for incarceration (Wesley & Ellis, 2017).

Children exposed to regular social emotional instruction formally in daycare or preschool settings as well as those who have informal instruction in the home setting have demonstrated higher rates of academic performance and cognition (DePaoli, Atwell, & Bridgeland, 2019, Fetting et al., 2022). The effects of high-quality early childhood programs and their focus on the social-emotional learning for young children hold even more promise for later academic achievement (Fetting et al, 2022; Vandell et al, 2020). However, caregivers of children with inherited bleeding disorders may be hesitant to send their child to an early childhood education setting due to concerns with being able to meet their medical needs while in the program, concerns for false allegations of child abuse, and concerns for potential injury while participating in early childhood education programs. Caregivers also may have difficulty finding an early childhood education setting that will accept their child due to concerns with liability (Arya et al., 2020).

A final consideration in this area is that the research suggests that early social-emotional learning has positive impacts on long term mental health and mortality (Jones, Barnes, Bailey, & Doolittle, 2017). Children with inherited bleeding disorders who may have their early social-emotional learning impacted negatively should have these concerns addressed as part of their comprehensive care team planning (Page, 2020). This will allow them to participate fully in activities and be successful both in navigating relationships at home and elsewhere. Mitigating some of the concerns with long-term mental health by providing supports in the home and community settings is necessary to ensure that all of the needs of young children with inherited bleeding disorders are being met effectively.

Attachment

Strong infant attachment is a key indicator for the learning of social-emotional skills and educational success. Increased regulation is associated with strong attachment, resulting in fewer concerns with behavior including attention, executive function, and interactions with others. This self-regulation is necessary for children to develop appropriate social-emotional skills as well as cognitive skills (Allee-Herndon & Roberts, 2019; Rademacher & Koglin, 2019). Children who fail to develop secure attachment to their caregivers lack the ability to fully develop resiliency, adapt to their changing environments, and regulate themselves in stressful situations (Rees, 2007; Zeanah, 2019).

Central to learning, early attachment is a significant factor when considering the role of social-emotional learning in early childhood (Opie et al., 2020; Zeanah, 2019).

People With Bleeding Disorders

People who have inherited bleeding disorders are considered a rare group who can present with a wide range of symptoms from mild to severe (Palla et al., 2015; Saes et al., 2020). Some are diagnosed shortly after birth while others not until adulthood as they do not exhibit symptoms until some physically traumatic event happens, such as postpartum hemorrhage after delivering a child or a surgery where bleeding was significantly more than expected (Khair & Pelentsov, 2019). Many studies that have been conducted with this group have been limited in scope due to the number of participants, which is naturally small due to the relatively rarity of the number of individuals who are living with inherited bleeding disorders (Saes et al., 2020). Additionally challenging is the number of different inherited bleeding disorders including several types of hemophilia, several types of Von Willebrand Disease, idiopathic thrombocytopenic purpura, factor deficiencies, and platelet dysfunction disorders among others Treatments for bleeding disorders can vary wildly from prophylactic treatment needed several times weekly to those who need treatment only prior to surgical procedures or in the event of injury (Khair & Pelentsov, 2019; Palla et al., 2015; Saes et al. 2020).

Most well-known but far less common is the diagnosis of hemophilia. Hemophilia A impacts 1:5000 males and Hemophila B impacts 1:30,000 males (Bhatnagar & Hall, 2017). These are both, like Von Willebrand Disease (VwD), are caused by deficiencies in the coagulation protein factors in the blood (Bhatnagar & Hall, 2017). Within these overall diagnoses, there are varying levels of severity for each, requiring different treatment approaches for each. Complicating treatment is a lack of understanding of these disorders by both the community at large as well as the medical profession, leading to stigma (Arya et al., 2020). Factor deficiencies are more common among the types of inherited bleeding disorders, but additional disorders surrounding platelet dysfunction including Quebec platelet disorder, Scott Syndrome, and Hermansky-Pudlack Syndrome among others are included when considering the type of inherited bleeding disorder than an individual may live with (Palla et al., 2015; Patel & Butterfield, 2015; Saes et al., 2020). There are also unspecified platelet dysfunction disorders which pose unique treatment challenges as the cause for bleeding has not been solidified beyond recognizing that the platelets are not functioning as they should.

Impact on individuals with bleeding disorders

There is extremely limited research available regarding social-emotional needs for individuals living with inherited bleeding disorders, in fact, only one study is available regarding adults and social-emotional skills. This study by Cassis et al. (2014) is outdated and not based in the United States. Further, it only addresses adults with hemophilia and does not include other inherited bleeding disorders which are a larger percentage of the population living with inherited bleeding disorders. While more than half were married and satisfied, that percentage was lower for those living with inhibitors which can make treatment more difficult (Cassis et al., 2014). Despite noting that the currently available research on the impacts of inherited bleeding disorders on social emotional learning and relationships with others is both minimal and quite outdated (Cassis et al, 2014), no further research has been conducted on this subject beyond this study. This points to a significant gap in the literature needing to be addressed.

Not only is there limited research available on social-emotional learning and impacts of living with an inherited bleeding disorder diagnosis for adults, this limited research that is available is indicative that there is a huge lack of knowledge regarding bleeding disorders and their impacts overall. Arya et al., (2020) studied the experiences of women living with bleeding disorders and described their experiences. Noting the significant impacts on daily life due to symptoms, stigma, and lack of knowledge from medical professionals, Arya et al., (2020) suggested further study regarding these impacts and barriers to care.

Another concern in regard to understanding the impacts on caregivers of children with inherited bleeding disorders as well as the children themselves are discussions surrounding the involvement of Children and Youth Services. The impact of a false allegation of child abuse can lead to significant trauma for both the accused adult and the child (Beker & Robin, 2014; Zeanah, 2017). However, here also the research is lacking, primarily focusing on false allegations in custody cases. The American Academy of Pediatrics released a policy statement in 2013 regarding suspicion of child abuse that doctors who are concerned about potential child abuse should consider medical causes including bleeding disorders before assuming that signs such as excessive bruising and bleeding are signs of child abuse (Kuehn, 2013). One example of another medical cause is congenital dermal meanocytosis which is a sometimes a cause of suspected child abuse (Patel & Butterfield, 2015). The wide range of bleeding disorders can frequently present with larger and more frequent bruises across all ages and in areas that may be concerning for child abuse (Collins et al., 2017; Kuehn, 2013). False allegations of abuse when in fact the concern would be explained by testing for an inherited bleeding disorder can lead to long term impacts such as removal of the child from the home and potential prosecution of innocent adults (Kuehn, 2013). This would also increase the ACE score for a child with an inherited bleeding disorder, leading to potential impacts to their overall social-emotional learning and concerns for longer-term impacts to relationships with their caregivers, their mental health, and long-term impacts to health (Matlin et al., 2019; Spehr et al., 2019).

Impact on children with bleeding disorders

Children with inherited bleeding disorders are a group who, like adults living with inherited bleeding disorders, also have had practically no research conducted on their needs. Of the available research, supportive care needs and parental experiences of caring for these children are the focuses (DeKoven et al., 2014; Khair & Pelentsov, 2019). There is no available research specifically on the social-emotional learning for children with inherited bleeding disorders. Both studies listed above address the needs of caring for children with bleeding disorders from the parent perspective, but they do not address specifically the learning of children with bleeding disorders, highlighting the need for further research in this area.

Parental concerns noted in these studies regarding children with inherited bleeding disorders include concerns about their participation in routine childhood activities such as daycare, sports, etc. Not being able to participate in these activities like their peers can have impacts on social-emotional learning and feelings of self-worth (DeKoven et al., 2014). Further, the stress associated in caring for children with inherited bleeding disorders can cause mental health concerns, thus potentially exposing the child to adverse childhood events (ACES), known to impact social-emotional learning (Khair & Pelentsov, 2019; Matlin et al., 2019).

Parents report being concerned about treatment, as since inherited bleeding disorders are rare, it can be difficult to receive adequate treatment (Arya et al., 2020; DeKoven et al, 2014; Khair & Pelentsov, 2019). This can lead to a reduction of focus on what could be seen as the less important tasks of supporting social-emotional learning as parents focus on ensuring that their children are receiving the appropriate medical treatment in order to meet their needs to continue to live. Khair & Pelentsov (2019) shared one mother's experience that "the huge impact of our situation on every aspect of our family life…has had a knock-on effect on my children. They both now need psych input, and I feel I have failed them." (p. 834).

In addition to concerns about receiving adequate treatment, fears regarding false accusations of child abuse because of the bruising that can be associated with an inherited bleeding disorder can impact children as well as their caregivers. In an article specifically related to the experiences of those with inherited bleeding disorders, a caregiver described the traumatic experience of going through investigation for child abuse due to unexplained bruising and how it impacted both her and her child (Arya et al., 2020). Unfortunately, due to the limited research that is available on this subject, the long-term effects are not understood. Bressan et al. (2020) and Kuehn (2013) review the American Academy of Pediatrics (AAP) policy statement on considering bleeding disorders when suspecting abuse and shares that a common indicator of abuse- intracranial hemorrhage- is also a common side effect of a child experiencing a bleeding disorder. While it is certainly appropriate to be concerned about abuse, it highlights the importance of due diligence in investigating the cause of bleeding especially in children with known inherited bleeding disorders. Removing a child from their home is a serious consequence of investigation for child abuse and doing so under false assumptions rather than fully investigating potential causes of can negatively impact the child, exposing them to ACES unnecessarily (Khair & Pelentsov, 2019; Kuehn, 2013; Matlin et al., 2019). One tool that can be used to successfully identify concerns with bleeding in children is the Bleeding Assessment Tool (Kaur et al., 2020) which can help alleviate some suspicions and guide practitioners in a different, potentially more accurate direction when evaluating concerns for bruising and bleeding.

Trauma can result from the number of procedures that need to be completed for children with inherited bleeding disorders and the way that these procedures are done. Gone are the days of having to go to the doctor's office to have an intravenous line placed in order to administer blood factor (Hay et al., 2017; Mahlangu et al., 2019). Instead, these procedures can now be completed at home, often by the child's parents (Bhatnagar & Hall, 2018; DeKoven et al., 2014; Hay et al., 2017, Mahlangu et al., 2019). Instead of the caregiver being the comfort for the child going through such procedures, they become the person who must conduct the procedure, potentially leading to concerns with psychosocial development and attachment, as that caregiver is no longer the child's safe person to rely on, but rather a source of trauma (Ainsworth, 1978; Bowlby, 1944; DeKoven et al, 2014; Erikson, 1950; Matlin et al., 2019). The effects of this potential trauma have not been studied. Exploring these effects would be impactful for children and adults living with inherited bleeding disorders.

One study was conducted by Lambing et al. (2017) regarding adolescents and young adults who live with inherited bleeding disorders and their perceptions of both pain and pain management in relation to management of their inherited bleeding disorders. This study provides a starting point for studying the younger population of children living with inherited bleeding disorders. This study showed that the perception of pain and pain management for the individual undergoing the treatment was higher than both the caregiver and provider perceptions of pain Lambing et al., 2017). The nature of inherited bleeding disorders means that progressive damage to the joints leading to disabling long term joint conditions such as arthritis can be a result of untreated bleeding, impacting pain perceptions (Lambing et al., 2017). This is of particular importance in the discussion regarding trauma for both pain and as those who have their concerns repeatedly invalidated can experience greater concerns with mental health and trauma (Lambing et al., 2017; Zeanah, 2017).

Medically complex children

Children who are medically complex, such as those with inherited bleeding disorders, are at a greatly elevated risk for concerns with their learning, adverse medical outcomes, difficulty with psychosocial development, and concerns with family relationships (Mooney-Doyle & Lindley, 2020, p.74). Those children living with medical complexity are more likely to live with psychiatric disorders, but as a result of their needs, are typically undertreated (An, 2016; Kuo & Houtrow, 2016; O’Herron, 2016). Looking at addressing these challenges, Mooney-Doyle and Lindley (2020) used the Family Adjustment and Adaptation Response Model to identify common characteristics and challenges in addressing the wide range of needs in medically complex children and their families, including mental health and emotional needs as well as developmental delay. This was the first study of its kind to look at these challenges, as other complex care models have primarily focused solely on the medical needs of children who are medically complex (Cuttin, 2020; D’Aprano et al., 2019)

Similar to children who are medically complex for reasons other than inherited bleeding disorders, children who live with inherited bleeding disorders typically are treated in a comprehensive care clinic (Page, 2019). In the United States, these are most frequently run by Hemophilia Treatment Centers and include a team of doctors, nurses, a social worker, a geneticist, a researcher, and a physical therapist (National Hemophilia Foundation, n.d.; Page 2019). This interdisciplinary team can collaborate to provide comprehensive, coordinated care to best meet the needs of individuals living with inherited bleeding disorders (National Hemophilia Foundation, n.d.; Page 2019).

Medical trauma is a concerning factor that can impact overall learning for children who are medically complex. While pediatric patients tend to demonstrate high resiliency, children may have severe reactions to medical trauma that impacts their ability to function in their environment. Children who have existing risk factors including perception of severe pain during procedures, being separated from their caregivers for procedures, and those who have had previous negative experiences or difficulty with social-emotional skills are at an even greater risk for ongoing traumatic stress reactions (National Child Traumatic Stress Network, 2017).

Specific diagnosis- unrelated to bleeding

Medical technology has advanced much in recent years so that children who are medically complex are living longer lives than they were previously able to. However, with this come concerns as noted above that their quality of life regarding developmental, psychosocial, and family interactions are often at risk. Clancy et al. (2019), Cuttin et al. (2020), and Taft et al. (2020) all share that the available literature on the psychological, social, and emotional effects of being a medically complex child is virtually nonexistent. This is concerning due to the number of children who are living much longer lives with diagnoses of metabolic disorders or birth defects that used to mean those children did not make it out of infancy. Even more common genetic concerns like Down Syndrome now bring a new light in that individuals are living longer lives due to advances in medical care . (Clancy et al., 2019; Cuttin et al., 2020; Taft et al., 2020).

Families are crucial to their children's overall development. In order to address the intensive needs of children who are medically complex, more research must be conducted in this area. Clancy et al. (2019), Cuttin et al. (2020), and Taft et al. (2020) report the need for this additional research based on the substantial gaps in the current available literature. All share that the research on social-emotional impacts is not only lacking in pediatric patients, but also lacking for adult patients (Clancy et al., 2019; Cuttin et al., 2020; and Taft et al., 2020). Given the importance of social-emotional learning, this is an area of need to be further explored. Page (2019) describes the important role that the comprehensive care clinic can play in managing the multiple needs for those who are medically complex, supporting families as well as the children they care for.

Specific diagnosis- related to bleeding

There is a significant gap in the literature regarding research on children with inherited bleeding disorders overall, but more specifically the social-emotional learning of these children. Children with inherited bleeding disorders are a rare but widely diverse group with needs ranging from treatment only with significant trauma to those who require prophylactic treatment to manage day to day (Khair & Pelentsov, 2019; Palla et al., 2015; Saes et al. 2020). There are multiple considerations to think about when conducting research with this group. The parent perspective, which has been researched in a limited capacity, is certainly important when considering the needs of children with inherited bleeding disorders. However, the actual impacts to children need to be more fully understood so those providing care and support to these children, either through a hemophilia treatment center, complex care medical clinic, or primary care office as well as the caregivers can understand the vast impacts of having an inherited bleeding disorder (D'Aprano et al., 2019; Khair & Pelentsov, 2019). There is currently no available research regarding the childhood experience or perception of living with an inherited bleeding disorder.

Further complicating the concern regarding lack of research is that while there is some very minimal research specifically on the impacts of hemophilia to the family unit, the study of other inherited bleeding disorders specifically for young children does not exist outside of the Khair & Pelentsov (2019) study, which was the first time that research was conducted for a range of inherited bleeding disorders rather than just one type. However, while there were some strengths to this study, such as the number of fathers who participated in the research, overall, there was only a twenty-two percent response rate and it did not focus on the child experience or perceptions, but rather the experiences and perceptions of the family.

The study by DeKoven et al. (2014) was different from Khair & Pelentsov (2019) in that it focused on the experiences of children living with hemophilia. This study primarily addressed caregiver burden, much like the Khair & Pelentsov (2019) study. Of note, caregivers in the DeKoven et al. (2014) study shared that the emotional impacts of their child living with hemophilia were difficult to manage, suggesting that more investigation could be completed in this area to assess the social-emotional needs of these children. The described emotional impacts on the caregivers lead one to question what the perceptions of the child are in these circumstances, how these emotional impacts reflect in regard to interactions with the child, and whether the emotional impacts lead to any restriction of activities that could promote social emotional learning.

While promoting programs that have research-backed frameworks, such as Pyramid Model practices, in place to promote social-emotional learning for children with inherited bleeding disorders would be ideal, many programs do not have such frameworks in place or have not yet reached fidelity implementation of these practices. Caregivers are often overwhelmed with the needs of their child or children with additional needs, creating high levels of stress (Jackson et al., 2016).

Education for Children with Special Healthcare Needs

Children who are medically complex require additional considerations when attending education programs at any age. This is especially true in early childhood when they are unable to adequately advocate for their needs due to developmental constraints (Fettig et al., 2021; Rantalainen et al., 2021).

Child Development

Children living with inherited bleeding disorders may have impacts on their development, especially in the social-emotional domain, which may be further exacerbated by parental reactions to the diagnosis. Fear of hurting their child through rocking, holding, and playing with them can impact the safe and secure attachments needed by young children to support their learning. While concerns for bleeding are real, children need to be supported to explore their environments to encourage cognitive, motor, communication, and social-emotional learning (D’Aprano et al., 2019; DeKoven et al., 2014; Khair & Pelentsov, 2019).

Some parents do develop significant fears over their children participating in activities that their peers who do not have inherited bleeding disorders participate in, including childcare and school programs (Jackson et al., 2016). It is generally recommended that young children with inherited bleeding disorders participate in the same activities they would if they did not have a bleeding disorder. However, these activities may need some modifications, particularly for large motor activities where small bodies that are still learning where they are in space are moving fast, such as riding a tricycle, running, and climbing (Hemophilia Foundation of America, 2022).

There are a few activities that children with inherited bleeding disorders should not participate in, mainly high-contact sports like wrestling, hockey, and tackle football due to the drastically increased risk for injury (Hemophilia Foundation of America, 2022). Some children begin participating in these activities around four to five years of age, making this an important consideration even in early childhood. High contact or high impact activities in the early childhood classroom also should be avoided in order to minimize the risk for bleeding while at school or childcare. Intra-cranial hemorrhage can occur with these activities, which is a huge risk factor for impacts to overall learning with more pronounced impacts to cognitive functioning (Gardner et al., 2019).

Much of what is known about hemophilia, which has been studied more extensively than other inherited bleeding disorders, comes from the Hemophilia Growth and Development Study (HGDS) conducted by Hilgartner et al. in 1993. This study discovered that children with hemophilia had lower scores across all areas of development, putting them at risk for behavior problems, difficulty with attention, and testing poorly on achievement measures. Children with hemophilia were more likely to be enrolled in special education programs, have difficulty building and maintaining positive relationships, and have a higher incidence of identified learning disabilities. Of note however, this study was conducted before home care and prophylactic treatments were readily available. With the advent of nasal sprays, home infusions, and other methods for treating bleeds these results may no longer be applicable. Therefore, there is a current ongoing study being conducted by Buranhirun et al. (2019) called the eTHINK study that aims to re-examine these issues for applicability given the changes that have happened over the last 27 years. Focusing solely on only one type of inherited bleeding disorder is a limitation for both the HGDS and eTHINK studies, however, generalizations can be made from this information given the similarity of various bleeding disorders and their impacts on both children’s lives and education.

Attendance

Children who are medically complex, which includes children with inherited bleeding disorders, are often impacted by attendance requirements. State law dictates that there may only be ten parent excused absences per school year, though does not limit absences when excused by a medical professional (Pennsylvania Department of Education, 2023). However, for families who are accustomed to treating many of the complicating factors that may be enough to keep a child home but not enough to go to the doctor, this can prove challenging. Focusing on building strong relationships between school officials and caregivers is key when evaluating concerns for attendance. An individualized approach should be considered for addressing attendance issues, however, the current blanket policies driven by state and federal laws that focus on punitive methods for addressing attendance present a barrier to this (Lissack & Boyle, 2022; Melvin et al., 2019).

Some doctors, aware of a child’s needs, will provide a note for families without an office visit. Others require an office visit for any note. There are multiple concerns with requiring a visit for such notes, including disproportionately higher rates of unexcused absences for those who are socioeconomically disadvantaged (Chang et al., 2023). Parents often must take time off to take their child to the doctor, have increased fuel or other transportation costs for traveling to appointments, and may need to arrange childcare for other children. With the COVID-19 pandemic, most doctor's offices are not permitting siblings to attend appointments with the child in question. Additionally, there may be co-pays or deductibles that need to be met in order to receive such care. All of these financial factors put additional strain on medically complex families. The logistics and organization required to attend appointments also is a complicating factor. Finally, some doctor's offices are not able to support same-day appointments, resulting in additional costs and time out of school for children with inherited bleeding disorders (Cady, 2017).

Attendance is highly correlated to school success, with some studies demonstrating that this begins as early as preschool (Sommer et al., 2017; UK Department of Education, 2017). When children have frequent absences from their early education programs, they miss out on vital instruction in core areas- most notably social-emotional learning. The ability to form close and secure relationships with early education teachers and peers is a key skill needed to develop other early learning skills (Bailey, 2015; Fettig et al., 2021; Hammond, 2014; Sandall et al., 2019). Students who attend school consistently are able to develop firm routines, learn the expectations of the classroom and activities, and develop relationships with both staff and peers in the class. They also have higher academic scores in reading, math, and overall achievement.

Time out of class is another factor when considering attendance in the program. While the child may be physically present at school, they may need to attend to medical needs within the classroom. Alternatively, they may need to go to the nurse's or director's office for treatment and/or monitoring during the school day. This additional time out of class is still an attendance issue as children are missing essential instructional time in class to attend to these needs (Cady, 2017; UK Department of Education, 2017).

Relationship building

Young children learn best through forming close and secure relationships with their caregivers and peers as they work on skill development. These early social skills set the stage for all other learning. Stress management, positive relationships, language development, reduction in externalizing behaviors, and increase in cognitive functioning are all seen in children who have a strong foundation in early social-emotional skills. (Fettig et al., 2021; Rantalainen et al., 2021; Wolf et al., 2021). When children are in an environment where healthy opportunities for learning and development take place in a safe and supportive atmosphere through strong relationship building, children are better equipped to learn and grow (Jackson et al., 2016).

The HGDS study (Hilgartner et al., 1993) noted significant impacts to social-emotional learning and relationship building for children living with hemophilia. Behavior problems and social-emotional concerns occurred at a higher rate for children with hemophilia than their peers without hemophilia. Baumann et al. (2017) noted that ninety-eight percent of study participants in the Hemophilia Experiences, Results, and Opportunities (HERO) study identified as having difficulty participating in activities that would promote social-emotional skills and relationship building due to concerns with their inherited bleeding diagnosis. This is particularly concerning given what is known about social-emotional learning and its critical importance. Without strong social-emotional skills, other learning becomes more difficult (Hemmeter et al., 2020).

Early childhood education programs can provide a strong foundation in these rapidly developing skills that promote school readiness whether these are at childcare centers, traditional preschools, non-traditional preschools, or early elementary classrooms. They also can assist caregivers in building strong relationships with the program and their child through parent education programs, which can help builds relationships among the early learning community while also reducing stress for caregivers (Behrendt et al., 2019; Colker et al., 2020; Jackson et al., 2016).

Summary

Children with inherited bleeding disorders are often subjected to significant medical trauma early in life as a result of their diagnosis. These children experience frequent procedures that are needed such as repeated bloodwork and regular infusions, sometimes administered at home by their parents (Hay et al., 2017; Mahlangu et al., 2019). Attachment is a crucial piece of developing social emotional skills in early childhood **(**Crittenden, 2017; Bowlby, 1944; Ainsworth, 1978). The traumatic and difficult experiences lived by children with inherited bleeding disorders could lead to concerns with attachment. The child's "safe" people who they are to form attachment to and who support their learning of strong social emotional skills are frequently present for or conducting these traumatic procedures (Colker et al., 2020; Curran et al., 2020; Fettig et al., 2021).

High-quality early childhood education programs may provide opportunities for social-emotional learning, which impacts all other learning (Bailey, 2015; Clayton et al., 2021; Cosso et al., 2021; Dusenbury & Weissberg, 2017; Phillips et al., 2017). Parents of children with bleeding disorders are often concerned about their children participating in typical childhood activities including accessing early childhood education programs for fear that their child will have a bleeding episode requiring treatment which can impact both social-emotional learning and attachment. At times, children are limited from activities due to concerns regarding bleeding and being able to support children in toddler and preschool education settings or daycares. Extended absences or tardiness to education programs is commonly seen as children who are medically complex have an increased number of treatments and medical appointments that must be tended to in order for them to be able to participate fully in home and community activities (Cady, 2017; UK Department of Education, 2017). This could result in impacts to these children's social-emotional learning.

Concerns with false allegations of child abuse further impact caregivers and their children living with inherited bleeding disorders. The AAP has released a policy statement urging practitioners to do their due diligence and thoroughly investigate all potential medical causes of abuse prior to assuming the child is victim of child abuse (Bressan et al., 2020; Kuehn, 2013). Due to the nature of inherited bleeding disorders, families are at a higher risk of being reported to child welfare agencies due to the similarity of bruises that is sometimes seen in children with inherited bleeding disorders to children who have experienced physical child abuse (Andherst et al., 2013). Concerns around false reporting can impact attendance for children as parents may keep them home instead of focusing on individualizing for child needs and engaging in positive supports for families (Anderst et al., 2013; Lissack & Boyle, 2022).

The impact of bleeding disorders on social-emotional learning in young children has not been studied. There is one study on the impact of a child's bleeding disorder on parents and one study on social impacts for adults living with bleeding disorders, but largely, young children and their bleeding diagnoses have not been studied (Baumann et al., 2017). There is one study with some learning implications, but the only population studied was those with hemophilia and does not cover the wide range of bleeding diagnoses that exist (Baumann et al., 2017). Some research exists on medically complex children, but again, this research is limited and focuses primarily on mental health versus specifically on social-emotional learning and is conducted through the lens of the caregivers' perceptions rather than the child's perceptions and experiences . Further, much of the research that is available is more than five years old. This leads to concerns with the validity regarding having the most current information in regard to current trends and discussions for children with inherited bleeding disorders.

It has been largely recognized that social-emotional learning of young children is critical to development (Bailey, 2015; Burroughs & Barkauskas, 2017; Spehr et al., 2019; Hemmeter et al., 2016; Murano et al., 2020; Ocansey et al., 2019; Rademacher & Koglin, 2018), though the impact on social emotional learning is not something that is focused on by medical practitioners in the field when treating medically complex children even when that treatment takes place primarily in a comprehensive care clinic designed to meet the comprehensive needs of the child and their family (Cady, 2017; Yoon et al., 2020). Through examination of social-emotional learning of young children with bleeding disorders, medical practitioners recognize the needs of these children and their families, creating a more comprehensive care plan that brings the early childhood education team into the fold, ensuring seamless integration of the skills necessary for these children to succeed. Programs aimed at supporting awareness of the needs of these children and making opportunities more accessible to them need to be refined to including not just the medical team, but also caregivers and educators of young children.

Caregivers are critical players in the learning of social-emotional skills in early childhood. In evaluating these needs through a comprehensive care team lens, parents recognize the importance of this and address social-emotional learning as well as work towards addressing their own biases. The comprehensive care team model works in supporting the social-emotional learning of these medically complex children with bleeding disorders to prevent delays in social-emotional learning (Cady, 2017; Cassis et al., 2014). The prevention of these delays is crucial for quality of life, prevention of long-term health concerns, and school achievement as young children begin to move through their academic life (Hilgartner et al., 1993). Through participation in early childhood programs and relationship building between educators, caregivers, and comprehensive care teams, positive outcomes can be achieved for children with inherited bleeding disorders.

It is exceptionally clear during the review of the available literature that children with inherited bleeding disorders as well as those who are medically complex are an under-studied population with many opportunities for research (Cady, 2017; Cassis et al., 2014; Hilgartner et al., 1993). These include the impacts of the diagnosis, perception of social-emotional learning, and long-term impacts of treatment on social-emotional learning among others. This research is necessary in order to assist comprehensive treatment teams and educators in understanding and implementing strategies to positively impact children with inherited bleeding disorders and support their participation in early childhood education programs.

CHAPTER THREE: METHODS

Overview

The purpose of this transcendental phenomenology is to explore caregivers' and early education professionals' experiences of supporting the social-emotional learning of young children with inherited bleeding disorders and its impact on early childhood education in Western Pennsylvania. This was done through interviews with caregivers and professionals as well as document analysis. This allowed me to investigate the shared experience of caregivers and professionals of young children with inherited bleeding disorders. There have been little to no studies conducted on the social-emotional experiences of young children with inherited bleeding disorders. A greater understanding of this phenomenon may result in increased quality of life for young children with inherited bleeding disorders due to the importance of social-emotional learning. Additionally, it could assist with identifying targeted needs when considering early childhood education programs for medically complex children. This chapter covers the research design, questions, setting, and participants as well as researcher positionality, role of the researcher, and procedures that were used during the course of this study.

Research Design

Due to the rare nature of inherited bleeding disorders, it was expected that the sample size for this research study would be small. It was best served by using qualitative methods such as interviews, focus groups, and document analysis. This allowed me to examine the shared experiences of caregivers of young children with inherited bleeding disorders while gathering data. This data was then used to enhance understanding of the perceived impacts to social-emotional learning and the impacts to early education.

Qualitative and quantitative research methods were considered in the design of this study. Quantitative research does not focus on experiences, which is key to this study. Therefore, phenomenology was chosen for this study as a result of wanting to understand the experiences of caregivers regarding their perceptions of social-emotional learning for their young children with inherited bleeding disorders. This qualitative study design is appropriate as it examined that personal connection and sought to understand an experience (Creswell & Poth, 2019). Case study was also considered for this design, however, wanting to gain a larger picture that included a greater number of caregivers made case study unrealistic for this study. Phenomenology is "the science of describing what one perceives, senses, and knows in one's immediate awareness and experience" (Moustakas, 1994, p. 2) and therefore the most relevant study design to examine the perceptions and experiences of caregivers who have young children with inherited bleeding disorders. I conducted interviews with eight caregivers of young children with inherited bleeding disorders as well as three early childhood professionals. Further, I completed a focus group with to better understand the experiences of these individuals in how they are all supporting the social-emotional learning of young children and its impact on early childhood education.

The experiences of caregivers and early education professionals are paramount to understanding this phenomenon further, and as such, transcendental phenomenology was utilized to complete this study. This type of research focuses on participant experience (Creswell & Poth, 2018). This research is a fresh take on an important subject- that of social-emotional learning, therefore it was necessary to develop common themes to set the stage for further research after we begin to understand the common experiences shared by caregivers (Moustakas, 1994). By using both structural and textural descriptions of the experiences of caregivers who have young children with inherited bleeding disorders, common themes were discovered that can aid in a more complete understanding of the perceptions regarding social-emotional learning for young children with inherited bleeding disorders and potential impacts to their early education (Moustakas, 1994; van Manen, 2014).

Research Questions

The research surrounding medically complex children is extremely limited and non-existent for social-emotional learning of young children with inherited bleeding disorders. Several questions were developed to be investigated during this study based on the lack of research currently available. Through the course of this research, the following questions were examined and answered.

Central Research Question

How do caregivers of young children with inherited bleeding disorders describe their experiences of supporting the social-emotional learning for their children?

Sub-Question One

How do caregivers describe their experiences of providing and receiving support for their young children with inherited bleeding disorders?

Sub-Question Two

How do caregivers describe their experiences with supports that are provided to enroll their child in early childhood education programs?

Setting and Participants

A detailed description of the proposed setting and participants is outlined in this section. This includes where the study occurred and the participants in the study. Caregivers and early education professionals were the primary participants, with the study occurring within the local chapter of the National Hemophilia Foundation.

Site (or Setting)

Through examining the geographical information and enrollment information from the local chapter of the National Hemophilia Foundation, it was determined that the best setting would be within the local chapter's New Parent Network membership and local early childhood organizations. To ensure accessibility for all participants, study activities were conducted virtually through an online meeting platform, Google Meet, as the coverage area for the chapter is large (Western Pennsylvania Bleeding Disorders Foundation, n.d.). This allowed caregivers the opportunity to share their experiences regarding their child's social-emotional learning in a manner that had less impact to daily life due to not needing to travel for participation. Documents were collected from caregivers for analysis via email. Email was always a viable method for document collection for the caregiver, however, if it had not been then a self-addressed stamped envelope would have been provided for mailing. Data was then reviewed and analyzed from these data collection methods.

Participants

The participants of this study were the primary caregivers of young children aged birth to seven who are living with inherited bleeding disorders and early education professionals. Approximately seven to ten caregivers who are members of the local chapter of the National Hemophilia Foundation and two to four early education professionals who work with these children were expected to participate in this study. Every effort was be made to include a diverse sampling of participants, it is recognized that many inherited bleeding disorders disproportionately affect males of all ethnicities (National Hemophilia Foundation, n.d.) which could impact the ability to equally sample participants. Throughout the course of the study, I was able to interview eight caregivers and three early childhood professionals who are impacted by a variety of bleeding disorder diagnoses. Of these participants, 3 of the affected children were female and the remaining 8 were male, aligning with concerns regarding disproportionality due to the higher number of males who are living with inherited bleeding disorders.

Researcher Positionality

When considering topics for research, I knew that I would study social-emotional learning in young children as this is my field of employment and I believe strongly in the importance of social-emotional learning as it relates to all other learning in education. However, as I moved through the program, I realized how little research there is on the impacts of having an inherited bleeding disorder for my own children. Three out of four of them have a platelet dysfunction disorder, and one of those three has an additional diagnosis of Factor VII deficiency. While I grew up unaware of my own disorder, my children were all diagnosed young and have faced different experiences and limitations in participation in community activities as well as educational opportunities as a result of their diagnosis. In our participation with our local chapter of the National Hemophilia Foundation, I found that many young children with inherited bleeding disorders have not been able to participate in the same activities and educational opportunities that children without inherited bleeding disorders have due to restrictions from doctors, agencies, or the parents themselves. This led me to question whether there are significant impacts to social-emotional learning for young children with inherited bleeding disorders and if so, what are those impacts? Identifying whether anything can be done to enhance the comprehensive care model to lessen any potential impacts to social-emotional learning for young children with inherited bleeding disorders was another area to examine. Using a phenomenological study will not answer these questions, but did allow me to explore caregiver experiences and expand the field of research for this subject.

Interpretive Framework

This research was conducted to understand more about the world of those living with inherited bleeding disorders. Understanding experiences is an aspect of research that aligns with social-constructivism (Vygotsky, 1978). The idea and perceptions of social-emotional learning vary greatly among caregivers depending on their own life experiences. Consideration of this while also considering the impact of what are generally accepted as social-emotional norms for learning and the impacts on education allowed me to examine this complex topic. My background as an adult living with an inherited bleeding disorder who works in the field of early intervention focusing on the social-emotional learning of very young children and parent of three children living with inherited bleeding disorders has definitely influenced and shaped my experience. Using the interview process as well as document analysis helped interpret the experiences and perceptions of those participating in the research to help create meaning from these accounts (Creswell & Poth, 2018). The comprehensive care model utilized by many hemophilia treatment centers further creates need for collaborative practices across the medical, community, and educational realms such as those common in social constructivism (Vygotsky, 1978).

Philosophical Assumptions

The three philosophical assumptions that were addressed during the course of this research include ontological, which focuses on my beliefs of the nature of reality, epistemological, which focuses on how that reality is known, and axiological, which is the role of the values (Creswell & Poth, 2018). These philosophical assumptions helped to guide my research. Understanding these assumptions helped ensure that there was consideration of any potential bias and how it may have impacted the research that I was conducting. It also helped ensure that there was a comprehensive view of the problem through development of common themes.

Ontological Assumption

The starting point of this study was within the themes developed from this research. These themes did in effect create different realities that can be examined for relevance to the comprehensive care model utilized by hemophilia treatment centers who treat those with varied bleeding disorders as well as the educational facilities where these students learn. Social-emotional learning is generally considered an objective topic, however, there are many different ways that it can be viewed by parents thus creating different realities for these. By using objective measurements such as the social-emotional questionnaire, knowledge can be gained to help reinforce the research. The different themes helped to define the varying perspectives that are reported by the primary caregivers of young children with inherited bleeding disorders.

Interviews are rarely identical and can be prone to interpretation (Höijer, 2008). The unique experiences of individuals creates subjective realties. Ontological assumptions understand that individuals have multiple realities of a phenomenon or situation based on their personal experiences (Creswell & Poth, 2018).

Epistemological Assumption

When thinking about this research and how it was conducted, it was critical to evaluate the epistemological side as qualitative research has fewer concrete, numbers-based data results with which to base results on. The belief that knowledge is constructed rather than found leads one to believe that the information regarding social-emotional learning of young children with inherited bleeding disorders already exists and simply needs to be compiled and shared (Höijer, 2008). The use of interviews paired with focus groups and document analysis helped to reduce some of the questions that may arise about the subjectivity of this research. My role in this research was to develop a relationship with the participants so that they are comfortable opening up and having frank, honest discussions with me about their experiences regarding the social-emotional learning of their child (Creswell & Poth, 2018). While I as the researcher am involved with the local chapter of the National Hemophilia Foundation, as a newer member, I do not have existing connections with those who I will be interviewing, lessening the chance for influence from this. As an early education professional myself, I reached out to local education facilities to connect with and gain the experiences of early childhood professionals as well as connected with professionals with whom I did not have a close relationship with.

Axiological Assumption

As an early interventionist, I believe in the importance of social-emotional learning on all areas of learning. That being said, this is not something that would bias the research as the importance of social-emotional learning can be found across the research. Despite the documented importance of social-emotional learning, often other areas of learning are anecdotally perceived as more valued in the work I do. My own personal beliefs are not seen as an influence to this research at this time due to the existing literature that supports the importance of social-emotional learning (Creswell & Poth, 2018).

The value in conducting this research lies in the fact that young children with inherited bleeding disorders are a part of the community yet may not have appropriate supports in place to assist them in ensuring their social-emotional needs are met in the home, community, or educational settings. The comprehensive care model would benefit from a better understanding regarding caregiver experiences and perceptions of social-emotional learning for young children with inherited bleeding disorders. Further, early intervention programs and early childhood education programs would benefit from recognizing those who may be more at risk of concerns with social-emotional learning and how this can impact overall learning as these children participate in activities in the communities where they live.

Researcher's Role

As I gathered participants and conducted this research, I worked with other members of the bleeding disorders community of which I am a member as well as the early education community of which I also am a member. However, I do not have close or personal relationships with these other members. I do believe that having an inherited bleeding disorder increases risk for concerns with social-emotional learning, hence why I conducted this study. It was my job as a researcher to ensure that I was looking at the data gathered objectively. This is why I used memoing paired with the interviews. Use of memoing helped to reduce any bias due to the assessments being analyzed for themes being previously developed and implemented with fidelity.

Interviews conducted both individually and through focus groups were analyzed using the whole-parts-whole process outlined by Vagle (2018). This process of reviewing the interviews reduces bias by evaluating the entire text, looking at parts of the text, then forming questions for the second interview if applicable. These follow-up questions allowed me to clarify any meaning from the first round of interviews rather than create assumptions. Themes can be developed from these repeated reviews of the text, creating the opportunity to analyze the data for further understanding (Moustakas, 1994). As the human research instrument, I utilized memoing throughout the research to ensure biases and presumptions did not interfere with data and to ensure that I was receptive to my participants (Moustakas, 1994).

Procedures

The procedures I used to conduct this study are outlined below. There are some concerns with the impact of living through a pandemic on children’s social-emotional learning that could impact this study, therefore it was important that these procedures were clearly outlined for replication. This section will allow other researchers to evaluate and replicate the study if so desired.

Permissions

Permission for this study was obtained by the IRB and the IRB approval letter resides in Appendix A of this document. Further, the local chapter of the National Hemophilia Foundation was be contacted in order to determine whether they would be a viable option for conducting this research. They were in agreement to reach out to their membership through the New Parent Network to identify participants for this study via informal conversations that have taken place thus far. Early education professionals will be located in Western Pennsylvania at various institutions and may include Early Head Start and Head Start programs, social workers at the local Hemophilia Treatment Center, and private preschools. Please see Appendix B for site approval.

Recruitment Plan

There are approximately thirty families of young children with inherited bleeding disorders who participate in the new parent network in the local chapter of the National Hemophilia Foundation (Western Pennsylvania Bleeding Disorders Foundation, n.d.). Of these, it was expected that between seven to ten caregivers will participate in this study through purposive sampling, specifically using homogenous sampling. An additional two to four early education professionals were identified in a similar manner. This sampling method was chosen due to needing to identify participants that have specific characteristics and not just random participants (Etikan, 2016). Caregivers were sent an email from the local chapter of the National Hemophilia Foundation asking them to participate. Several Facebook posts were made seeking participants. The participation rate within the local chapter for events and research is higher than what would be considered a “good” typical rate of thirty percent, so I believed that there would be no issue with recruiting the participants outlined here. For example, the last new parent network chapter event had seventeen out of thirty families participate, some traveling from three hours away to participate. This fifty percent participation rate is higher than the typically expected thirty percent participation rate (Etikan, 2016). However, when recruitment began, there were several extenuating factors including several major bleeding disorder foundation events that were running concurrently to the recruitment effort, making it difficult to recruit the needed number of participants. Through connections in the bleeding disorder community, the participants were all identified and interviewed by the beginning of November.

Purposive sampling was utilized for this study design due to the nature of the research being conducted, specifically homogenous sampling. I sought to understand social-emotional learning specifically in young children with inherited bleeding disorders in relation to their early childhood education experience, therefore it was important to ensure that the sample meets these criteria (Creswell & Poth, 2018). Members of the bleeding disorder community and the early childhood education community were uniquely qualified to answer these questions in a way that other people are not, and therefore this method is the most appropriate.

Informed consent (see Appendix B) was obtained from all participants in this study. This was done in writing before participation in the study began. Since participants were meeting through Google Meet, DocuSign was utilized as an electronic signature service to capture these signatures. Consent documents and any other documents with identifying information were stored on a password protected computer with two-factor authentication in order to maintain confidentiality.

Data Collection Plan

When beginning this research, I engaged in data collection by conducting the interview with participants following obtaining all proper consents. These two steps took place during the same session and fall into the orientation and overview phase and focused exploration phase as defined by Lincoln and Guba (1985).

Following completion of the interview, caregivers were asked to provide any recent assessments conducted by the early intervention program. This falls into a further focused exploration phase (Lincoln & Guba, 1985). Email access was utilized for this portion, though a self-address stamped envelope would have been provided had a participant not had email access. I reviewed these documents as part of the data analysis plan.

A focus group occurred during stage three of the data collection plan. This focus group provided an opportunity for me to discuss social-emotional learning and caregiver experience within a small group. By conducting this small group interview, it allowed me to discuss experiences with the group. The group also had the opportunity to recall additional experiences as a result of the broader discussion.

A constant comparison allows for the data to be analyzed at the same time it is being collected (Glaser & Strauss, 1967). I completed this constant comparison to aid the data collection process. This then allowed me to develop a hypothesis about the data based on the initial data and refine it as I gathered more information through return and analysis of the documents that were provided by families regarding services they are already receiving in relation to their child’s social-emotional learning in early intervention programs.

Individual Interviews (Data Collection Approach #1)

The research questions for the initial interview are listed below. Interviews allowed for information to be gathered about experiences including feelings and how a person perceives those experiences (Lincoln & Guba, 1985). As the researcher in this study, I framed the questions and expected the participants to respond to each of these questions, using the structured interview approach. Interviews were conducted online via recorded Google Meet sessions and later transcribed. Each interview took approximately one hour.

Individual Interview Questions for Caregivers

1. Please tell me about your child’s inherited bleeding disorder diagnosis. (CRQ)
2. What challenges, if any, has your child faced with this diagnosis? (CRQ)
3. What supports, if any, does your child receive from early intervention? (SQ2)
4. Tell me about your experiences with accessing programs for your child such as daycare, early education programs, community classes, etc due to your child’s bleeding disorder. (SQ1)
5. Please describe any challenges you may have had with accessing these programs or if you have had no challenges, describe your experience with these programs. (SQ1)
6. Have you had any concerns with your child’s social-emotional learning? (CRQ)
7. Tell me about your experience with discussing your child’s social-emotional learning with doctors, family, or teachers. (SQ2)

8. If you have had concerns with your child's social-emotional learning, tell me about the discussion you have had about these concerns with your child's comprehensive care team. (SQ2)
9. What is your experience with the supports that you have been provided with by the comprehensive care team? (SQ2)
10. Are there supports you would like to see offered to help support your child's social-emotional learning? (SQ2)
11. Please describe how the social-emotional needs of your child are met. (CRQ)
12. Please tell me whether you feel adequately supported by the comprehensive care team including medical, social, and educational supports. (SQ2)
13. Share your experiences of what has gone particularly well as you have supported your child's social-emotional learning in the home, school, and community settings. (SQ2)
14. Tell me what you think early childhood professionals need to know in order to effectively support your child. (SQ3)

These questions were chosen for inclusion in this interview protocol in order to better understand the experiences of caregivers as they navigated the diagnosis as well as the social and educational challenges that come with having a young child with an inherited bleeding disorder and their participation in early childhood settings. They specifically outlined the type of inherited bleeding disorder, which may later be coded into mild, moderate, or severe which relates to the central research question. Challenges faced with the diagnosis align with concerns with social-emotional learning and so were discussed and analyzed for potential common themes and are also relevant to the central research question. Access to early childhood education programs also can potentially impact social-emotional learning, hence questions three, four, and five. Finally the remaining questions six through fourteen cover information that we needed to evaluate concerning all three subquestions. Concerns with social-emotional learning as well as any supports currently being received allowed me to analyze whether participants are already experiencing concerns or whether caregivers or early education professionals perceive that additional supports could be provided to assist young children with inherited bleeding disorders.

Individual Interview Questions for Early Childhood Professionals

1. Please tell me about your experiences in working with children/students with inherited bleeding disorders. (CRQ)
2. Describe your experiences providing social emotional learning support for students with inherited bleeding disorders? (SQ2)
3. What strategies do you use to when providing social emotional learning for your students? (SQ2)
4. What professional development experiences have you had in social emotional learning? (SQ2)
5. Describe any training that you've had for working with students/children with inherited bleeding disorders or other medical issues. (SQ2)
6. What differentiation occurs when working with students with inherited bleeding disorders when compared to traditional students who do not have these types of medical issues? (SQ2)

These questions were chosen for inclusion in this interview protocol in order to better understand the experiences of early childhood professionals as they navigate the inclusion of a child with an inherited bleeding disorder diagnosis into their early childhood program. Questions one, two, and six specifically focus information related to both the central research question as well as the subquestions. The social and educational challenges that come with having a young child with an inherited bleeding disorder and their participation in the early childhood setting are also answered through questions one, two, and six. Questions three, four, and five talk about the overall experience and education that the early childhood professional has with social-emotional learning and is relevant to their perceptions of what young children with inherited bleeding disorders may need. Challenges faced with training in social-emotional learning, differentiation, and supporting children who are medically complex align with concerns with social-emotional learning and so were discussed and analyzed for potential common themes and are also relevant to the central research question. Concerns with social-emotional learning, ability to differentiate and identify needed supports, and training of early childhood professionals allowed me to analyze whether early education professionals perceive that additional supports could be provided to assist young children with inherited bleeding disorders.

Individual Interview Data Analysis Plan (Data Analysis Plan #1)

Once all of the interviews were completed, they were be transcribed and analyzed via thematic content analysis. This allowed me to determine the common themes and their importance by labeling the most important categories and subcategories. Thematic content analysis allowed me the flexibility in developing the most common and critical themes, which were aligned with the themes from the questionnaires. Themes included in the questionnaires that aided in analysis of data from the interviews included self-regulation skills, the ability to communicate wants and needs, responsiveness to caregivers and peers, sleep, feeding, joint attention, and maladaptive behaviors. Codes were assigned to each of these categories as well as any other themes that came up during the course of the interviews. Each of the themes were defined, named, and described. These were then triangulated with the other data sources such as document analysis.

Document Analysis (Data Collection Approach #2)

Families were asked if they are receiving any type of early intervention or education supports as part of the interview process. These supports could come from Early Head Start or Head Start programs, the county birth to three early intervention program, or the three to five early intervention program. Families who received these supports were asked to share the social-emotional information and summary from their child's multi-disciplinary evaluation for services or recent assessments completed in the Early Head Start or Head Start programs. These assessments were an important consideration if children had been evaluated due to concerns with social-emotional learning or were already receiving services to consider how the receipt of such services may impact parental perception of social-emotional learning and experience in early education programs as discussed during the interviews. Creating themes from the narrative section of these documents helped to align experiences between the interviews and in education settings. This type of document was not available for every participant and may have impacted data integrity. Only two participants were able to share information from their early intervention experiences.

Document Analysis Data Analysis Plan (Data Analysis Plan #2)

The data from the available multi-disciplinary evaluations for those children who have been previously evaluated for early intervention services and the assessments completed in the Early Head Start or Head Start programs was analyzed by coding the social-emotional concerns by theme. This was challenging as not every early intervention agency utilizes the same assessment, and so it was important to consider the relevance of the provided information according to the same themes across assessments, such as social communication, maladaptive behavior, and so on. Furthermore, only two participants were able to share documents related to their early intervention experiences. Local Early Head Start and Head Start programs utilize the Ages and Stages Questionnaires: Social Emotional, Second Edition for assessment of social-emotional skills, so there are no concerns regarding coding themes across different assessments for children participating in Early Head Start and Head Start programs. There were no children who were enrolled in Early Head Start or Head Start programs during the course of this study. The creation of these themes from the narrative section of the documents provided helped align experiences between the caregiver interviews and education settings.

Focus Groups (Data Collection Approach #3)

The research questions for the focus group are listed below. Focus groups allow for information to be gathered about experiences including feelings and how a group perceives those experiences (Lincoln & Guba, 1985). I framed the questions during the focus group and asked the participants to respond to these questions. This was completed by using a structured interview approach. The focus group was conducted online via recorded Google Meet sessions due to geographical constraints and later transcribed.

Focus Group Questions

1. What is your experience with early childhood social-emotional learning? (CRQ)
2. Tell me about your experiences with supporting your child’s social-emotional learning. (CRQ)
3. What has your experience been with exploring options for early childhood education including daycare, preschool, toddler classes, etc. (SQ2)

4. Describe any challenges you have encountered when enrolling your child in these types of programs? (SQ2)
5. What has gone well when enrolling your child in early education programs? (SQ2)
6. Tell me about your experience with supporting your child's social-emotional learning when enrolling them in early education programs. (SQ1)
7. Please describe your experiences with receiving support, if any, from your child's early education setting. (SQ1)
8. How has your comprehensive care team assisted in supporting your child's early social-emotional learning, and if so, how? (SQ1)

Focus Group Data Analysis Plan (Data Analysis Plan #3)

The data analysis plan for the focus groups was similar to the individual interview data analysis plan due to the nature of the format. Once the focus group was completed, the meeting was transcribed and analyzed via thematic content analysis. This allowed me to determine the common themes and their importance by labeling the most important categories and subcategories. Thematic content analysis allowed me flexibility in developing the most common and critical themes, which were then aligned with the themes from both the individual interviews and the document analysis. Themes included in the interviews and document analysis that aided in analysis of data from the focus group included self-regulation skills, the ability to communicate wants and needs, responsiveness to caregivers and peers, sleep, self-regulation, feeding, joint attention, and maladaptive behaviors. Each of these categories were coded as well other themes that came up during the course of the focus group, which were then analyzed for relevance to the study. Each of the themes were defined, named, and described. These were then triangulated with the other data sources such as document analysis and interviews.

Data Synthesis

Once all the data was collected and analyzed individually, data synthesis began. The data was triangulated using the aforementioned sources, examining for the common themes among the various sources. This thematic synthesis resulted in developing descriptive themes which can be translated and triangulated through these themes. Quality assessment occured through use of these themes and member checking.

Member checking occured throughout, giving me the opportunity to ensure that I did not misinterpret information and creating less potential bias in the analysis of the research. Encouraging participants to participate in member checking by reflecting on their answers allowed them to correct any errors I made in interpreting their answers (Lincoln & Guba, 1985). This thematic synthesis is considered the most common in qualitative research (Drisko, 2019) and is most definitely appropriate for this research as we aim to understand the common themes regarding the education of social-emotional learning for children with inherited bleeding disorders. Merging all data sources to create common themes is a core element of phenomenology.

Trustworthiness

Credibility, dependability, and confirmability are all essential elements of establishing trustworthiness in research. Each of these areas has been considered when thinking about the best way to conduct this research and produce meaningful results. There must be established truth in the findings as well as relevance to other contexts in order to establish trustworthiness (Lincoln & Guba, 1985). Both internal and external validity can be considered when working to establish trustworthiness in addition to credibility, dependability, and confirmability as previously mentioned.

Credibility

In order to establish credibility, I engaged participants in prolonged engagement, which has been described as a trust-building strategy and enhance the chances that "credible findings will be produced" (Lincoln & Guba, 1985, p. 301). I have a unique perspective in building trust as a fellow parent of multiple children with inherited bleeding disorders, and thus it is imperative that while engaging in this prolonged engagement, bias did not seep in in an effort to discredit these findings. As a result, in addition to memoing, member-checking was also be employed in an effort to establish credibility. Lincoln and Guba (1985) describe member-checking as "the most crucial technique for establishing credibility." The paired formal and informal method also provides numerous opportunities for implementation, making it a natural choice to ensure credibility within this study. I clarified some elements from the interviews with my participants as a way to member-check. Triangulation is another method of building credibility that was utilized during data analysis. Utilizing three of the five methods of credibility outlined by Lincoln and Guba (1985) enhances the credibility of this research study.

Transferability

Transferability is a "condition of representativeness" (Lincoln & Guba, 1985, p. 297) that is more the responsibility of the researcher who seeks to replicate the study than of the original researcher. Using empirical evidence is critical in order to attempt to replicate the study. This is why the inclusion of the document analysis of early intervention records when available to generate themes and compare to the interviews was an appropriate choice for this study. The multidisciplinary evaluation is based off of previously researched assessments found to be both reliable and valid through empirical evidence (Squires et al., 2015). No guarantee of transferability can be made with this study, however, an effort to create a setting of transferability was made through use of detailed narratives and thick descriptions from the interviews that take place with participants (Appleby et al., 2020).

Dependability

Lincoln and Guba (1985) describe dependability as “synonymous with reliability.” As such, it should be predictable and consistent so that the results could be replicated by another researcher. To ensure dependability in this study, an inquiry audit was conducted as per Liberty University policy. The Qualitative Research Director and dissertation committee reviewed the completed research process prior to publication to ensure consistency with the findings. They also examined whether sufficient detail is included for replication of the study (Lincoln & Guba, 1985).

In addition to these methods, the document analysis that was conducted was from assessments that have been previously researched and met reliability standards (Squires et al., 2015). This offers assurance that the themes taken from this analysis accurately and reliably identify social-emotional concerns for young children regarding their eligibility for early intervention services, regardless of their inherited bleeding disorder status. Squires et al. (2015) demonstrated that reliability scores stayed constant over time through an examination of convergent validity with other similar analysis.

Confirmability

Confirmability to establish whether these results could be corroborated by other researchers was established in this study via two methods. An audit trail was completed to ensure that the findings from this study are data-based. The second step was triangulating data to ensure there is no researcher bias and that the researcher is a neutral party. This resulted in some corroboration of evidence in regard to perceived social-emotional skills for young children with inherited bleeding disorders without concern that the results are not impacted by researcher bias (Lincoln & Guba, 1985).

Ethical Considerations

During the course of this study, informed consent was obtained from all participants via written consent, ensuring voluntary participation, confidentiality, and right to withdraw at any point. Additionally, data was deidentified and stored electronically on a password protected laptop with two-factor authentication. All data will be destroyed three years post-study completion. There was intent to utilize participants from vulnerable populations such as children, prisoners, or those who are cognitively impaired (Creswell & Gutterman, 2019), and it was confirmed that none of these populations were represented. There was a chance that someone who is HIV positive or has AIDS would be a participant due to the increased population of people with bleeding disorders who live with these diseases, however, this information was not disclosed as a part of this study and therefore is not relevant as their status as a vulnerable person does not need to be revealed as a result of this study (Creswell & Gutterman, 2019).

Participants were recruited from the local chapter of the National Hemophilia Foundation, of which I and my family are members. A request to participate was sent to all members of the New Parent Network, which specifically serves families of children with inherited bleeding disorders who are under age seven. I do not have a stake in the chapter other than membership and no one in the family is in a leadership role at the chapter. Three of my

The New Parent Network identifies children under age seven for participation, and thus the decision to conduct this research with children under age seven was made based on availability of community supports. Children under age five are supported through Part C Early Intervention services while children over age five are supported by their local school district through the Individuals With Disabilities Act (IDEA) (US Department of Education, 2021). The document analysis section includes review of documents from these services so to preserve data integrity and the focus on early childhood education so only participants who met the age criteria for the study were included.

The risks from this study include data security and this was addressed as outlined above. There may have been some emotional toll for families as they participate in the study as they reflected on their child's perceived functioning. Families were provided with a list of resources to address their own mental health concerns if needed, including the Pennsylvania state mental health hotline, the social worker names and phone numbers at the local hemophilia treatment center, and the new parent support network mentor program. As part of the informed consent, families were notified that I am a mandated reporter and concerns regarding potential child abuse will be reported to the appropriate agency.

Benefits to participants of this study included providing resources to identified support systems if families choose to take advantage of these. Families did not have any other direct benefits as a result of this study. Permission was obtained from sites and individual participants as appropriate. Informed consent was reviewed thoroughly, including the voluntary nature of this study and the right to withdraw from participation at any time. Pseudonyms are utilized to protect the confidentiality of all participants.

Summary

During the course of my research, I used a variety of data collection methods that included interviews, document analysis, and a focus group. The data was then synthesized into one data set with common themes using major categories and subcategories. It was important to consider the information sources, particularly with any information obtained from early intervention or education providers, to ensure that it was analyzed appropriately. The thematic synthesis helped to develop a stronger knowledge base in the field so that comprehensive care model providers can better understand the caregiver experiences and perceptions surrounding social-emotional learning for young children with inherited bleeding disorders and early childhood education.

This phenomenological research design allowed me to develop themes based on data collected from seven caregivers of young children under age seven with inherited bleeding disorders and their experiences regarding social-emotional learning and three early childhood professionals. It examined caregiver experiences with early childhood education programs. Implications of caregiver perceptions and experiences regarding treatment including supports for engaging their children in early childhood education programs utilizing the comprehensive care model employed by the local hemophilia treatment center were examined through this thematic analysis.

CHAPTER FOUR: FINDINGS

Overview

The purpose of this transcendental phenomenology was to explore the caregivers' and professionals' experiences of supporting young children's social-emotional learning in the classroom and its impact on early education in Western Pennsylvania. The results of the data analysis as findings are presented in this chapter.

Participants

The participants in this study included eight caregiver participants and three professional participants. Table 1 represents an overview of the caregiver participants in this study. They are identified first by pseudonym, then the child ages, and finally by their child's bleeding diagnosis. Table 2 represents an overview of the early childhood professional participants in this study. They are identified first by pseudonym, then by their current role in the early education field.

Table 1

Caregiver Participants

Participant Name	Age of Child	Diagnosis of Child
Fran	3	Hemophilia A (Severe)
Bob	5, 7	FVII & Platelet Function Defect
Sue	6	Hemophilia A (Mild)
Stacy	7	Hemophilia A (Severe)
Lori	3, 7	Von Willebrand Disease

Pat	4	Glanzmann Thrombasthenia
Mel	2	Hemophilia A (Mild)
Tracy	2,4	FVII

Fran

Fran is the mother of a three-year-old son with severe hemophilia A who had just turned one year old when he was diagnosed after a minor injury that left him bleeding for days. She described the experience as “traumatizing because they had no idea what was going on.” She shared that grandma watched him until he went to preschool this year, so they did not have experiences with childcare settings. The preschool they chose was “really good with it, reaching out to the caseworker to get information from them.” She’s had no concerns with social-emotional learning and shared that no one else has reported concerns either. Fran did state when asked what has gone well with supporting social-emotional learning at home, school, and in the community that “nothing has gone particularly well. Things are going ok, but nothing stands out.” She is worried about the transition to kindergarten in a couple of years.

Bob

Bob is the father of three children with inherited bleeding disorder diagnoses. All three have a diagnosis of platelet function defect and one also has a second diagnosis of factor VII deficiency. Bob shared that childcare and other early childhood education programs have been difficult to access due to program concerns around being able to keep the children safe during the school day as a result of their bleeding diagnosis. He reported one instance where the school "asked if one of the children could use scissors" at school. All of his children have received multiple therapies both in and out of school for social-emotional learning concerns among other things. Overall, he feels that the comprehensive care clinic is helpful. He would like to see more availability of community services to support children with inherited bleeding disorder diagnoses.

Sue

Sue is the parent of a 2-year-old with mild hemophilia A. She reports that he has not needed any supports from early intervention nor does she or anyone else have any concerns with his social-emotional learning. As a result of not having any concerns, she has not experienced discussing concerns with her pediatrician, school staff, or the comprehensive care clinic. Sue reported some barriers to enrollment in a childcare program, such as "jumping through all the hoops of ADA and paperwork" but reported no concerns with enrolling him at the center. She also works at the same early childhood learning center that her osn attends.

Stacy

Stacy is the parent of a kindergartener with severe hemophilia A. Mom knew she was a carrier so he was tested at birth. She reported that the first two years of his life were very challenging. He "started to become active, then developed an inhibitor and was in and out of the hospital due to his lines getting infected. He needed factor every day. It felt like chaos all the time." She reported that he did receive speech services and was able to share the evaluation report with me. It showed that there were both communication and social-emotional learning concerns. She feels that there was so much trauma early on that it did impact him developmentally. They had no concerns accessing an early learning program as she had a close friend who worked at one. She reported that the daycare was “nervous but didn’t question having him there.” She would like to see more educational supports offered by the comprehensive care clinic and also more options for therapy.

Lori

Lori is the parent of three children with Von Willebrand disease, two of whom were age-eligible for this study. The two who were age eligible both have Type 1 severe per her report. She shared that the biggest challenge she faced was with false child abuse allegations for her then five-week-old daughter. It took nearly seventeen months to resolve these, when her daughter finally received the diagnosis of moderate Von Willebrand disease. She shared that when they started looking for early childhood learning programs, her biggest concern was having a nurse that was present all day. When she did find this, she found resistance still from the school nurse who “refused to complete training with the hemophilia treatment center and kept sending her daughter home with nosebleeds.” There is a new nurse who is “on top of things.” She feels that her children have had impacts to their social-emotional learning but that her concerns have been “kind of dismissed” and that there is not enough focus on the social-emotional aspects during appointments. She would like to see people be responsive and respectful of the needs of the children.

Pat

Pat is the mother of a four-year-old boy with severe Glanzmann Thrombasthenia. He was diagnosed at one month old and she feels very fortunate that her comprehensive care clinic was familiar with it as it is exceptionally rare. She expressed some sadness about her initial plans to return to work to manage a restaurant as she was excited to do this, but when her son was diagnosed, those plans changed for her to become a stay-at-home mom so she could care for her son due to his diagnosis. She stated she “never planned or wanted to do this.” This is the first year that they have been able to engage in any early learning programs and are doing this through a local homeschool co-op that she attends with him. This was a necessity due to his diagnosis. She shared that one day, she forgot his lunch and she asked the other parents if she could leave him there for a few minutes while she ran to the store quickly, but they were all too uncomfortable to allow this so she had to take him with her. He has had some concerns with social-emotional learning and is currently receiving some outpatient therapy for this. She would like to see an increase in supports offered to include family counseling and individual child therapy.

Mel

Mel is the parent of a six-year-old kindergartener with mild Hemophilia A. She described not being able to enroll him in full-time childcare. Initially, he was enrolled part-time, and during this time, he was diagnosed with hemophilia. When she needed full-time care, there “was no availability for his age group” which continued until he went to kindergarten. When enrolling in kindergarten, the school “wanted all kinds of letters from the doctor saying he could participate in activities including gym and to store his medication in the school refrigerator.” She’s had no concerns with his social-emotional learning so has not discussed any concerns with the comprehensive care team. She would like to see some of the misconceptions about bleeding disorders addressed on a wider level so that children with inherited bleeding disorders “aren’t put in a bubble.”

Tracy

As the parent of a three-year-old son and one-year-old twin daughter with factor VII deficiency, Tracy has experienced some concerns with receiving the supports her family needs.

She also has two other children, a one-year-old twin daughter without factor VII deficiency and an eight-year-old son with factor VII deficiency. They had an unusual route to diagnosis as her now three-year-old was hospitalized for a virus and some bloodwork came back abnormal, so he was sent to the hemophilia treatment center for further evaluation. This revealed the diagnosis of factor VII deficiency, and thus the other children were tested. She reported some experiences with early intervention with her oldest, who was not age eligible for this study, but shared that due to “such a terrible experience, I declined services for the other kids even though they would qualify.” She has concerns with social-emotional learning for the three-year-old because he was a COVID baby so was not able to interact with other kids. When she has brought up concerns, her pediatrician “kinda blew it off.” She has not talked about them with the comprehensive care clinic yet. She would really like to see more supports offered by the comprehensive care clinic around explaining to kids why they might not be able to do things or handling peer pressure and bullying around doing things that they should not do due to their bleeding diagnosis. Tracy would also like to see the comprehensive care clinic offer a child psychologist for the children to speak with but also the adults as well as an increased focus on mental health.

Table 2

Professional Participants

Participant Name	Participant Role
Louann	Kindergarten Teacher
Beatrice	Preschool Teacher
Melissa	Social Worker

Louann

Louann is a Kindergarten teacher at a local private school. She previously had no experiences with dealing with children with inherited bleeding disorders until last year when Lori's child was enrolled in her classroom. She shared that she had to adjust the ways she did some things and thought about providing supports that would work. Louann described many ways she focused on individualization, including adapting movement activities to accommodate movement restrictions, allowing pillows for seating, allowing varied seating options, and finding ways for the child to be part of the class. She shared that when Lori's child was not feeling her best, she would need more support in the social-emotional areas. Louann shared that her social-emotional learning training has mostly been around The Responsive Classroom curriculum. She was able to have discussions with the school nurse and parent to prepare for having a child with an inherited bleeding disorder in her class. Louann feels that "trying to really focus on individualization based on children's needs and being open to what is needed by individual students is really important."

Beatrice

Beatrice is a preschool teacher with over 25 years of experience. She has had one child with an inherited bleeding disorder in her class, three years ago. There have been no others children with inherited bleeding disorders enrolled her in classes prior to that or since then. Initially, she described the idea of having this child in her class as "overwhelming before meeting the parent, but the parent made things easier by educating the team beforehand and this was helpful." She has participated in many social-emotional learning trainings including Conscious Discipline, Love and Logic, and positive behavior supports among others. However, her training on working with children with inherited bleeding disorders or other medical issues was very limited. Beatrice talked about the importance of recognizing that everyone learns differently and the need to be aware of each child's needs so that the classroom can be set up to meet the individual needs of children.

Melissa

As a social worker at the local comprehensive care clinic, Melissa has seven years of experience working with children, adults, and "lots of families." A primary function of her role is providing trainings to schools and early childhood programs as well as addressing barriers and challenges with early childhood programs and schools. She shared experiences with social-emotional learning around trauma-informed practices and care as well as education that is provided to families, especially when a child is newly diagnosed. Melissa talks about the importance of attachment, stating that "this is huge as all of the things that come with bleeding disorders impact attachment for the kid and the parents." She shared how so many people have misconceptions about what having a bleeding disorder means and how important it is to address those misconceptions.

Results

The purpose of this transcendental phenomenology was to explore the caregivers' and professionals' experiences of supporting young children's social-emotional learning in the classroom and its impact on early education in Western Pennsylvania. Eight caregivers of young children with inherited bleeding disorders participated and three professionals who work with children in early childhood participated. Once all of the information was gathered through interviews and a focus group, they were transcribed, and codes created manually. These codes then were further developed into themes. The results of this are summarized below in tabular and narrative format.

Table 3

Themes and Subthemes

Theme	Subtheme
Hesitancy From School Staff	School Staff are Overly Cautious
	Unable to Find Programs
Individualization and Extra Supports	Meeting Students on Their Level
	Social Skills Supports
Communication is Key	Building Trust
	Overcoming Fear

Hesitancy from School Staff

Of the caregiver participants, six reported concerns within difficulty accessing early childhood education programs including reluctance, resistance, and uncertainty from school staff. Tracy described school staff using a restraint chair and the nurse not being responsive about bruising concerns related to the bleeding disorder. She shared “they were using a cube chair and securing him in the chair and he was coming home with bruises from the straps. I called a meeting and we had an education session. The nurse never talked to us or seemed to care about the bleeding disorder. She didn’t want to ask about it. He’s in a specialized school now and there are no issues.”

School Staff are Overly Cautious

Bob and Mel described staff being “overly cautious,” a sentiment repeated by other caregivers. “They didn’t want to let him use scissors in case he would cut himself,” and “he got sent to the nurse for a paper cut and the nurse called me because she was concerned about him bleeding," were some of the things that caregivers shared. Feeling overwhelmed by the amount of paperwork that was needed to enroll their child in a program also fell into this subtheme. However, also in this subtheme is training provided by the local comprehensive care team as an item that went well when considering schools being cautious. Bob, Lori, and Stacy shared that the comprehensive care clinic has come out to provide education sessions at the schools their children attend in order to assist staff in feeling more confident in caring for their children. All three early childhood professionals also touched on training, with the teacher participants talking about how beneficial the training around bleeding disorders was and the social worker touching on how that training is provided and offered to any of the patients who attend the comprehensive care clinic.

Unable to Find Programs

Several of the participants shared their experiences with finding programs that were willing to support the needs of their children. While a few had favorable experiences with programs being willing to learn and open to having the children in the program, several had at least one experience where they had difficulty with accessing early learning programs as a result of their child's inherited bleeding disorder diagnosis. Mel described how "they wouldn't move him to full time care due to concerns with supporting him in childcare." Pat described not being able to return to work as "there was no one who was trained to care for her child and even now, in preschool, I must attend with him in order for him to be able to participate in the program." The experience of caregivers who had difficulty with accessing programs was that it is the fear of the unknown that often impacts programs and their willingness to consider enrolling a child with a bleeding disorder as there are often misconceptions about what having a bleeding disorder means.

Individualization and Extra Supports

Caregivers consistently discussed the need for extra supports of varying degrees within early childhood programs. Six of the eleven children whose caregivers participated received some sort of additional formal supports such as physical therapy, occupational therapy, speech therapy, or developmental therapy. A review of the documents provided by two of the caregivers revealed that social-emotional concerns were present for the three children represented in the document analysis. Early childhood professionals also reiterated the need for individualization and extra supports, with Beatrice sharing that it is “important to set up your room to meet all the individual needs of the children in your classroom.”

Meeting Students on Their Level

Early childhood professionals agreed that they have limited training in working with children who are medically complex. Two of the three had never previously had a child with an inherited bleeding disorder in their classroom. The social worker who participated regularly supports children through her work in the comprehensive care clinic but also touched on the need to identify individualized supports for each child. “Find ways for her to be a part of the class” was shared by a Louann as a necessary part of supporting children with bleeding disorders in early childhood settings, which required things like adjusting the expectations, encouraging self-advocacy, and adapting activities as needed. Recognizing that every child learns differently so it is important to meet the need and not the diagnosis was also identified by early childhood professionals.

Social Skills Supports

Caregiver experiences largely centered around the need for more supports in regard to trauma and building community. Three caregivers suggested access to more social skills groups could be beneficial in meeting the social-emotional learning needs for their children. They discussed the barriers to participation, including needing to obtain many different forms and have extra meetings with the school as a barrier to participation in programs. Caregivers described the need for early education professionals to recognize the parents as the experts can be difficult and another barrier as early childhood professionals tend to rely on what the doctors say, but sometimes the doctors do not even know what to recommend. Finally, caregivers discussed the trauma that their children have experienced as a result of their inherited bleeding disorder diagnosis and how that can impact how they react to things including their interactions with peers. Tracy shared concern with one of her children feeling "bullied by peers who wanted him to do something that he should not do due to his diagnosis." While they generally describe a sense of community within the bleeding disorders community, these events do not provide the close relationships in the same way enrollment in early childhood programs does where the children can interact with the same peer group daily.

Communication is Key

Caregivers and professionals both discussed the need for upfront, clear communication about the inherited bleeding disorder diagnosis and what it means for enrollment in early childhood learning programs. Beatrice and Louann both shared that as teachers with no previous experience with supporting children with inherited bleeding disorders in the classroom, communication with the parents about this made things feel less overwhelming. Mel and Melissa both touched on misconceptions around inherited bleeding disorder diagnoses. Melissa shared that this is a "huge part of education, focusing on recognizing that for the most part, this kid can do everything that any other kid can do. When they have access to the medications they need, they don't need to be bubble wrapped and protected."

Building Trust

Part of the discussion around building trust includes teaching children with inherited bleeding disorders to self-advocate. Lori touched on the importance of people "being responsive and respectful of needs of the children. Teaching self-advocacy can be challenging because not everyone understands and takes it seriously." Melissa also discussed the importance of teaching self-advocacy including "kids knowing their own bodies and becoming self-advocates" and needing "to honor and respect children's perceptions of pain and bleeding as they often know about it before we can see it." Pat touched on the need for early childhood professionals to understand that "while things might be normal for most children, they might not be normal for her child and vice versa." Tracy talked about the importance of being curious and not apprehensive. "If I tell you that my child had a bleeding disorder, and you freak out, I've lost confidence in you. If you show me that you're apprehensive, nervous, or scared, it worries me that you're not competent in other areas." Sitting down for team meetings to discuss questions and concerns was mentioned by the majority of caregivers and all early childhood professionals.

Overcoming Fear

Fear about the unknown was a theme identified by both caregivers and professionals. Professionals shared fear at the beginning, before working with the children who were identified as having inherited bleeding disorders. This fear was alleviated some by open communication with the families, including meetings that the entire team attended to answer questions and concerns. Melissa shared that much of the fear in her experience is around misconceptions about inherited bleeding disorders and believing that children will have massive bleeding in front of them, when in reality it is just that children with inherited bleeding disorders will bleed much longer. Mel did describe the school nurse calling her "over everything, including a paper cut last week. She was worried that he would bleed out due to a paper cut" and further reported that the school treats him like a "porcelain doll." Stacy shared that "all kids have a history and you might not know their history" which is particularly relevant when thinking about fear and the fear of the unknown for those who are experiencing a child with an inherited bleeding disorder for the first time. Fran shared another aspect is worrying every day if her child has a bleed because he is only recently able to tell her how he is feeling and symptoms that could be associated with having a bleed. Bob also shared concerns with knowing about joint bleeds and whether school staff would adequately be able to recognize these and inform parents. Mel offered a reassuring story of when her child was in childcare, he had an unknown bleed in his thigh due to his vaccines that were administered and the staff picked up on it and notified her.

Outlier Data and Findings

During the course of this study, there were two unusual findings. One was in regard to access to early childhood programs. The second was in regard to those who had identified social-emotional learning concerns.

Early Childhood Programs

It was interesting to note that three of the children who were diagnosed with Hemophilia A had no reported concerns with finding and enrolling in early childhood programs who were willing to work with them. One child with Hemophilia A did have some difficulty in both the childcare and kindergarten settings. The remaining seven children who had more rare bleeding disorders all reported increased difficulty in accessing early childhood education programs.

Social Emotional Concerns

Only one of the four children with Hemophilia A had reported social-emotional learning concerns. The seven children with more rare bleeding disorders including Factor VII deficiency, Von Willebrand Disease, and Glanzmann's Thrombasthenia all were reported to have some concerns with social-emotional learning by their caregivers. Of these eight children total, seven received some form of support with social-emotional learning.

Research Question Responses

This section offers concise answers to the research questions. Short and direct narrative answers to each of the research questions are supplied here through use of the themes defined previously. Responses came from two groups of participants: caregivers of young children with inherited bleeding disorders and early childhood education professionals.

Central Research Question

How do caregivers and early education professionals describe their experiences of supporting social-emotional learning and education of young children with inherited bleeding disorders? The participants' perspective is that supporting the social-emotional learning of young children with inherited bleeding disorders is best achieved by ensuring that programs are individualized as appropriate for students, with extra supports put into place as needed. Trying to "really focus on individualization based on children's needs and being open to what is needed by individual students is really important."

Sub-Question One

How do caregivers describe their experiences of providing and receiving social-emotional and educational support for young children with inherited bleeding disorders? Caregiver participants felt that the sense of community provided by the bleeding disorders community is amazing, with many events to help connect families who are going through the same thing. "Our local hemophilia center does everything for us" was how Mel felt. Stacy shared that the local bleeding disorder foundation chapter events "are great and helpful, proving many opportunities to get kids together and families to network." They felt that teaching self-advocacy is important but were not sure how best to achieve this. Caregivers reported wanting more support with social-emotional learning, specifically using trauma-informed care practices and recognizing that their children "might react differently than expected to what seem to be typical situations."

Sub-Question Two

How do early education professionals describe their experiences of providing and receiving social-emotional and educational support for young children with inherited bleeding disorders? Early childhood professionals also recognized the need for trauma-informed care practices but both teachers reported that they have not received any education or training in this. Melissa reported that she has received formal training in this as well as "motivational interviewing training, child development and developmental milestones, and attachment." There is some professional development around social-emotional learning such as Louann sharing that "responsive classroom is a training we do every year for two or four days" and Beatrice sharing "positive behavior support trainings are offered by the program", but much of the professional development time is often taken up by mandated trainings like first aid and CPR. Beatrice shared that training specific to working with children with inherited bleeding disorders or other medical issues is "very limited and usually just on epi pens, inhalers, and a basic first aid class." Early childhood professionals shared that they work on individualizing for children's needs and recognize that sometimes they may need to adjust their expectations, though Beatrice recognized that students with inherited bleeding disorders are "typical, lively, and energetic just like any other child." Both Louann and Beatrice did describe feeling somewhat overwhelmed but education provided by the parent or comprehensive care team was beneficial and allowed them to focus on what they needed to do to support children with inherited bleeding disorders. Melissa shared the importance of educating others by taking “all the misconceptions with bleeding disorders off the table” when providing education to caregivers and early childhood programs.

Sub-Question Three

How do caregivers describe their experiences with supports that are provided to enroll their child in early childhood education programs? Caregivers of children with Hemophilia A reported having little difficulty with enrolling their child in early childhood education programs. Programs were largely easy to work with. Stacy reported that she had no issue with their early childhood learning program and “the transition to kindergarten was super smooth.” She shared that when she “accepted a teaching job at a daycare, I enrolled my son in another class at the same facility.” Caregivers of children with other inherited bleeding disorders did not report the same ease in accessing early childhood education programs. They shared hesitancy, reluctance, and resistance from early childhood programs or their staff when trying to find a program to enroll their child in. Bob shared that “daycare and other programs that would accept the children have proven difficult to find.” His family chose to have private-duty nursing coverage that “can provide care to enable the children to attend programs that would not take them without the added support.” Tracy described initially not telling the school to eliminate any potential issues, but then when they did tell the school, the “nurse never talked to them or seemed to care about the bleeding disorder.” They shared that the comprehensive care clinic would help with training staff in programs, and that this was beneficial when it happened. However, the comprehensive care clinic was reported to focus largely on medical needs rather than developmental needs and a need for more support in accessing early childhood programs was identified. Some caregivers did not face initial resistance in enrolling, but other barriers came up such as Mel and Pat sharing that they had programs “requiring a note for clearance and that the parent doesn’t leave” during activities.

Summary

The purpose of this transcendental phenomenology was to explore the caregivers' and professionals' experiences of supporting young children's social-emotional learning in the classroom and its impact on early education in Western Pennsylvania. Several themes emerged during the completion of this study. Caregivers of children who have inherited bleeding disorders other than Hemophilia were identified to have more concerns with accessing early childhood education programs and their children's social-emotional learning. All caregivers reported the need for individualizing for their children and the need for tailored supports, which was reinforced by the early childhood professionals who were interviewed for this study. Only three participants, all with Hemophilia A, were reported to have no concerns with social-emotional learning. This is especially important when considered in the context of reluctance, resistance, and barriers to enrolling in early childhood education programs.

Early childhood professionals reported minimal training in social-emotional learning and no training in working with children who are medically complex, including those with inherited bleeding disorders. While they all recognize the importance of social-emotional learning and weaving trauma-informed care into the social-emotional learning landscape in their classrooms, they are not prepared for this in the classroom. Ensuring that children can be good self-advocates is a critical skill that is part of the social-emotional learning process, but the supports for teaching children to be strong self-advocates are not consistently in place.

This research has highlighted some of the needs present in the community when it comes to supporting social-emotional learning for children with inherited bleeding disorders. There is a lack of knowledge and supports in place. Information garnered through this research can be used to further expand the research in this area as be used in consideration of continuing to support children with inherited bleeding disorders in their home communities.

CHAPTER FIVE: CONCLUSION

Overview

The purpose of this transcendental phenomenology was to explore the caregivers' and professionals' experiences of supporting young children's social-emotional learning in the classroom and its impact on early education in Western Pennsylvania. The study was designed to answer several research questions in order to understand these experiences. This chapter presents a summary of the findings across five subsections that include (a) interpretation of findings, (b) implications for policy and practice, (c) theoretical and methodological implications, (d) limitations and delimitations, and (e) recommendations for future research. The chapter ends with the delimitations, limitations, and recommendations regarding research for the future.

Discussion

Findings from the individual interviews, focus group, and document review revealed the themes that are documented in Chapter four. Through individual interviews with eight caregivers of young children with inherited bleeding disorders and three professionals working as early childhood professionals, these themes were developed and explored.

Interpretation of Findings

Several themes emerged during the course of this study and are summarized here with interpretations.

Summary of Thematic Findings

Several themes emerged during the course of this study including reluctance, resistance, and uncertainty from school staff resulting in caregivers being unable to find a program or staff being overly cautious. There was also a theme that followed the line of individualization and extra supports needed to enroll in early education programs. These included needed social skills supports, professional development needs, and being able to meet students on their level which ties further into the individualization theme.

There is reluctance, resistance, and uncertainty in enrollment in early childhood education programs. The population of young children with inherited bleeding disorders anecdotally can have impacts to their education due to lack of access to early education programs. During this study, six caregivers were able to reflect on their experiences with early childhood education programs, describing challenges in enrolling their child due to programs being reluctant or unwilling to learn about inherited bleeding disorders and how to best accommodate children in their programs. These included childcare and preschool programs. There were two caregivers who were able to reflect both on their childcare experiences as well as making the transition to a public kindergarten program. There are many misconceptions about what an inherited bleeding disorder can look like which creates bias and reluctance from programs. Early childhood professionals reported during their interviews that training is lacking when it comes to supporting children with inherited bleeding disorders in their programs. More education and professional development regarding children with inherited bleeding disorders is needed in the education field to address these concerns.

Individualization and extra supports are needed for children with inherited bleeding disorders. Individualized supports are often needed in order to effectively support children with inherited bleeding disorders. These include activity restrictions at times, adjusting expectations, encouraging children to be self-advocates for what they need, and adapting activities to make them safer. Meeting the need instead of the diagnosis was identified by early childhood professionals and caregivers alike. All of the supports that were described through the course of the interviews and focus group were minor adjustments in terms of feasibility and manpower. Students with inherited bleeding disorders should not be excluded from early childhood programs on account of their inherited bleeding disorder diagnosis.

Delays in social emotional learning for children with inherited bleeding disorders. Despite only having one formal document to review that shared concerns and delays in social emotional learning, there were other reports of children receiving multiple services including speech therapy, occupational therapy, physical therapy, and developmental therapy from early intervention. Social emotional learning was identified as a need from both caregivers and early childhood professionals during interviews and the focus group. Social emotional learning for children with inherited bleeding disorders could be impacted by medical trauma at a young age, and these children should be considered for additional therapy to address the needs surrounding these traumatic experiences. Caregivers also reported wanting more opportunities for social emotional learning activities like social groups and family therapy that could bolster potential concerns with attachment as a result of trauma. Trauma can cause learning delays beyond just concerns with attachment and social emotional learning. It can result in cognitive and speech delays as well. It is important to consider the impact that trauma has on children with inherited bleeding disorders in order effectively and efficiently identify and address delays in any area of learning.

Implications for Policy or Practice

The implications for policy and practice are relevant here as there are tangible and achievable takeaways from this research study that can be implemented to improve the social emotional learning outcomes for children with inherited bleeding disorders.

Implications for Policy

At the policy level, consideration should be given to screening every child with an inherited bleeding disorder diagnosis through the local early intervention program in order to address concerns with trauma and learning delays that result from this trauma. Further, increasing funding for comprehensive care clinics to support family based and child-led therapy would provide opportunities for children to address social emotional learning in a supportive environment that can be individually tailored to their needs while being intimately familiar with the challenges associated with the diagnosis.

Implications for Practice

While it is clear that the findings of this study linking concerns with social emotional learning and children with inherited bleeding disorders apply to this population, it may also be applicable to children who are otherwise medically complex. Consideration should be given to further exploring this topic in children who have other diagnoses that result in medical complexity. It would be prudent to recommend that comprehensive care clinics examine the supports they provide patients in terms of their educational needs including ensuring there are processes in place for referring children to early intervention programs, maintaining a list of early childhood programs familiar with supporting children with inherited bleeding disorders, and assisting in identifying other relevant community supports to help support the child and family with concerns with social emotional learning.

Theoretical and Empirical Implications

This study was able to provide novel information to the field of education as there is almost no research available on the implications of having an inherited bleeding disorder on early childhood or school-age learning. By identifying the link between having an inherited bleeding disorder and implications on social emotional learning, the door has now been opened to explore this important topic further. Much of the research previously has focused either specifically on children with hemophilia or the medical implications rather than considering the wider population of inherited bleeding disorders or the learning implications for this group. Exploring the themes of trauma and attachment in children with inherited bleeding disorders would further inform the field, including comprehensive care clinics on how to best meet the comprehensive needs of children in their care.

Theoretical Implications

This study was based around Bowlby's theory on attachment as children who develop safe and secure attachment with their caregivers have greater social emotional competence in life (Zeanah, 2019). Melissa shared during the interview that attachment is huge within the bleeding disorders community as all the complications from diagnosis to treatment when it comes to inherited bleeding disorders can impact attachment for both the child and parent. It is essential for children to develop through the four stages of attachment to develop early social social-emotional skills. Five caregivers reported concerns with social-emotional learning, feeling this was a result of trauma early on that impacted attachment and other early learning. The earliest interactions between caregivers and children can have tremendous, life-long impacts for children. Children who have inherited bleeding disorders experience medical trauma, often at an early age, and their parents may go through stages of grief that can impact attachment as well.

Empirical Implications

Throughout the course of this study, there was alignment with the initial hypothesis that social-emotional learning might be impacted for children with inherited bleeding disorders. As a result of their inherited bleeding disorder diagnosis, medical trauma is thought to have resulted in concerns with social-emotional learning for five out of the eight families identified. All of the families who participated in the study have experienced medical trauma as a result of their childrens’ bleeding diagnoses, which is considered one of the ACES (Matlin et al., 2019; Spehr et al., 2019). Having experienced one or more ACES poses threats across all domains of learning. Interestingly, three of the four families identified who had children with hemophilia reported no concerns with social-emotional learning while all four of the families with other inherited bleeding disorder diagnoses reported concerns with social-emotional learning for all of their affected children. Further, nearly all of the caregiver participants identified a need for more support with mental health, therapy, and other counseling that would boost social-emotional learning. Social-emotional learning is the cornerstone of all other learning, laying the very groundwork for school success so children who are at risk for impacts to their social-emotional learning should be identified and supported early on (Cressey, 2019; Rausch et al., 2021). This was identified by caregivers and professionals as a need that is not fully met within this study. Three caregivers described bringing their concerns to professionals and feeling as though their concerns were “brushed off” and not taken seriously. This points to a lack of education in the medical field about the importance of social-emotional learning.

Concerns about the lack of training around social-emotional learning in early childhood programs also is identified in this study. Beatrice described that while there have been some trainings on social-emotional learning “much of the training time is taken up by mandatory trainings like child abuse and CPR.” Louann shared that they do training on responsive classroom annually. Research shows that children who have formal social-emotional instruction from an early age have higher academic scores and increased cognition in their later school years than children who have not had this formal instruction (DePaoli, Atwell, & Bridgeland, 2019;

Fetting et al., 2022; Vandell et al., 2020). If early childhood programs are not able to provide training time for teachers to participate in formal social-emotional learning trainings on a regular basis, children with inherited bleeding disorders will be further impacted in their social-emotional learning as they have already been impacted by ACES and now by lack of training provided by their early childhood teachers. This could be resolved with communication about the importance of social-emotional learning and the impact of ACES when considering educating early childhood programs about children with inherited bleeding disorders.

When thinking about the empirical implications of this study to the bleeding disorders community, this study is one of the only studies that has examined the spectrum of bleeding disorders and social-emotional learning impacts. The majority of other studies have focused primarily on the medical implications for children with bleeding disorders (DeKoven et al., 2014; Khair & Pelentsov, 2019). Only one study was found to examine factors outside the medical complications and this study was specifically for children with hemophilia (Cassis et al., 2014). Caregivers and early childhood professionals both spoke about the importance of developing self-advocacy which ties to the Lambing et al. (2017) study around provider versus patient perceptions of pain and the importance of recognizing that when children consistently have their experiences invalidated, they can experience higher rates of trauma and mental health concerns (Lambing et al., 2017; Zeanah, 2017).

Limitations

Limitations of this study included having difficult recruiting participants and completing the interviews in a short time frame. Instead, interviews took place over the course of three months, which then impacted participation in the focus group as it was far removed from the initial interview. Several interview participants did not respond to repeated requests to participate in the focus group. Further, two of the three early childhood professionals were preschool teachers, which meant that other types of early childhood programs such as childcare, Head Start, and public kindergarten were not represented in this study.

Delimitations

Delimitations included only interviewing caregivers with children ages seven or younger who have inherited bleeding disorders and early childhood professionals, which was necessary in order to narrow the scope to the intended topic. As this study involved a topic with which the researcher was intimately familiar with, potential bias served as another delimitation. This was addressed by member checking and triangulation which occurred throughout to minimize interpretation errors and bias.

Recommendations for Future Research

The reality is that there are many children with inherited bleeding disorders who are not diagnosed in early childhood. Lack of access to appropriate medical care and mild or vague symptoms create barriers to diagnosis. These children were not identified due to the nature of this study. More comprehensive research that reflects on the social emotional learning needs of children with a greater age range and medical need would be beneficial to further understand this phenomenon. Expanding the site would also increase knowledge and create more ability to generalize the findings.

Additionally, further investigation into the impact of medical trauma on attachment and social emotional learning would be beneficial for children with inherited bleeding disorders as well as other children who are medically complex in order to identify and treat these concerns early which would lead to better long-term outcomes.

Conclusion

The problem is that social-emotional learning and the overall education of young children with inherited bleeding disorders is impacted by many of the routine procedures that must be done as a result of having an inherited bleeding disorder (DeKoven et al., 2014; Khair & Pelentsov, 2019; Taft et al., 2020).The purpose of this transcendental phenomenology was to explore the caregivers' and professionals' experiences of supporting young children's social-emotional learning in the classroom and its impact on early education in Western Pennsylvania. This phenomenon was investigated through eight individual caregiver and three early childhood professional interviews, a focus group, and document analysis. Throughout the study, an analysis of themes that were identified that had potential impact on social emotional learning for children with inherited bleeding disorders took place. These included reluctance and resistance of early childhood programs when supporting children with inherited bleeding disorders, programs who were overly cautious in their responses to children with inherited bleeding disorders as a result of misconceptions about bleeding disorders, and communication. Identification of medical trauma impacting social emotional learning for these children and then supporting them through a trauma-informed care lens with different therapy options is an identified need by both caregivers and early childhood professionals. It was surprising to note that three out of four of the caregivers of children with hemophilia noted easier experiences with early childhood programs and supports as well as less concern for social-emotional learning while all four of the caregivers of children with other inherited bleeding disorders reported increased concerns with accessing programs and supports for their children's social emotional learning as well as increased concerns with social emotional learning. Future studies should be conducted in order to understand this phenomenon more thoroughly for children with all types of inherited bleeding disorders as well as consideration be given to implications for children with other types of medical complexity.

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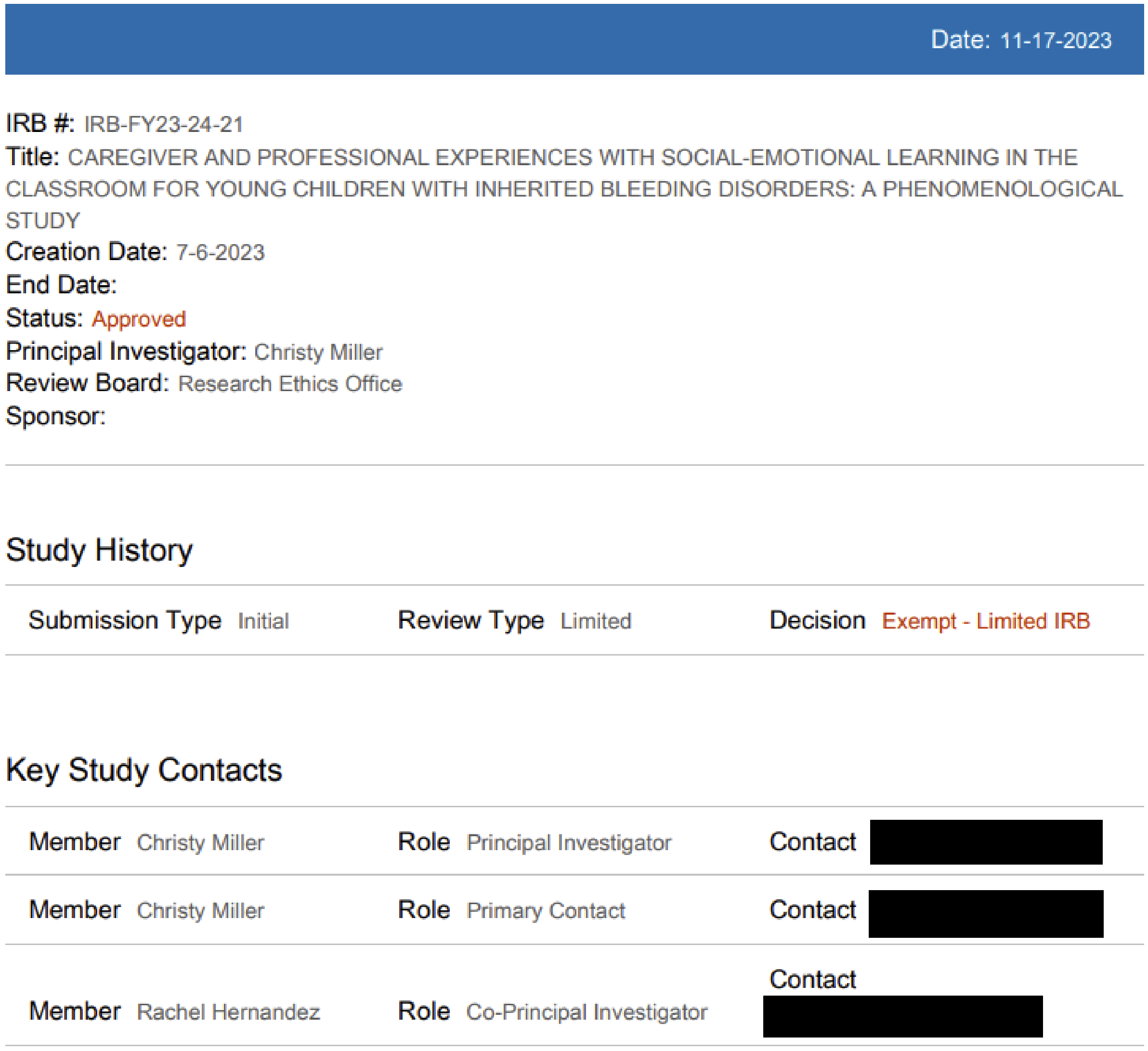
Appendix A

IRB application



Date: 11-17-2023

IRB #: IRB-FY23-24-21
Title: CAREGIVER AND PROFESSIONAL EXPERIENCES WITH SOCIAL-EMOTIONAL LEARNING IN THE CLASSROOM FOR YOUNG CHILDREN WITH INHERITED BLEEDING DISORDERS: A PHENOMENOLOGICAL STUDY
Creation Date: 7-6-2023
End Date:
Status: Approved
Principal Investigator: Christy Miller
Review Board: Research Ethics Office
Sponsor:

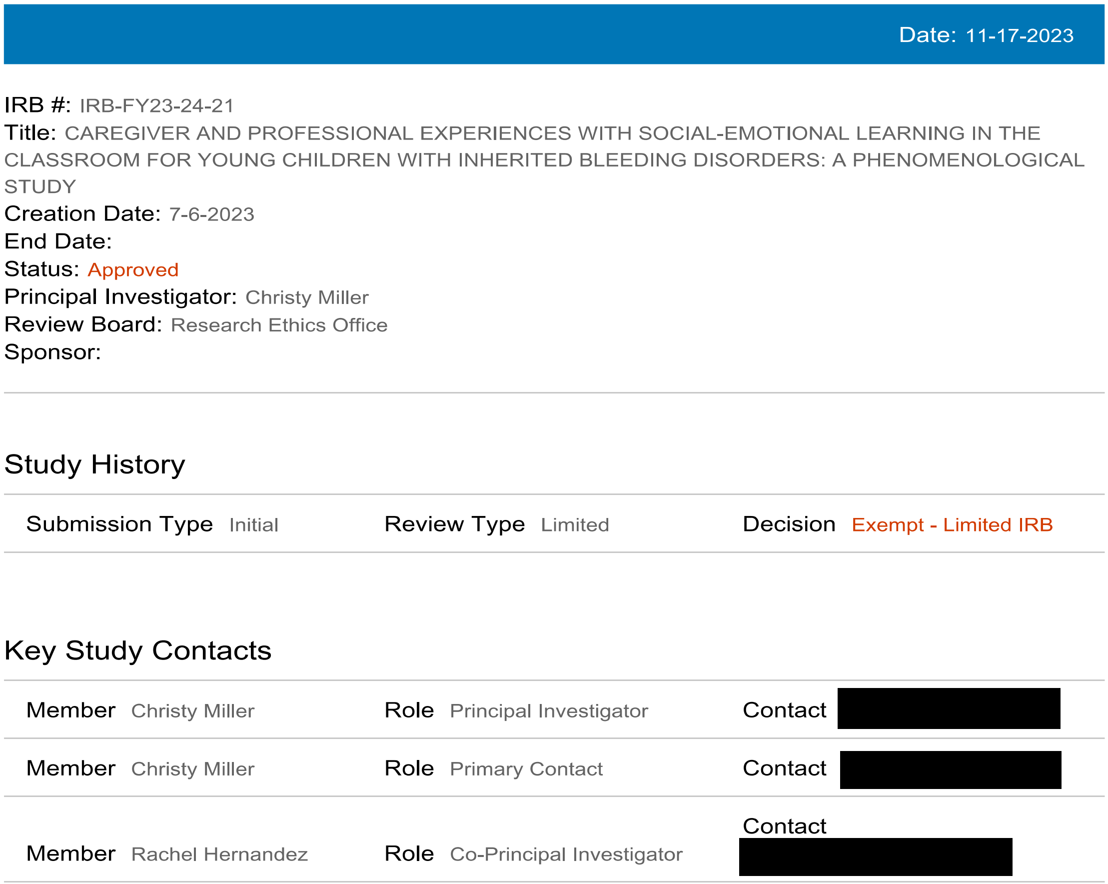
Study History

Submission Type Initial	**Review Type** Limited	**Decision** Exempt - Limited IRB

Key Study Contacts

Member Christy Miller	**Role** Principal Investigator	**Contact** [redacted]
Member Christy Miller	**Role** Primary Contact	**Contact** [redacted]
Member Rachel Hernandez	**Role** Co-Principal Investigator	**Contact** [redacted]

Appendix B
IRB Approval



Date: 11-17-2023

IRB #: IRB-FY23-24-21
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Creation Date: 7-6-2023
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Principal Investigator: Christy Miller
Review Board: Research Ethics Office
Sponsor:

Study History

Submission Type	Initial	Review Type	Limited	Decision	Exempt - Limited IRB

Key Study Contacts

Member	Christy Miller	Role	Principal Investigator	Contact	[redacted]
Member	Christy Miller	Role	Primary Contact	Contact	[redacted]
Member	Rachel Hernandez	Role	Co-Principal Investigator	Contact	[redacted]

Appendix C

Informed Consent Form

Consent

Title of the Project: CAREGIVER AND PROFESSIONAL EXPERIENCES WITH SOCIAL-EMOTIONAL LEARNING IN THE CLASSROOM FOR YOUNG CHILDREN WITH INHERITED BLEEDING DISORDERS: A PHENOMENOLOGICAL STUDY

Principal Investigator: Christy Miller, Special Education Doctoral Candidate, Liberty University

Invitation to be Part of a Research Study

You are invited to participate in a research study. To participate, you must be a parent or caregiver of a young child (under age 7) who has an inherited bleeding disorder or be an early childhood education professional (teacher, social worker, classroom assistant, etc.) who works in an early childhood setting (Early Head Start, Pre-K Counts, public school kindergarten, etc) and has had or currently has a student with an inherited bleeding disorder in their class or on their caseload. All participants must be over age 18 and have a minimum of 6 months experience supporting young children with inherited bleeding disorders either personally or professionally. Taking part in this research project is voluntary.

Please take time to read this entire form and ask questions before deciding whether to take part in this research.

What is the study about and why is it being done?

The purpose of the study is to explore caregivers’ and early education professionals’ experiences of supporting the social-emotional learning of young children with inherited bleeding disorders and its impact on early childhood education in Western Pennsylvania.

What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following:

1. Participate in either a virtual, video-recorded or an in-person, audio-recorded interview that will take no more than 1 hour.
2. Participate in a video-recorded focus group with other caregivers and/or early childhood education professionals that will take no more than 1 hour.
3. If applicable, provide the social-emotional information and summary from your child’s multi-disciplinary evaluation for services or recent assessments completed in the Early Head Start or Head Start programs (only for caregivers who have children participating in these programs. This should take less than 5 minutes.

How could you or others benefit from this study?

Participants should not expect to receive a direct benefit from taking part in this study.

Benefits to society include increasing the research base for children with inherited bleeding disorders, potentially increasing the quality of life and identifying targeted needs when considering early childhood education programs. It also may serve as a catalyst for larger, more comprehensive studies for children with inherited bleeding disorders and their educational needs.

What risks might you experience from being in this study?

The expected risks from participating in this study are minimal, which means they are equal to the risks you would encounter in everyday life. The risks involved in this study include the possibility of psychological stress from being asked to recall and discuss prior trauma. To reduce risk, I will monitor participants, discontinue the interview if needed, and provide referral information for counseling services.

I am a mandatory reporter. During this study, if I receive information about child abuse, child neglect, elder abuse, or intent to harm self or others, I will be required to report it to the appropriate authorities.

How will personal information be protected?

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher will have access to the records.

- Participant responses will be kept confidential by replacing names with pseudonyms.
- Interviews will be conducted in a location where others will not easily overhear the conversation or virtually.
- Confidentiality cannot be guaranteed in focus group settings. While discouraged, other members of the focus group may share what was discussed with persons outside of the group.
- Data will be stored on a password-locked computer. After three years, all electronic records will be deleted.
- Recordings will be stored on a password locked computer for three years and then deleted. The researcher will have access to these recordings.

How will you be compensated for being part of the study?

Participants will not be compensated for participating in this study.

Is study participation voluntary?

Participation in this study is voluntary. Your decision whether to participate will not affect your current or future relations with Liberty University or the researcher. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

What should you do if you decide to withdraw from the study?

If you choose to withdraw from the study, please contact the researcher at the email address/phone number included in the next paragraph. Should you choose to withdraw, data collected from you, apart from focus group data, will be destroyed immediately and will not be included in this study. Focus group data will not be destroyed, but your contributions to the focus group will not be included in the study if you choose to withdraw.

Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Christy L. Miller. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at [redacted] or [redacted] You may also contact the researcher's faculty sponsor, Dr. Rachel Hernandez at [redacted].

Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the IRB. Our physical address is Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA, 24515; our phone number is 434-592-5530, and our email address is irb@liberty.edu. *Disclaimer: The Institutional Review Board (IRB) is tasked with ensuring that human subjects research will be conducted in an ethical manner as defined and required by federal regulations. The topics covered and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.*

Your Consent

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researcher will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

☐ The researcher has my permission to audio-record and video-record me as part of my participation in this study.

____

Printed Subject Name

____

Signature & Date

Appendix D
Dissertation recruitment letter

Dear Potential Participant,

As a doctoral candidate in the School of Education at Liberty University, I am conducting research as part of the requirements for a Special Education degree. The purpose of my research is to explore caregivers' and early education professionals' experiences of supporting the social-emotional learning of young children with inherited bleeding disorders and its impact on early childhood education in Western Pennsylvania. I am writing to invite you to join my study.

Participants must:

- Be a parent or caregiver of a young child (under age 7) who has an inherited bleeding disorder
- Be an early childhood education professional (teacher, social worker, classroom assistant, etc.) who works in an early childhood setting (Early Head Start, Pre-K Counts, public school kindergarten, etc) and has had or currently has a student with an inherited bleeding disorder in their class or on their caseload

Participants will be asked to:

- take part in a one-on-one, audio-recorded, interview
- take part in a video-recorded focus group
- if applicable, share social-emotional information and summary from their child's multi-disciplinary evaluation for services or recent assessments completed in the Early Head Start or Head Start programs.

It should take approximately 1-2 hours to complete the procedures listed. Names and other identifying information will be requested as part of this study, but participant identities will not be disclosed.

To participate, please contact me at [redacted]. If you meet my participant criteria, I will work with you to schedule a time for an interview.

A consent document will be emailed to you if you meet the study criteria at the time of the individual interview. The consent document contains additional information about my research. If you choose to participate, you will need to sign the consent document and return it to me at the time of the interview.

Sincerely,

Christy L. Miller

Christy L. Miller
Doctoral Candidate in Special Education, Liberty University

[redacted]