

EXPLORING THE LIVED EXPERIENCES AND COPING STRATEGIES OF
PARENTS OF CHILDREN WITH PROFOUND INTELLECTUAL AND MULTIPLE
DISABILITIES

by Anne Glaeser Hubach

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

School of Behavioral Sciences

Liberty University, Lynchburg, VA

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APPROVED BY:

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Abstract

The purpose of this transcendental phenomenological study was to describe the lived experiences and coping strategies of parents of children with profound intellectual and multiple disabilities (PIMD) in Central Virginia. Research questions used to frame this study are: How do parents of children with PIMD describe their experiences as parents of children with PIMD? How do the parents of children with PIMD describe the impact of their experiences on their well-being? How do the parents of children with PIMD describe their understanding of and perspectives regarding their children's disabilities? How do parents of children with PIMD describe the impact of having children with PIMD on their families and outside of family social and other interactions? The theories guiding this study are the Vélez-Agosto, Soto-Crespo, Vizcarrondo-Oppenheimer, Vega-Molina, and García Coll's (2017) expanded bioecological theory and family systems theory (White & Bregman, 2011). Data was collected from eight parents of children with PIMD using semi-structured interviews, cognitive representations and focus groups. Data was analyzed using Yin's (2011) five-phase qualitative data analysis approach. Two major themes emerged: My Life with My Child with PIMD is Like a Roller Coaster and Balancing the Stressors: From Surviving to Thriving. The implications of the results apply to parents of children with PIMD, their family members and friends as well as the medical, mental health and educational providers who serve them

Keywords: intellectual disabilities (ID), profound intellectual and multiple disabilities (PIMD), developmental delay (DD), spousal support, social support, caregivers, parents, children, families, siblings, stress, coping strategies, existential perspectives, education, medical provider.

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Dedication

This manuscript is dedicated to my family, my husband Kurt, daughters Jessica, Allison, Joanna and Amelia and our precious son Josiah who has PIMD. In addition, I want to acknowledge my father, Robert Glaeser (now deceased) who loved and encouraged me from afar through many difficult years. I also want to dedicate the manuscript to my lifelong friends Jane Campbell, Lisa Anderson and Lori Bennett who have walked alongside me through the very tumultuous, spiritually joyful, often traumatic, sometimes humorous, often challenging and eternally rewarding journey of life with Josiah. I especially want to honor my husband Kurt who has supported me through many work-filled days and nights and who tolerated my high stress levels throughout the doctoral process. I also want to express deep appreciation to Sandy Lewis and her amazing family who became Josiah's very adoring second family when he lived with them for six years. Mostly, I give thanks to God, who in His great love, wisdom and mercy saw fit to love me just the way I am but love me too much to leave me that way and who has used Josiah as well as those mentioned above (and others) to bring me closer to the conformity of the image of Jesus Christ.

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List of Abbreviations

Autism Spectrum Disorder (ASD)

Cerebral Palsy (CP)

Down Syndrome (DS)

Developmental Delay (DD)

Intellectual Disability (ID)

Multimorbidity and Multiple Disabilities (MMD).

Multiple Disabilities (MD)

Profound intellectual and multiple disabilities (PIMD)

Typically Developing (TD)

CHAPTER ONE: INTRODUCTION

Overview

Intellectual disabilities (ID) are defined by the *Diagnostic and Statistical Manual-5* (DSM-5; American Psychological Association, 2015) as neurodevelopmental difficulties that begin during childhood and manifest as intellectual difficulties and problems in social, conceptual and practical aspects of life. The DSM-5 (APA, 2015) also qualifies ID as intellectual and adaptive functioning deficits that begin during childhood. According to Maulik, et al. (2011), there are 10.37 individuals with intellectual disabilities (ID) per every 1,000 individuals in the world. The U.S. children who received special education services in the 2014-2015 school year had various levels of ID, hearing impairments, orthopedic impairments, visual impairments, traumatic brain injuries, deaf-blindness and multiple disabilities (MD; National Center for Education Statistics, 2019). Individuals with *profound* ID often have comorbid congenital illnesses or syndromes, are unable to live independently and must have support for self-care; additionally, individuals with profound ID are typically nonverbal and have multiple disabilities (MD; Boat & Wu, 2015).

Parents of children with profound intellectual and multiple disabilities (PIMD) face extraordinary challenges and stressors (Luijkx, Putten & Vlaskamp, 2017). This study was designed to reveal the lived experiences and coping strategies of the participants. The data that emerged was deep, including the existential and spiritual perspectives of the participants as well as their experience-based, helpful insights and understanding of the full spectrum of experiences that described their lives as parents of children with PIMD. Additionally, factors affecting the participants' well-being, such as coping mechanisms, personal, familial and social strengths and

weaknesses were revealed, which supplied the information upon which implications for stakeholders was based.

The end goal of the study was to provide insight, information and understanding to other parents of children with PIMD and those who are involved in their lives. With the themes that emerged, and the associated implications and suggestions for future research, all stakeholders involved in improving the well-being of parents of children with PIMD and their families will be better informed. With the understanding from this study, parents of children with PIMD may be able to extend the length of time that they will be able to care for their children with PIMD by assisting them to avoid burnout, mental health problems, physical health problems and other negative consequences of long-term caregiver responsibilities (Adams, Rose, Jackson, Karakatsani, & Oliver, 2018). This chapter presents the background of ID, PIMD, parent-caregiver stress and its effects as well as parent perspective and coping. In addition, the researcher's situation to self, problem statement, purpose statement and significance of the study, along with the research questions and definitions related to the study are presented.

Background

It is important to understand the differences in severities of PIMD as well as the potential challenges faced by those who care for them. This section describes the study of the lived experiences of parents of children with PIMD in Central Virginia. This section also includes the problem statement and purpose statement, both of which guided the approach to the study.

Children with PIMD

Intellectual disability (ID), previously termed *mental retardation* in the U.S., is defined as cognitive limitation with scores greater than two standard deviations below the mean on intelligence quotient (IQ) measures, and includes limitations in adaptive functioning, self-care,

life skills and social skills (Boat & Wu, 2015). Tasse, Luckasson and Schalock (2016) assert that ID begins during development and significantly limits intellectual function as well as adaptive behaviors in the realms of social, practical and conceptual development and skills. In the U.S., ID is typically classified by providers using either the *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (DSM-V; American Psychiatric Association, 2015), the classification assessment presented by the American Association on Intellectual and Developmental Disabilities (AAIDD; Clinical characteristics, 2016), or the National Institutes of Health description (Boat & Wu, 2015), all of which classify the severity of ID according to the child's support needs for daily functioning (Table 1). Individuals with *profound* ID often have comorbid congenital illnesses or syndromes, are unable to live independently and must have support for self-care. Additionally, individuals with *profound* ID are typically nonverbal and have other physical limitations (Boat & Wu, 2015). It is therefore accepted that children with PIMD are among the most complex children to care for.

There does not seem to be a common or shared global definition for MD, but it is generally accepted that the term describes an individual with more than one disability. However, Kohzuki (2015) suggested a definition that would change the term *multiple disabilities* to the term *multimorbidity and multiple disabilities* (MMD). According to Kohzuki's (2015) new definition, MMD can involve more than one of any of the following: impairments of speech, voice, vision, hearing, mastication, mobility, internal organs, brain, or any other physical, mental, intellectual or functional impairments. Individuals with PIMD also meet the qualifications for MMD (Kohzuki (2015).

Individuals with PIMD who require around-the-clock supervision and care to remain safe and free from medical danger or self-harm are included in the general category of MMD and, in

the context of this study, have been referred to as individuals with PIMD. There is an abundance of research literature available addressing prevalent types of disabilities such as Autism Spectrum Disorder (ASD) and Down syndrome (DS) as well as literature addressing the needs of the caregivers of those populations. However, research literature regarding children with PIMD and their parents is scarce.

Parents of Children with PIMD

Research regarding parents of children with any level of ID has presented evidence that parenting children with an ID can be exhausting, frustrating, confusing, rewarding as well as beneficial (White & Hastings, 2008). In comparison to parents of typically developing (TD) children and parents of children with mild to moderate ID, parents of children with PIMD are called upon to provide not only educational, emotional and other typical parenting tasks, but to perform those tasks round the clock and to also be called upon to perform medical tasks to keep their children alive and as healthy as possible in the midst of sometimes extremely difficult medical conditions. Some of these additional tasks include tube feeding (requiring training and large amounts of time for food preparation and feeding), round the clock observation to ensure that the child is breathing, performance of cardio-pulmonary resuscitation (CPR) and accident prevention to an intense degree due to the intellectual deficits of the child (requiring high vigilance). These additional tasks often exact physical, mental and emotional tolls that are unforeseen and unpredictable, which can result in negative emotional, physical and financial outcomes (Chou, Chiao, & Fu, 2011; Geuze & Goossensen, 2019).

Then too, with the severity of the disabilities of children with PIMD, primary caregivers (usually parents) of children with PIMD often face different types of physical, mental and emotional experiences than caregivers of typically developing (TD) children or children with

mild to moderate intellectual disabilities (ID), children with ASD, DS (Norton, Dyches, Harper, Roper, & Caldarella, 2016) and other specific disabilities related to specific diseases or syndromes (Zebracki, 2018). This study provided understanding regarding the parents of children with PIMD, their experiences and the effects of these experiences on their lives.

Situation to Self

An important aspect of phenomenological research is the inclusion of epoche, or “suspension of judgment” (Moustakas, 1994) that leads to an introspective self-awareness by which the researcher may observe the phenomena being studied with consideration of the researcher’s actual inability to be objective. This study originated from my own experiences as the mother of a child with PIMD who for 18 years carried most of the burden of care of my son with PIMD. I have preconceived ideas about the levels of stress experienced as a parent and primary caregiver of a child with PIMD due to my personal experience, having invested most of my waking hours during those years in the job of keeping my son alive and healthy while trying to parent my other four daughters.

Some of the difficulties of my own experiences as a parent of a child with PIMD include having to resuscitate him numerous times, having to prepare and feed him pureed food, administer anti-seizure medication three times daily, sitting in the hospital with him 24 hours at a time sometimes over a period of weeks while he clung to life by a thread, providing transportation for him to schools and frequent medical appointments, not being able to attend family or social functions due to his fragile condition, engaging my other children to help me because I was burned out, and feeling guilty for not being a good mother to my other children.

The mental health diagnoses related to my experiences include post-traumatic stress disorder, severe depression and caregiver burnout. Additionally, I experienced loneliness,

isolation, lack of support and inability to practice some of the coping skills that may have prevented the mental and emotional symptoms of the diagnoses above.

I have been both comforted and affirmed that the lived experiences of other parents of children with PIMD is similar to my own and that there are additional prevention and coping strategies that they may have used to effectively prevent or decrease the prevalence of mental and emotional health problems among parents of children with PIMD. In addition, I have learned from this study that parental wellness may be related to the parent's fundamental perspective regarding the role of disability in their lives. I have been encouraged that my personal experience does not have to be repeated by other parents of children with PIMD if they are informed in advance of ways to prevent burnout, PTSD, depression and other negative outcomes from their experiences and educated regarding the resources available to them.

My frame of reference, in addition to being the parent of a child with PIMD, is that I am a licensed K-12 educator, have been both a regular classroom teacher and a special education teacher for emotionally disturbed students, a swimming and volleyball coach, a home school mother and a medical office manager. I am a pastoral counselor and a doctoral student at Liberty University. These careers and roles have given me varied perspectives on my son with PIMD, my TD children and my role and experiences as their mother.

When I experienced depression in the early years of my son's life, I was treated with anti-depressants. Unfortunately, my depression deepened, the workload of my parenting roles increased when my son started having seizures and additional medical conditions which required multiple surgeries and multiple near-death experiences. In addition, two of my daughters witnessed my son's near-death experiences and assisted in resuscitation efforts; they have since estranged themselves from our family and claimed that their role in their brother's care was too

much, purporting that their contributions to his care constituted emotional abuse and that my attention to their brother to their exclusion constituted emotional neglect. These two daughters continue to be estranged at this current time with no attempts at reconciliation on their part for a period of six years.

I wondered to what degree my own experiences as a mother of a child with PIMD were responsible for my mental health challenges and the resulting unhappiness and estrangement of two of my daughters. I realize that this started as a self-focused study to normalize my own experience but grew to understand that the results of the study could help other parents in similar situations to avoid the unfortunate personal (and family) outcomes that I experienced. My questions about the experiences of parents of children with PIMD come from my own bioecological perspective, as described by Rosa and Tudge (2015) which posits that a person is influenced by the micro, meso and macro-environments as well as the proximal processes within the individual's systems in which she is contextualized. Bronfenbrenner's bioecological theory (phase three) posits that these processes may affect personal and contextual outcomes (Rosa & Tudge, 2015).

Furthermore, my desire, according to Christian biblical instruction has been and is to comfort others with the comfort with which I have been comforted (1 Corinthians 1:4,) to assure other parents in similar parenting situations that they are not alone in their struggles and to equip such parents with additional strategies to improve their lives as parents of children with PIMD. My Christian worldview also motivates me to carry out this study with sensitivity, with love and respect as my guide for my interactions with the participants during the interviews, cognitive representations and focus groups and as I analyze the data collected.

Problem Statement

There is a large volume of research available regarding children with DD (Acosta, Garcia, & Bagner, 2019; , ID (Adams, et al., 2018; Beadle-Brown et al., 2018; Beighton, & Wills, 2019), ASD (Norton, Dyches, Harper, Roper, & Caldarella, 2016), DS (Nelson Goff et al., 2016) and other disabilities; however, most of the previous research has targeted parents of children with all disabilities (as a general category) or within the categories of parents of children with DD, ID, ASD, DS and other specific syndromes as well as parents of children with mild to moderate ID. There is little research that has specifically investigated the lived experiences of parents of children with PIMD. Children with ID often have comorbid ASD, and children with severe and profound intellectual disabilities often have comorbid and multiple physical disabilities as well as autistic characteristics (ID & ASD, 2016). The fact that many of these individual traits of children with disabilities have been studied led me to wonder whether any studies have investigated the experiences of those with a combination of many of these disabilities or those with profound ID.

Upon conducting the literature review, it became clear that there are very few studies that have investigated or described the great, complex needs of children with PIMD or the needs of those who care for them, typically their parents. Exploration into the complex lives of individuals with PIMD and their parents was thus warranted to deepen the understanding of the lived experiences of parents of this specific population. The problem was that the understanding of the lived experiences of parents of children with PIMD had not been sufficiently studied.

In the literature review, only ten empirical studies were found that focused on the needs of parents of children with ID (Blacher & Baker, 2007; Caicedo, 2014; Dos Santos & Pereira, 2016; Foster, Mangione-Smith, & Simon, 2017; Gallagher, Phillips, Oliver, & Carroll, 2008;

Gertstein, Crnic, Blacher, & Baker, 2009; Kuo et al., 2014; O’Connell, O’Halloran, & Doody, 2013; Redmond & Richardson, 2003; Slattery, McMahon, & Gallagher, 2017; White & Hastings, 2004). Of those, only one focused on the *lived experiences* of parents of children with ID (O’Connell, O’Halloran, & Doody, 2013) and only two studies considered the needs of mothers of children with PIMD (Chou, Chiao, & Fu, 2011; Redmond & Richardson, 2003). One recent study was found regarding mothers of children with life-limiting neurodevelopmental disabilities in Ireland (Courtney et al., 2018), but no qualitative research has been found regarding parents of children specifically with *profound* intellectual *and* multiple disabilities except the study by Redmond and Richardson (2003) that described the experiences of mothers of children with PIMD in the context of their service needs, not in the full life context of those parents.

Although societal efforts have been made, especially through special education laws and provisions, to address the needs of the children with PIMD, there did not appear to be sufficient data or resources to address the needs of their parents. Only the parents themselves could provide insight into the challenges, positive aspects and needs they encountered as the caregivers of children with PIMD (Luijckx, van der Putten & Vlaskamp, 2017; Seliner Latal, & Spirig, 2016; Bullen, Luger, Prudhomme, & Geiger, 2018; Wilder & Granlund, 2015). Only the parents themselves could provide insight into ways that they have personally found to be effective to cope with their unique challenges and needs as they relate to caring for their children with PIMD.

In order to understand and effectively help parents of children with PIMD, my research was conducted to ask parents about the specific challenges they faced and the specific coping strategies they have found to be helpful. The findings will be shared with others with similar

circumstances and with other stakeholders, such as medical and mental health care providers and educators so that they may more effectively assist these parents to have more positive outcomes in their personal, family and social lives. Therein lay the focus of this investigation.

Purpose Statement

The purpose of this transcendental phenomenological study was to describe the lived experiences and coping strategies of parents of children with PIMD in Central Virginia. The researcher collected data from eight parents of children with PIMD; profound ID is defined as an individual with an IQ below 20 and requiring 24-hour care and multiple disabilities are regarded as having more than one disability. Parents of children with PIMD were chosen for this study because they had previously been excluded from most of the previous research, yet these children and their parents have the highest level of needs and support. Children with PIMD were identified by their parent (participant) when the parent filled out the initial screening questionnaire (Appendix C) . Note that no question was asked regarding the child's intelligence quotient (IQ) because for most parents of children with ID, this number is either unable to be attained, unavailable (Van der Molen et al., 2010), or insignificant. The questionnaire contained the demographic information to include the level of severity of ID as identified by Table 1. For the purposes of this study, lived experiences were generally defined as those experiences described by the parents in response to semi-structured interviews, cognitive representations and focus groups.

Bronfenbrenner's bioecological theory (Eriksson, Ghazinour, & Hammarström, 2018) and family systems theory White and Bregman (2011) assisted me in understanding the personal and interpersonal relationships, intrapersonal and interpersonal stressors, coping strategies and the effects of all these on the participants' lives. The themes extracted from the semi-structured

interviews, cognitive representations and focus groups have deepened my understanding of the lived experiences of parents of children with PIMD so that those in supportive roles (medical, mental health, educational professionals as well as family members and friends) may assist these parents in experiencing greater life outcomes despite the great challenges of parenting children with PIMD.

Significance of the Study

This study contributes knowledge to the field of intellectual disabilities as well as to the field of parenting, specifically as it related to parenting children with PIMD (Gertstein, et al., 2009; Jackson, Steward, Roper, & Muruthi, 2018). Similar studies in the field of ID have addressed parents of children with special needs (Caicedo, 2014; Barnett, Clements, Kaplan-Estrin, & Fialka, 2003), generalized disability specific syndromes such as ASD, DD (Lee, 2013 Dos Santos & Pereira-Maria, 2016; Slattery, et al., 2017; Doo & Wing, 2006), DS or CP (Maenner, et al., 2016) and children with general ID or mild to moderate ID and their parents (Blacher & Baker, 2007; Cooper et al., 2015; Gallagher, et al., 2008). Closer to this study's participants, other studies have been conducted regarding children with severe ID (White & Hastings, 2004), severe or profound ID (Redmond & Richardson, 2003) and children with specific medical illnesses and their parents (Foster, et al., 2017; Kuo et al., 2014; Ouyang, et al., 2014). Additionally, caregiver stress has been researched to draw upon the current understanding of parent and caregiver stress in general (Amankwaa, 2017). The current study has the impact of deepening understanding of the experiences of parents of children with PIMD and all those who are involved in their lives.

The importance of the study is that many who have not personally experienced parenting children with PIMD but who work with or interact with parents of children with PIMD will gain

insight and understanding of the experiences of parents of children with PIMD so that they are more aware and possibly better able to assist these parents as they navigate life with children with PIMD. This broadened understanding will inform medical and mental health providers as well as educators, friends, fellow congregants and family members as to the challenges, joys, perspectives and coping factors that are involved in parenting children with PIMD.

Empirically

Studying the lived experiences of parents of children with PIMD is significant in several ways. Approximately 1% of the U.S. population includes children with PIMD, which translates into approximately 3.72 million with PIMD and many, many more parents, siblings, extended family members and friends who are affected by PIMD (Zablotsky, Black, & Blumberg, 2016). This study adds to the body of knowledge that informs stakeholders including the parents, family members, educational members and medical and mental health providers of children with PIMD and assists them in understanding and meeting the needs of parents and families with children with PIMD.

This study is related to research previously conducted regarding parents with children with disabilities (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Blacher & Baker, 2007; Caicedo, 2014; Cooper et al., 2015; Doo & Wing, 2006; Dos Santos & Pereira-Maria, 2016; ; Gallagher, et al., 2008; Maenner, et al., 2016; Slattery, et al., 2017; Tsai & Wang, 2009), but addresses a population of parents with children with a much more specific diagnosis, PIMD. Some parents of children with disabilities asserted that they have had positive outcomes and improved lives as a result of their experiences (Ellingsen, Baker, Blacher, & Crnic, 2014); others report the opposite, that their dreams (Brown, 2016) and desires for themselves and their families were disrupted and stymied by the high level of needs of their child with disabilities (Courtney,

et al., 2018). This study adds to the literature regarding how the stressors, perspectives and coping strategies specific to parents of children with PIMD affect their life outcomes.

Theoretically

This study contributed to both Bronfenbrenner's bioecological theory (Eriksson, et al., 2018), and family systems theory (White & Bregman, 2011), as it has revealed, within the specific group of participants who are the parents of children with PIMD, how chronic and intense levels of daily challenges that accompany the disabilities of their child have affected their mental, emotional, physical and relational well-being. Emotional stressors have been studied; mental stressors have been studied; physical stressors have been studied; the interrelationships between these types of stressors have been studied, and the interrelationships between these types of stressors in parents of children with disabilities have been studied. However, these interrelationships in the context of a parent with children with PIMD have not been adequately studied. This study has revealed similar findings as well as some new findings, such as the impacts of seizure disorders of the child with PIMD, the impact of the dealing with the child's behavioral problems, as well as existential considerations, such as the impact of any helpful parental perspectives regarding disabilities, their child with disabilities and the life that they have experienced as a result. In addition, this study exposed the helpful coping strategy of online support groups, which had not been specifically investigated in previous literature, most likely because they are new.

Practically

This study provided a platform to give voice to a population who has not yet been heard from regarding their experiences as parents of children with PIMD. It is possible that their typical experiences of being a stigmatized, isolated, chronically stressed group of parents

(Scherer, Verhey, & Kuper, 2019) have contributed to their exclusion from the world of research, despite their courage and strength in difficult situations. This study gives other parents of children with PIMD, family members, educational, mental health and medical providers as well as their church families and friends, insight into the lived experiences, joys, challenges, stressors, perspectives and important coping strategies of the participants. With this information, those whose lives intersect with the parents of children with PIMD can be more attuned to their struggles, their needs and their perspectives and step up to become more involved to care for, advocate for and offer assistance to these parents and their families. The results of this study have the potential to increase sensitivity to and positive responses to the often stigmatized, isolated, anxious, fatigued and depressed population of parents of children with PIMD.

Research Questions

Research questions were formulated to define the purpose of the research, to identify the gap in the literature, to determine the methods to best answer the research questions, to guide the planning of the study and to help frame the analysis and findings (Curry, 2018). The research questions were intended to reveal some of the complex familial, social, physical, spiritual, emotional and mental processes involved in the parents' experiences of parenting children with PIMD as well as any felt needs of the parents (met or unmet) and their thoughts regarding the individual, familial and social impact of being parents of children with PIMD.

This study attempted to approach the research questions from an inductive and exploratory perspective, to be specific regarding the setting and the sample, to establish questions based on interest regarding a single phenomenon using verbs and not alluding to preconceived outcomes (Curry, 2018). An included purpose of this study (within the primary

purpose) was to characterize the mental and emotional challenges, spiritual perspectives and coping strategies of parents of children with PIMD.

Central Research Question

I desired to gather information from and insight regarding the participants' lived experiences and coping strategies as parents of children with PIMD with this Central Research Question: How do parents of children with PIMD in Central Virginia describe their experiences and coping strategies as parents of children with PIMD? Parents of children with disabilities typically face extraordinary challenges and stressors (Luijkx, Putten & Vlaskamp, 2017) and due to the severity of the disabilities of children with PIMD, primary caregivers (usually parents) of children with PIMD often face different types of physical, mental and emotional experiences than caregivers of typically developing (TD) children or children with mild to moderate ID, children with ASD, DS (Norton, et al., 2016) and other specific disabilities related to specific diseases or syndromes (Zebracki, 2018).

Additional Research Questions

The following additional research questions were designed to address the participants' emotional and mental well-being as related to their role as a parent of a child with PIMD.

RQ1: How does the participant describe how the experience of being a parent of a child with PIMD affects the participant's mental and emotional well-being?

RQ2: How do participants describe the coping strategies they have used to deal with their experiences as parents of children with PIMD?

RQ3: How do participants describe their existential and spiritual understanding and perspectives regarding their children's disabilities?

RQ4: How do participants describe the impact of having children with PIMD on their families and outside of family social and other interactions (Vélez-Agosto et al., 2017)?

Definitions

The following definitions were used to clarify the terminology in this study:

1. *Developmental disability or developmentally delayed (DD)* – described as a group of conditions related to impairments in at least one of the following areas: behavior, language, learning or physical development. The disability begins during development and usually extends across the lifespan (Centers for Disease Control and Prevention, 2019).
2. *Down Syndrome* - a congenital disorder arising from a chromosome defect, causing intellectual impairment and physical abnormalities including short stature and a broad facial profile. It arises from a defect involving chromosome 21, usually an extra copy (trisomy-21) (Oxford Dictionary, 2019).
3. *Intellectual disability (ID)* - an impairment in the adaptive behavior and intellectual functioning of an individual (AAIDD, n.d.). ID is described as significantly limiting intellectual function as well as adaptive behaviors in the realms of social, practical and conceptual development and skills (Tasse, Luckasson & Schalock, 2016).
4. *Mild intellectual disability* – described as having an IQ in the range of 50-69, can live independently with minimal support (APA, 2015).
5. *Moderate intellectual disability* – described as having an IQ in the range of 36-49; independent living would require moderate levels of support (APA, 2015).
6. *Multimorbidity and multiple disabilities (MMD)* - can involve more than one of any of the following: impairments of speech, voice, vision, hearing, mastication, mobility,

- internal organs, brain, or any other physical, mental, intellectual or functional impairments (Kohzuki, 2015).
7. *Profound intellectual disability* - described as having an IQ of less than 20 and requires 24-hour care. The individual with profound ID needs pervasive support for all aspects of daily living.
 8. *Profound intellectual and multiply disabilities (PIMD)* – individuals with a profound intellectual disability as well as a profound motor disability and usually several additional severe or profound secondary impairments (Nakken & Vlaskamp, 2007).
 9. *Severe intellectual disability* – described as having an IQ in the range of 20-35 and requires daily assistance with most self-care activities and supervision for safety (APA, 2013).

Summary

This chapter provided an introduction to ID and to PIMD and has described some of the challenges faced by parents of children with PIMD (Luijkx, et al., 2017). In addition, this chapter pointed out that the majority of research in the field of ID has been on children or parents of children with mild to moderate ID (Blacher & Baker, 2007), children and parents of children with ASD (Shepherd, Landon, & Goedeke, 2018) and children and parents of children with other comorbid medical and intellectual diagnoses. It has further been presented that the caregiver burdens that the participants bear often place these parents at higher risk of both physical and mental health problems (Adams, et al., 2018; Geuze & Goossensen, 2019).

With those points in mind, this chapter also revealed the purpose statement of the study, which is to describe the lived experiences and coping strategies of parents of children with PIMD

in Central Virginia. In addition, this chapter has provided empirical, theoretical, and practical significance of the study.

CHAPTER TWO: LITERATURE REVIEW

Overview

This literature review provides descriptions of existing research beginning with the theoretical framework of the study. This review includes first a general description regarding children with disabilities or special needs, then narrows the literature review to children with ID or DD, including DS and ASD, and then delves more specifically into research regarding children with *PIMD*. Finally, this review focuses on the *parents* of children with disabilities or special needs, ID, or DD (including DS and ASD) and filters to the literature regarding *parents of children with PIMD*. This literature review lays a foundation for the study by describing the research that had previously been conducted regarding children with various disabilities, with different types of needs and severities, and then focuses on the parents of children with PIMD, who are the participants in this study. The literature provides a backdrop for highlighting the gap in the literature, thus providing a rationale for the study.

In addition to this overview, this chapter provided a theoretical framework for the study. Additionally, the literature review includes studies of the factors related to these children's and their parents' stressors, existential and spiritual perspectives, and the specific coping strategies that the parents found to be successful. Finally, this review in its entirety pointed to the need for additional exploration into the experiences of parents of children with PIMD.

Theoretical Framework

The theories that guided this study were an expanded version of Bronfenbrenner's bioecological theory of human development as expanded by Vélez-Agosto, et al. (2017) and family systems theory (White & Bregman, 2011). These theories explain the interrelationships between individuals (including intrapersonal cognitions) and family members as well as

interactions and meanings of life experiences within one's culture. Together these theories provided a theoretical foundation for better understanding the factors affecting the lived experiences and coping of parents of children with PIMD.

Bronfenbrenner's Bioecological Approach to Human Development

The foundation of Bronfenbrenner's ecological theory posits that both an individual's personal characteristics and her contextual systems, as well as the intertwining of these systems, explains human development (Eriksson, et al., 2018). An updated version of Bronfenbrenner's theory expands the ecological system and adds that "human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate external environment" (Bronfenbrenner & Evans, 2002, p. 117). A more recent and thorough description of the bioecological theory is called the Process–Person–Context–Time model (PPCT), in which the original model, consisting of the micro, meso, exo and macro systems, were adapted by adding the chronosystem to the theory, to include the process of individual development, the person and her characteristics in both social and individual development, over time (Bronfenbrenner & Morris, 2006). This newer, adapted model takes into consideration the fact that systemic interactions typically occur on a somewhat chronological scale (Bronfenbrenner & Morris, 2006). Intrapersonal and interpersonal aspects of parenting children with PIMD may be better understood within the framework of Bronfenbrenner's theory while PPCT explains how individuals at different stages of life may be differently affected.

Expanded Bioecological Theory

Bronfenbrenner's bioecological theory of human development is a well-known theory of human development. Velez-Agosto et al. (2017) view Bronfenbrenner's theory as problematic or

even incomplete, as Bronfenbrenner's understanding of culture is limited to the context of the macrosystem and as separated from the functions of the microsystem. However, based on other theories, Velez-Agosto reconceptualized Bronfenbrenner's theory by situating culture as an integral part of the processes of proximal development (Velez-Agosto et al., 2017) Velez-Agosto et al. (2017) conceptualize culture as superimposing microsystems, defining and organizing them, and therefore is part of the central process of development.

Culture is a constantly evolving system that contains all the daily practices of communities, including neighborhoods, schools, and families, as well as the language through which it those practices are communicated and interpreted (Velez-Agosto, et al., 2017). Velez-Agosto et al. (2017) further asserts that culture contains certain signs and tools that are foundational to the community and are therefore part of an individual's microsystem. As a result, developmental processes are considered acceptable, indirectly defining, and being defined by the culture (Velez-Agosto et al., 2017). The same authors (Velez-Agosto et al, 2017) call upon the researcher to consider the cultural context (including social interactions, religious beliefs, language, traditions, etc.) of a person as part of what affects his or her life outcomes.

In the current study, the socio-cultural aspects of individual and family development stimulated the researcher to include the effects of culturally influenced existential and spiritual perspectives regarding disabilities, recognizing that different cultures view and treat individuals with ID differently due to cultural variations (Benomir, Nicolson, & Beail, 2016). In addition, Song, Mailick and Greenberg (2018) found that the social stigmatization of children with PIMD produced negative effects not only on the children with PIMD, but on their parents' health as well. It is evident that both cultural attitudes and spiritual perspectives affect how people with disabilities are treated and cared for. The understanding of the expanded bioecological theory

Velez-Agosto et al., 2017) helped to structure the current research so that the many personal, familial and socio-cultural considerations would be included in the investigation of and resulting understanding of the phenomena being studied.

Family Systems

Bowen's Family Systems Theory (White & Bregman, 2011) posits that human beings function at many levels, including individual, family, and societal levels. Within these relationship systems, the multiple interactions of each individual within each subsystem determine the functioning of each individual and each relationship (White & Bregman, 2011). Family systems theory includes the theoretical position that the members of relationships affect each other and each other's relationships (White & Bregman, 2011). Furthermore, family systems theory asserts that these relationships are affected on multiple levels and within multiple social contexts and that they also affect the emotional functioning of all within the various system levels (White & Bregman, 2011).

One of the underpinnings of the family systems theory (Mullens et al., 2018) is that serious life challenges and crises affect the entire family and each member's adaptation to the situation or event, and therefore affect how each unit, family system and subsystem relates to the others (Walsh, 2016). Family systems theory proposes that crises in a family will have long-lasting effects throughout the interrelationships of the entire family and will be part of the building of or deconstruction of individual and family resilience (Walsh, 2016). Since the birth (or adoption) of children with disabilities and the ensuing family's experiences are often experienced as crises (Heiman, 2002) family systems theory guided this study's pursuit of understanding the responses of participants regarding their perceptions, interpretations and

family interactions as well as the effects of those perceptions, interpretations and interactions on other family members, systems and subsystems.

Together these theoretical frameworks provided a foundation for the design of this study in pursuit of understanding the lived experiences of parents of children with PIMD. The participants' experiences were understood within the framework of the above theories. In addition, the above theories guided the researcher in developing questions and in conducting semi-structured interviews, cognitive representations and focus groups with the participants so that the questions reflected their experiences within their corresponding systems and subsystems, including experiences with spouses, other family members, formal and informal social supports, medical and mental health workers, educational systems and government agencies and how those experiences affected the participants' emotional well-being, relationships, existential and spiritual perspectives and coping strategies that contributed to their lived experiences.

Related Literature

There is an abundance of research literature available addressing prevalent types of disabilities such as DD (Gallagher, 2017), ID (Hastings & Beck, 2008), DS (Norton et al., 2016), ASD (Su et al., 2018) and other types of disabilities, many of which may fall into the general category of DD or ID. Many of these studies address the difficulties faced by the parents of individuals with these disabilities because the parents are typically the primary caregivers. Many of the studies also reveal that there are both positive and negative effects on family members with a child with DD (Nurullah, 2013), ID (Yoong & Koritsas, 2012), DS (Farkas et al., 2019), ASD (Lim & Chong, 2017) and other disabilities. It must be understood that many of these categories of disabilities overlap, though DD encompasses ID as well as physical disabilities. DD and ID are often used interchangeably, because of the commonalities between them. Similarly,

DS falls into both categories of ID and DD, and ASD may also fall into the larger category of either DD or ID. Additionally, most of the diagnoses regarding disabilities also fall under the broader category of what educators call special needs. However, since the prevalent extant literature was regarding the specific disabilities mentioned above (DD, ID, DS and ASD), this section is divided into subsections according to these disabilities, though in some cases the child is simply described as having special needs.

Since PIMD also falls into the category of DD and ID, and since children with PIMD have many commonalities with children with other levels of severity of DD and ID, they are included in this section. Therefore, although the following sections contain research regarding children with DD, ID, DS and ASD and their parents, as well as parents of children with life-span shortening conditions (Geuze and Goossensen, 2018), which can be also be a characteristic of children with DD, ID, DS and ASD, it is hereby noted that many of these diagnoses overlap, and that although they are not exactly the same, these diagnoses also share some characteristics with children with PIMD, thus their relevance to this study.

Parents of Children with DD and ID

Panicker and Ramesh (2018) stated that carers of children with ID are usually family members and that since caregiving for these populations demands more physical, financial, emotional and social resources, parents of children with disabilities report more stress, lower levels of well-being and lower levels of marital satisfaction compared to those who care for TD children. This same research purports that 18%–47% of carers of individuals with disabilities suffered from depression (Panicker & Ramesh, 2018). Additionally, in a qualitative phenomenological study exploring the lived experiences of mothers of children with ID, the major themes that arose were: painful emotions, difficulty with acceptance, a relationship

between the child's well-being and the mother's mental health, insufficient family and social support and anxiety regarding the child's future (Kermanshahi et al., 2008).

Caicedo (2014) revealed that parents of children with special needs reported being fatigued upon awakening in the morning, being too tired and having too little energy to participate in recreational or social activities. Caicedo (2014) also asserted that the parents of children with special needs felt angry, anxious, frustrated, hopeless and helpless, had trouble concentrating, worried about their child's medicines, medical treatments and negative side effects and experienced anxiety related to their child's future and how the child's condition would affect the rest of the family.

A study by Bourke-Taylor, Pallant, Law, and Howie (2012) described how child, maternal and environmental factors affect maternal mental health among mothers of children with DD. In addition to studies related to effects of DS on parents' well-being, Ferrer, Vilaseca and Bersabe (2016) indicated that families with children with ID who had higher levels of positive perceptions also reported higher levels of family quality of life. Zeedyk and Blacher (2017) reported that in mothers of children with or without ID, child behavior problems, financial struggles and low optimism were related to the mother's symptoms of depression. Blacher and Baker's (2007) study regarding parents' perceived positive impact of ID on their families found that the parents' positive perceptions decreased as the child's behavior problems increased. In the same study, the positively perceived impact of the child's disability was a moderating factor for parental stress, although these latter results differed by ethnicity (Blacher & Baker, 2007).

Research by Adams et al. (2018) found that mothers of children with ID experienced more mental health problems and that their mental health was negatively affected by their child's challenging behaviors.

Parents of Children with DS

Another study by Norton et al. (2016) reported that families with a child with DS report overall higher levels of stress, more difficulties with adjustment, and less effective coping abilities. Additionally, Blacher and McIntyre (2006) reported that mothers of children with DS have more positive experiences and less stress, depression, and caregiver burden than mothers of children with other DD. Norton et al.'s (2016) study also found that mothers and fathers of children with DS described their marriages as having less quality when they were stressed, but that the stress of one spouse did not affect the perceived marital quality of the other spouse.

In their study regarding ego-resiliency and parent satisfaction for parents of children with DS, Kózka and Przybyła-Basista (n.d.) found a difference in perceived stress, psychological well-being and some aspects of parental satisfaction between parents with high ego-resiliency compared to parents with low ego-resiliency. Ego-resiliency is considered one factor in general resiliency, which is described as containing the factors that contribute to one's ability to adapt to traumatic events as well as daily life (Kózka & Przybyła-Basista, n.d.). Ego-resiliency, a subset of resiliency, is considered as the ability of a person to regulate his impulses and vary his level of self-control amid stressors (Kózka & Przybyła-Basista, n.d.). It must be understood that resiliency is considered a personality trait and that those with psychological resiliency are able to overcome difficulties and grow stronger as a result (Kózka & Przybyła-Basista, n.d.). Resiliency and ego-resiliency play a role in the coping process under difficult life circumstances (Kózka & Przybyła-Basista, n.d.). With that

understanding, Kózka and Przybyła-Basista (n.d.) found that parents of children with DS who had higher levels of ego-resiliency also experienced lower levels of perceived stress and higher levels of parent satisfaction than parents with lower levels of ego-resiliency. Although ego-resiliency of parents of children with PIMD has not been investigated, it is a factor to be considered, perhaps in future investigations, when considering parents' ability to cope with difficult circumstances.

Parents of Children with ASD

Bonis and Sawin's (2016) research regarding parents of children with ASD found that it is challenging for parents to acquire a diagnosis and related services for their child with ASD, that the parents are frustrated with their medical providers' lack of knowledge regarding ASD and communication with parents regarding their child's condition. The same authors found that parents of children with ASD are at high risk for stress and that the risks outweigh the protective factors for managing their stress (Bonis & Sawin, 2016). In addition, the same study concluded that medical staff could assist these parents in managing their stress by recognizing it and assisting parents of children with ASD with stress management (Bonis & Sawin, 2016). There are also positive aspects of having a child with PIMD, such as increased family cohesion, increased resilience, increased inner strength and increased community involvement (Ellingsen, Baker, Blacher, & Crnic, 2014).

Freedman, Kalb, Zablotsky, and Stuart (2012) discussed the additional stressors placed on parents and families of children with ASD, although in their study, they determined that a child's ASD did not affect parental divorce rate. Karst and Van Hecke (2012) found that due to the severe and pervasive deficits of children with ASD, parents may be less efficacious, have more stress and have an increased likelihood of mental and physical health problems compared

to parents of TD children and children with other DD. Parents of children with ASD have higher rates of divorce and lower family well-being than parents of TD children (Karst & Van Hecke, 2012). The same authors as well as Parish, et al. (2012) also stated that parents of children with ASD experience greater financial challenges and higher levels of time pressures, both of which lead to additional stress for parents. Minjarez, Mercier, Williams and Hardan (2013) confirmed that the parents of children with ASD experience high levels of stress and in their research found that parents' stress levels were decreased and that their sense of empowerment was increased after participating in a pivotal response training group therapy specifically designed for parents of children with ASD.

The study by O'Connell, O'Halloran and Doody (2013) presented one mother's feelings about her role as the mother of a child with ASD, including her ability or lack of ability to cope and grow during sad times. Other related research revealed the specific struggles of parents facing end of life decisions for their children with PIMD (Zaal-Schuller, Willems, Ewals, van Goudoever, & de Vos, 2018). Su, Cai and Uljarević (2018) investigated the effects of parental intolerance of uncertainty, broader autism phenotype, sensory sensitivity, autism severity and comorbidities on the mental health of Chinese parents of children with ASD. This research revealed that parents' broader autism phenotype and intolerance of uncertainty as well as the child's internalizing challenges had a direct effect on the mental health of the parents (Su, Cai & Uljarević, 2018). Additionally, they found that sensory sensitivity has an indirect effect (via intolerance of uncertainty) on the parents' mental health (Su, Cai, & Uljarević, 2018). This study revealed that parental traits are significant when studying associations between a child's ASD and the mental health of parents.

There is one study that revealed the lived experiences of parents of children with ID (O'Connell, O'Halloran, & Doody, 2013), one study that revealed the lived experiences of parents of children with ID (Kermanshahi, et al., 2008) and one study that revealed the time use of parents of children with PIMD ((Luijkx, Putten, & Vlaskamp, 2017), indicating that parents of children with PIMD spend 1.5 hours more time per day on care tasks related to their child with PIMD, which means they have 1.5 hours per day less to spend on recreation and self-care, both of which contribute significantly to parental well-being. The same authors added that it is important to consider not only the needs of the child with PIMD but also the needs of the parent in order to facilitate their ability to continue to provide their child's daily care needs (Luijkx, Putten, & Vlaskamp, 2017). Together the related literature provided information related to many aspects of parents of children with ID, DD, physical disabilities and ASD and incomplete information regarding the lived experiences, existential and spiritual perspectives and coping strategies of parents of children with PIMD. The following sections describe multiple factors involved in both the positive and negative aspects of parenting a child with PIMD.

Children with PIMD

All children have basic needs such as nutrition, shelter, safety, education, access to medical care, social interaction, and emotional, mental and spiritual nurturance. The special needs of children with PIMD make the provision of these needs more complex due to the nature of the child's disabilities. This section describes the detailed needs of children with PIMD.

It is evident that the needs of individuals with PIMD vary and can be somewhat ambiguously divided into partially overlapping categories of needs: emotional, medical, educational, social, financial and spiritual, most of which are typically met by parents, medical providers and educators. In addition, many government or community services may be available

to provide various types of assistance to families who care for individuals with PIMD. Support needs are needs that are described in terms of their pattern and intensity, which vary according to the severity of the child's disability (Thompson et al., 2009). Several categories of needs are described below.

Emotional Needs. The emotional needs of individuals with PIMD can be intensified by their frequently painful medical needs which may cause frustration due to their inability to communicate their physical pain or mental and social frustration as children with PIMD cannot easily self-report sources of pain or pain levels (Quinn, Seibold & Hayman, 2015). Caicedo (2014) stated that in the U.S. alone there were 11.2 million children who had special healthcare needs and the incidence of comorbid medical diagnoses with ID was 90.6% in 2003 (Arvio & Sillanpaa, 2003). The frequent doctor visits, surgeries and associated hospitalizations contribute to the discomfort, pain, emotional anguish and time constraints experienced by this special population and those who care for them (Zebracki, 2018; Seliner et al., 2016).

Medical Needs. Often parents of children with PIMD must research (Kiernan, Mitchell, Stansfield, & Taylor, 2019), question and advocate for their child's rights to and access to appropriate medical care (Krueger et al., 2019). Close to 50% of caregivers of children with complex health and medical needs self-reported that there were issues gaining access the specific medical needs of their children (Foster et al., 2017). A study by Erven, Hennen, Merrick and Morrad (2014) stated that there are still many barriers that prevent access to quality medical care to assist patients with ID, including a lack of training for medical providers concerning the multi-morbidities of their ID patients, a lack of communication between multiple providers and their patients, difficult and confusing financial systems that impede access to health care services and the unawareness on the part of healthcare providers of other services available to assist their

patients. Referring to the need for additional research in the area of the medical needs of individuals with PIMD, Ndengeyingoma and Ruel (2016) stated that additional research is needed to achieve a deeper understanding of these patients' and their parents' expectations.

Educational Needs. The educational needs of individuals with PIMD are often met in public, private and home-based educational settings; however, although in the U.S. the Individuals with Disabilities Education Act (IDEA; Lipkin & Okamoto, 2015) states that students with special needs are entitled to a free and appropriate education, parents must often be much more involved with their child's education and must often advocate for the child so that those educational needs are actually met (Kiernan et al., 2019). The Individualized Education Plans (IEP) written and implemented by special educators are intended to maximize the educational gains and hopefully integrate the educational progress of students with PIMD into both the educational and personal life situations. Great strides have been made over the last twenty years to educate students with PIMD to their fullest potential through collaboration with all educators and special service personnel as well as with the parents. However, the IEP process is not always smooth or enjoyable; a study by Zeitlin and Curcic (2014) found that the parents of children with ASD in their study felt like the IEP process was depersonalizing and emotionally upsetting, sometimes causing the parents to feel judged and powerless.

Social Needs. Socially, individuals with PIMD are more isolated than TD children (Rodrigues, Fontanella, Avó, Germano, & Melo, 2019) due to the complexities of preparing for and attending outings. Hall (2010) asserted that individuals with intellectual disabilities are marginalized and excluded from many social opportunities, sometimes due to the inaccessibility and inappropriateness of public facilities (Rodrigues, et al., 2019). Parents of these individuals are also excluded since their caregiving job does not end when there is a social event; many

simply opt out due to the difficulty of navigating a new environment with their child with PIMD or the challenges of trying to socialize in the midst of a prejudiced or uncomfortably curious public (Rodrigues et al., 2019). Beadle-Brown et al. (2016) purport that people with ID and DD spend a larger percentage of their time isolated and disengaged from social interaction and that the more severe the disability, the more isolated they are.

Financial Needs. The financial needs of PIMD individuals and those caring for them are similar to the needs of most families. However, there are additional financial needs that must be considered for this population, such as the cost of transportation to and from special schools and specialized medical care (Rodrigues et al., 2019). A study evaluating the financial burden of parents of children with Fragile X, ASD and ID, Ouyang, et al. (2014) found that parents of all three groups experienced financial burdens as a result of their children's conditions, some having to leave employment completely to provide the care needed by their children. Additionally, even if services may be available to offset financial costs, families may be unaware of or may find the burden of accessing assistance overwhelming (Catherall & Iphofen, 2006). Surprisingly, Kuo et al. (2014) stated that 56.8 % of caregivers of children with complex health and medical needs report financial problems and over 54% reported they had to stop working because of the child's health.

Spiritual Needs. Author Watts (2011) questions whether there is a level of intellectual disability beneath which an individual is unable to comprehend the spiritual. However, Macquarrie (1995) argues that all human beings are capable of experiencing the resurrection of Christ in some form, so even the most severely ID individual cannot be excluded from spiritual import or growth. Carter and Boehm (2019) found that among children with ID, at least half of the youth studied participated in worship services, Sunday school, religious classes or

congregational social gatherings. Liu, Carter, Boehm, Annadale, & Taylor (2014) found that spiritual involvement and expression can be quite important in the lives of individuals with ID (Liu, Carter, Boehm, Annadale, & Taylor, 2014). However, Ault et al. (2013) found that over half of parents of children with disabilities did not participate in religious services because appropriate supports were unavailable. Additionally, 32% of parents of children with ID changed their worship venues because they felt that their children were either not welcomed or not included appropriately (Ault et al., 2013).

Parents of Children with PIMD

As stated above, children with PIMD have needs beyond those of TD children, which in turn affects the needs of those who care for them. For decades, the focus of psychological, educational and medical programs and studies for individuals with PIMD has appropriately been on the individual with PIMD himself. As is inferred by the family systems theory and Bronfenbrenner's theory, when a child has severe problems, these problems will affect the entire family as well as their meso and macro-systems. Parents of children with PIMD must face these problems on a daily basis, often with limited resources. In their quantitative study on parents of children with PIMD, Jensen, van der Putten and Vlaskamp's (2013) investigation found that professional support and partnerships are important to the families. Additionally, Chou, Chiao and Fu (2011) study among carers of children with PIMD in Taiwan found that those who care for adults with PIMD have a significantly lower quality of life, health status and formal social support than those who cared for individuals with less severe disabilities, and that those differences were associated with the caregiver's employment, income, educational level and social networks. Suggestions by the researchers included creating more supportive environments

for those with PIMD and their lifelong caregivers, particularly when the individual and caregiver are socially underprivileged (Chou, Chiao, & Fu, 2011).

Wilder and Granlund (2014) conducted a qualitative study regarding stability and sustainability of the daily routines and social networks of families of children with PIMD in Sweden and found three themes regarding family accommodations for daily routines, including marital connection between spouses, father's involvement and emotional support. Furthermore, the same authors confirmed previous research regarding increased parental stress for parents with disabilities (Risdal & Singer, 2004), and the significance of social support during challenging life circumstances (Wilder & Granlund, 2014). Wilder and Granlund (2014) also found that parental connectedness acted as a buffer against stress and single mothers had less sustainability than married couples with high connectedness. All participants in the Wilder and Granlund (2014) study reported that both formal and informal support were significant and that when stress outweighed the family's resources, the level of emotional and social support decreased, whereas when external support was provided, including mothers working outside the home, the family's environmental stability was more likely to increase over time.

Challenges of Parents of Children with Disabilities

Parents of children with PIMD face different types and intensities of challenges than parents of children with other types of disabilities or than parents of TD children (Tadema & Vlaskamp, 2010). These parents experience increased emotional, psychological and physical stress as well as the grief, guilt, loss of control and social challenges. Parents deal with these challenges with great resilience and coping, resulting in better individual and family experiences, or with less resilience and less coping, which can result in poor individual and familial outcomes (Patterson, 2002).

Increased Stress. As previously stated, the caregiving demands on parents of children with PIMD are great. Tadema and Vlaskamp (2010) conducted a study to assess the care burden for children with PIMD using questionnaires sent to special education centers in the Netherlands for parents of children with PIMD to complete. Of the 243 questionnaires sent to parents, 139 questionnaires met the screening requirements, and the data from those questionnaires revealed that parents of children with PIMD provide for all the basic care needs of their child with PIMD and that the burden of care affects the entire family (Tadema & Vlaskamp, 2010). Additionally, the same authors found that the types of care tasks and the time parents spend completing the tasks may not fluctuate throughout the life of the child (Tadema & Vlaskamp, 2010). Tadema and Vlaskamp's (2010) study detailed the subjective burden of parents on a scale of one to ten as well as the effect of age on the burden experienced by parents and showed that parents of younger children (aged one to eight years) with PIMD seem to experience a higher burden of care in the following areas: tube-feeding, facilitating the child's drinking and eating, the child's behavior, caring for the child at night, and the child's mental condition (Tadema & Vlaskamp, 2010). It was also interesting to note that fathers and mothers of children with PIMD experienced different degrees of distress with the caregiving tasks (Tadema & Vlaskamp, 2010).

The parents of children with PIMD in Tadema and Vlaskamp's (2010) study also indicated that social support was significant for the parents of children with PIMD, though the participants deemed formal support more supportive than informal support (Tadema & Vlaskamp, 2010).

Parents of children and adolescents with ID were found to report lower levels of life satisfaction than parents of typically developing children and adolescents, likely due to the increased stressors they face (Adams, et al., 2018). One of the stressors that parents of children

with ID face is that of the stigma associated with disability (Cantwell, Muldoon, & Gallagher, 2015). The same authors reported that parents of children with disabilities reported more symptoms of depression and that there was an association between stigma and depressive symptoms, and further that this association was mediated by self-esteem (Cantwell, Muldoon, & Gallagher, 2015). In other words, the parents in this study who experienced more stigma had lower self-esteem, and those with lower self-esteem experienced higher levels of depressive symptomology.

Tsai and Wang (2009) found that the stress of caregiving responsibilities for parents of children with disabilities decreased the ability to adequately care for all children and negatively affects the whole family. Another study by Smith and Grzywacz (2014) found that parents of children with disabilities self-report lower levels of mental health, higher numbers of depression and more restrictions in their daily living activities. Smith and Grzywacz (2014) also report that their negative symptoms worsen over time and that the parents' perceived amount of control was a predictor of the parents' overall health over time. An additional study by Griffith et al. (2011) found that parents of children with three rare genetic syndromes resulting in PIMD have a higher risk of stress and problems with mental health than parents of typically developing children. Additionally, parents of children with MD experience higher levels of stress than parents of TD children, which can affect the marital quality of the parents (Robinson & Neece, 2015).

Gallagher and Whitely (2013) likewise report that parents of children with ID have higher rates of health problems than those of parents of TD children. This additional stress of a health problem on top of the ID may cause parents to have negative emotional outcomes due to their having to continue to function as a family yet redefine their familial roles in every sphere, sometimes repeatedly as new medical challenges arise. Parental stress is exacerbated by the

unpredictability of the child's health problems as well as the emotional weight and time demands related to meeting the child's needs (Pelchat, Lefebvre, & Levert, 2007). Additionally, as children with comorbid physical disabilities become more difficult to carry or assist (lift, transfer, etc.) due to increased weight, the potential for physical injury to the parent increases, especially musculoskeletal pain syndromes (Geere et al., 2013).

Mörelus and Hemmingsson (2014) stated that children with physical disabilities only (not ID or DD) also often have sleep problems related to their conditions, including seizures, difficulty breathing, incontinence, problems breathing, incontinence, pain or the need for repositioning . Research by Hemmingsson, Stenhammar, and Paulsson (2009) stated that 48% of children with moderate to severe physical disabilities had chronic sleep problems, and 37% of those children required parental night-time attention nightly. Children's persistent sleep problems and need for night-time attention may impact the health of parents who have to cope with sleep disruptions for many years while caring for their children, and for children with both ID and comorbid physical disabilities, as is the typical scenario for children with PIMD, the interrupted sleep, lack of sleep and unusual amount of wakeful hours for parents may be exacerbated.

Other sources of emotional distress for parent-caregivers can arise from grief, social isolation (He, 2017), sleep deprivation (Micsinszki, Ballantyne, Cleverley, Green, & Stremler, 2018), anxiety (Scherer, Verhey, & Kuper, 2019), not having a normal degree of control over the child's and family's life outcomes, poor relationship quality with children (Robinson, Weiss, Lunsky, & Ouellette-Kuntz, 2016), financial burdens (Parish, Rose, Swaine, Dababnah, & Mayra, 2012) and time burdens (Luijckx, Putten, & Vlaskamp, 2017). Caicedo (2014) reports that mentally, parents of special needs children were frustrated, angry and anxious and often felt hopeless and helpless. Caicedo (2014) also reports that parents of special needs children had

difficulty remembering and focusing on their tasks, were anxious about their child's medications, medical treatments, and potential side effects as well as about the child's future and the potential negative effects of the child's disability on other members of the family. Children with PIMD are often unable to feed, clothe, medicate, transport, toilet or manage self-care, all of which create emotional and physical stress on the parent (Luijkx, Putten, & Vlaskamp, 2017).

Grief. Another challenge that is unique to parents of children with special needs is the presence of cyclical grief. Most parents are excited to discover that they are expecting a child and look forward to the day when the baby will arrive. Parents who discover that their unborn or newborn child has disabilities must come to grips with the reality of the possibility shattered dreams of a normal life, both for the child and for the family (Brown, 2016). Grief experiences, exhibited in shock, negation, fear, sadness, guilt or anger were found to be common among parents whose children are newly diagnosed with ASD, and while some parents are able to resolve their grief, others encounter more difficulties and obstacles to overcoming the grief (Fernandez-Alcantara et al., 2016). Grief is a known stressor, perhaps especially to those who may have to grieve repeatedly over perceived losses in milestones never achieved, perceived losses in activities never to be enjoyed (Brown, 2016) and possibly by the anticipation of an early death of their child with PIMD (Zaal-Schuller et al., 2016).

Guilt. Svetlana (2019) stated that parents of children with disabilities experience more parental self-blame and guilt than other parents and that this guilt may persist throughout the child's life. Sources of guilt may include thoughts such as, "Did I do something during my pregnancy to cause this disability," or "What did I do in this life to deserve this?" Parents of children with PIMD question themselves consistently, which adds to the parents' stress (Svetlana, 2019).

Loss of Control. All parents must make some decisions for their children. However, parents of children with PIMD are often required to make almost all decisions for their child with PIMD, and some of those decisions may be life-impacting medical decisions (Seliner, et al., 2016). In many cases, the parents' options are limited, giving the parent a sense of having less internal locus of control and more external locus of control, which Lloyd and Hastings (2009) assert may make the parents more susceptible to anxiety and depression. In addition, the child's educational and social opportunities are more limited by external sources compared to the typically developing child, furthering a sense of less internal control (Lloyd & Hastings, 2009).

Social Challenges. Caicedo (2014) conducted a study with parents of special needs children using the *Pediatric Quality of Life Family Impact Module* and found that parents were tired when awakening, too exhausted to do the things they enjoyed and had little energy for completing household chores or engaging in social activities. Caicedo (2014) also found that these parents felt isolated and that others were unable to understand their families' circumstances. Parents of children with multiple disabilities may need to rely on extended family members and others, although these supports may be unsure or lack confidence in their ability to take care of the child's complex need (Hebbeler & Spiker, 2016; Wilder & Granlund, 2015). McCann, Bull and Winzenburg (2012) assert that due to the time-intensive needs of the child with multiple disabilities, families have limited time for social interaction. Additionally, parents of special needs children had difficulty talking with others about their special- needs child, including talking to medical personnel (Caicedo, 2014).

Results of Stress

High levels of stress associated with the above challenges of caring for children with PIMD may cause increased incidence of compromised emotional, cognitive and social

functioning for the parent-caregiver (Caicedo, 2014). In addition, high levels of parent stress can weaken the immune system, cause the heart to be unhealthily reactive and cause blood pressure to rise (Amankwaa, 2017). Dos Santos and Pereira-Maria (2016) add that the parental stress associated with caring for children with PIMD is typically high and can produce changes in family dynamics and coping approaches but that social support is strongly associated with building the strength of the family unit, whereas self-blame, wishful thinking, and social isolation tend to disunify the family.

Coping Factors and Strategies

Factors affecting the ability of parent-caregivers to adequately cope with their challenges caring for the child with PIMD include resilience (Mohan & Kulkarni, 2018), marital satisfaction (Kwok, Leung, & Wong, 2014), parent adaptability, perspective, support of spouse, amount of sleep, amount of physical activity and exercise, parents' own physical impairments, participation in healthy activities, parental sense of empowerment, the child's level of functioning, the degree of unmet service needs, parents' spiritual beliefs, parents' social support system (Hebbeler & Spiker, 2016; Dos Santos & Pereira-Martins, 2016; Kyzar, Turnbull, Summers, & Gómez, 2012) and parents' pre-morbid mental or emotional illness. Dos Santos and Pereira-Martin (2016) found that parents of children with ID benefited from seeking social support from their families and from professional services, that marital unity and support was associated with higher levels of mental and emotional health and that social support strengthened the family. The same authors also found that self-blame, wishful thinking, withdrawal and social isolation had a negative association with family unity (Dos Santos & Pereira-Martin, 2016).

Additionally, Adams et al. (2018) confirmed that with mothers of children with ID and challenging behaviors, their coping strategies were not related to the age of the child or the

degree of disability but were associated with the mother's mental health. Additionally, the more the mothers had positive, problem-focused coping strategies, the higher their positive affect; conversely, the coping strategy of active-avoidance was associated with negative affect and higher incidence of depression and anxiety (Adams et al., 2018). Another study regarding coping strategies and post-traumatic growth among parents of children with disabilities revealed that positive reassessment, acceptance of responsibility, confrontational coping and search for social support have a positive effect on post-traumatic growth, while planning revealed a negative effect on post-traumatic growth (Sergienko & Kohlmogorova, 2019). Furthermore, based on the data from the study, recommendations were made to provide psychological assistance for parents of children with disabilities to strengthen their post-traumatic growth (Sergienko & Kohlmogorova, 2019).

Resilience and Social Support. Parents of children with Asperger's Syndrome who reported higher levels of resilience were better able to handle the difficulties of caring for children with Asperger's (Bekhet & Zauszniewski, 2013). In a study by Ruiz et al. (2014), it was found that parents who had higher levels of resilience also self-reported greater physical health. In addition, Ruiz et al. (2014) reported that social support was positively related to resilience and that social support mediated the association between self-reported health and resilience and that it is possible that resilience offers a protective factor from the negative consequences of the chronic stress experienced by parents of children with ASD. In addition, McConnell, Savage and Breitkreuz (2014) reported that families with children with ID function better with stronger social relationships and support and less financial hardship and that the presence of strong support and absence of financial strain could be more important than the child's level of challenging behaviors. In addition, it is purported that social support is inversely related to

anxiety and depression in parents of children with ID, and children's problematic behaviors tend to affect the parents' emotional well-being (White & Hastings, 2008).

Marital Satisfaction. At first observation, it appears that high marital satisfaction may moderate or buffer the degree of parenting stress experienced (Gertstein, Crnic, Blacher & Baker, 2009). However, there is also evidence to support that the children with severe special needs can decrease marital satisfaction (Santamaria, Cuzzocrea, Gugliandolo, & Larcan, 2012). Barnett, Clements, Kaplan and Fialka (2003) asserted that family well-being can be improved by assisting parents to adapt to their child's disability by addressing parents' cognitive, emotional and behavioral needs. Furthermore, the parents' ability to adapt to the child's condition is a predictor of the family's sense of well-being and the disabled child's healthy attachment (Barnett, et al., 2003).

Kwok, Leung, & Wong (2014) asserted that parents (especially mothers) of children with ASD experienced higher incidence of psychopathology, higher incidence of family dysfunction and less marital satisfaction than parents of typically developing children. Tossebro and Wendelborg (2015) asserted that the divorce rate of parents of children with intellectual disabilities likely depends on the broader family context, including social context and family structure. Research does indicate, however, that Chinese parents with children with Down syndrome and ASD have lower marital satisfaction and attribution patterns negatively related to satisfaction in marriage (Santamaria et al., 2012). However, Saini et al. (2015) found that there were multiple variables and themes which must be considered when evaluating marriage satisfaction of parents of children with disabilities, including parental mental health, co-parenting, social support and conflict. The same authors also assert that in their study of parents of children with ASD, the development of common goals seemed to improve individual well-

being and couple relationships; such goals include increasing mutual respect among partners, acquiring and maintaining social support, reducing stress, and instilling hope (Saini et al., 2015). An additional study by Brown et al. (2019) regarding parents of children with ASD found that couple-based coping increased marital satisfaction and decreased parental stress.

Parental Existential and Spiritual Perspectives. A study by Slattery, et al. (2017) indicates that the parents' perspective on the disability can be a moderator of parental stress. They also found that an optimistic perspective predicted a higher level of positive reappraisal and social support, leading to the parents' finding greater benefits from their circumstances (Slattery, et al., 2017). John and Roblyer (2017) discovered that a family with a negative perspective regarding their child with ID will experience more stress. Blacher and Baker (2007) also found that a positive perspective was inversely associated with the child's negative behavior, and positive perspective of parents moderated the link between the child's negative behaviors and parents' stress. Additionally, parents who have a strong sense of their ability (self-assessed empowerment) to handle the disability were less stressed and more able to self-regulate emotions and coping skills through soliciting social supports (Pisula & Kossakowska, 2010).

Baines and Hatton (2015) assert that the parents' religion can either serve as a source of motivation and a coping resource for parents of children with disabilities, or as a source of stress. A study of Catholic priests displayed various spiritual perspectives regarding disabilities, including viewing the individual with ID as being in a special relationship with God, viewing the child as an eternal child, and seeing the child as part of the diversity of the human race, and on the negative end, seeing children with ID as defective and needing to conform to existing circumstances rather than have special treatment (Patka & McDonald, 2015). In an article on theology and disability, Bongmba (2017) asserted that some theologians believe that biblical text

and African culture may attribute disabilities to supernatural causes, which can contribute to the marginalization of individuals with disabilities.

An additional study, by You, Lee and Kwon (2018), regarding Korean mothers of children with various disabilities to investigate the tri-dimensional aspects of parenting stress (parental distress, parent-child disfunction and difficult child) as well as the impact of stress on their life satisfaction. This study found that religious orientation, which these authors considered an intrapersonal (spiritual) resource, moderated parental stress (You, Lee, & Kwon, 2018). The results of their study showed that parental distress and having a difficult child were negatively associated with life satisfaction and that in parents with moderate and high intrinsic religiosity, their religion weakened the association between life satisfaction and parent stress, suggesting that intrinsic spiritual resources may counter the negative effects of parental distress (You, Lee, & Kwon, 2018). This study addresses the role of spirituality on coping with maternal stress in children with disabilities, but not specifically with children with PIMD.

Adequate Sleep. One of the causes for a decrease in coping ability for any person is the absence of adequate sleep; sleep deprivation increases state anxiety and depression as well as general stress (Babson, Trainor, Feldner & Blumenthal, 2010). Sleep deprivation can account for various mental and physical illnesses (McEwen & Karatsoreos, 2014). Lee (2013) reports that mothers of children with DD often suffer from depression, poor sleep quality and high levels of stress. Stuttard et al. (2015) state that sleep problems are often common and severe in children with ID, affecting both the child and the parent, and resulting in poor life outcomes, including increased parental stress and related irritability. Woo and Wing (2006) as well as Acosta, Garcia and Bagner (2019) found that a large percentage of children with pervasive DD (often a subset of PIMD) also had sleep disorders. Acosta, Garcia and Bagner (2019) further found that parent-

child interaction therapy helped parents to decrease sleep problems in children with DD and borderline DD.

Typically, when a child has sleep problems, the parents do too. McQuillan, Bates, Staples, and Deater-Deckard (2019) and Bonis and Sawin (2016) state that lack of sleep for mothers is associated with less positive parenting. Children with DS have an increased risk for sleep problems, including difficulties with both falling asleep and staying asleep, napping during the day, sleep walking and breathing disorders during sleep (Choi, Jung, Van Riper, & Lee, 2019). There was no available research regarding the specific sleeping patterns of children with PIMD or the implications of sleeping patterns for parents of children with PIMD. Additional research regarding sleep patterns and their effects on children with PIMD and their parents should be considered when developing studies to address the needs of parents of children with PIMD.

Other Needs. There are many other needs that parents of children with PIMD must have met to be mentally healthy, including recreation, empowerment and accessible and available services for their child with disabilities (Bourke-Taylor et al., 2012). The above-mentioned research indicates that the use of social supports, having a positive spiritual, existential and mental perspective, having highly satisfied marriages, and having support services (respite care, medical services, mental health services, therapies, etc.) are coping advantages that can help to alleviate the stress associated with being a parent of children with disabilities. With the exception of research regarding support groups for parents of children with ID (Jackson, et al., 2018; Young, Shakespeare-Finch & Obst, 2019), research has been general and vague regarding practical, educational, and systemic approaches to increase the quality of life, decrease mental or emotional illness and family breakdown.

The above considerations, exposed by the literature review, would warrant further study regarding education to families and providers regarding assisting the parents of children with PIMD with helpful stress-reducing opportunities and developing and implementing programs that would increase social support, assist parents to establish a positive perspective, and provide marriage counseling or enrichment services for parents or develop programs or services (other than general respite services). Without such support and services available and in place for these parents, they are left to experience, often in isolation and silence, the unique and intense stresses of being the parent of children with PIMD, which can have devastating consequences for the child with PIMD, her parents and their families. This is information gleaned from the literature found in this review which would provide a springboard for additional qualitative inquiry.

Research Gap Regarding Parents of Children with PIMD

As noted above, there exists abundant research regarding the needs of the parents of children with various types of disabilities (Jackson, et al., 2018). However, only one study was found regarding the needs of parents (specifically mothers in this study) of children with PIMD, but that study addressed only the professional service needs of those mothers (Redmond & Richardson, 2003) and not the full lived experiences of the mothers. The other (qualitative) phenomenological study was regarding Indian mothers' perceptions of their lives with children with mental retardation (Kermanshahi et al., 2008). Additionally, relationships between medical personnel and parents of children with PIMD was studied (Jansen, van der Putten, & Vlaskamp, 2017) as were communications courses for parents of children with PIMD (Zentel, Engelhardt, Kraemer, & Sansour, 2019).

Seliner et al. (2016) describe the burden of parental care during a child with PIMD's hospitalization, and Onodera, Iwasaki, Goma, Arthur-Kelly and Suemitsu (2019) describe the

challenges of life transitions (from home to a facility) and adjustment for the parents of children with PIMD. In summary, specific aspects of lives of parents of children with PIMD have been studied, and one qualitative study investigated the perspectives of Indian mothers (only) of children with ID, but not PIMD. Of the qualitative studies found, none addressed the *lived experiences and coping strategies* of parents of children with PIMD in Central Virginia.

Although limited research is available regarding parents of children with PIMD, it has been shown that the severity of a child's disability is significantly linked to the parents' stress (Adams, et al., 2018). The increased stressors for this population include less sleep, less social interaction (Jackson et al., 2018), higher caregiving demands, higher financial strain, higher levels of stigma (Scherer, Verhey, & Kuper, 2019) and more medical emergencies and hospitalizations (Zebracki, 2018; Seliner et al., 2016). Additionally, family quality of life (FQoL) is affected by profound ID, with the more severe degrees of ID having a greater impact on family well-being (Chou, Chiao, & Fu, 2011). No studies that include the well-being and related stress factors, coping strategies and mental health of parents of children with PIMD were found.

Additionally, research on children with medical disabilities and severe or profound ID indicate that the parents, who are the typical caregivers of individuals with PIMD, have higher incidence (compared to some other types of disabilities and compared to non-disabled individuals) of distress, depression, anxiety and other psychiatric problems (Panicker & Ramesh, 2019) as well as decreased marital satisfaction and lower relationship satisfaction between mothers and their children (Robinson, Weiss, Lunskey, & Ouellette-Kuntz, 2016).

Because of the similarities in needs between PIMD and ASD, many assume that the stresses and challenges encountered by individuals with ASD and their families are also very similar to those of children with PIMD and their families. Studies reveal that although 38% of

children with ASD also have comorbid ID, it is also true that children with severe and profound intellectual disabilities often have comorbid physical disabilities as well as autistic characteristics (Cooper et al., 2015). Since the specific group of parents of children with *PIMD* has not been sufficiently studied to date, it was evident that there was a need for additional exploration into the lived experiences and coping strategies of parents of children with PIMD.

Summary

While much research has been conducted to assist children with disabilities and their families, most research has been dedicated to children with only DD, ID, DS or with ASD, and the majority of that research relates to the children with those conditions but not the parents of those children. Children with ASD and children with specific medical diagnoses or syndromes have been studied, as have the stressors and factors affecting stress levels for some of those populations. However, to date, very little research is available concerning the exploration of the full lived experiences, including the unique stressors and corresponding coping mechanisms, specifically of parents of children with PIMD. Additional research needed to be conducted to explore the lived experiences of these parents so that understanding could be deepened as they describe their unique joys, challenges, stressors, coping strategies, spiritual and existential perspectives, and perhaps the yet-unidentified unmet needs of the parents of children with PIMD.

The following conclusions have been drawn based on extant research: children with PIMD require special care needs from their parents; the burden of care can produce immense stress for their parents, which affects their quality of life and mental and physical health (Gallagher et al., 2008), and the needs of parents of children with PIMD often go unrecognized and unmet (Caicedo, 2014). Because one's lived experiences include life's challenges as well as various responses to those challenges, the literature review included research regarding

distinctions of types of disabilities, challenges of parents of children with various disabilities, and coping strategies and factors related to coping for parents of children with other types of disabilities. However, according to the literature investigated to date, the specific challenges, joys, perspectives, and coping factors in the family environment and the coping strategies employed by parents of children with *profound* intellectual *and* multiple disabilities, until this study, had not yet been focused upon for study.

This phenomenological study explored the lived experiences of parents of individuals with PIMD and included the following four research questions to answer the central research question: How do the experiences of being a parent of children with PIMD impact the mental and emotional well-being of parents of children with PIMD? How do participants describe their existential and spiritual understanding and perspectives regarding their children's disabilities? What coping techniques and resources do parents of children with PIMD find helpful? How does the experience of being a parent of children with PIMD affect other relationships, such as with family members and other social relationships?

Interview questions, cognitive representations and focus groups (all listed in the Methods Section of this dissertation) were conducted to assist the participants in describing their lived experiences as parents of children with PIMD. The data collection and the themes observed will be used to inform and encourage other parents of children with PIMD as well as the other stakeholders in the lives of those with PIMD. Based on the results of the study, the stakeholders may develop support programs and strategies to assist parents of children with PIMD to increase their and their families' overall well-being .

CHAPTER THREE: METHODS

Overview

The purpose of this transcendental phenomenological study was to describe the lived experiences of parents of children with PIMD in Central Virginia. This study revealed the participants' descriptions of their experiences regarding the perspectives, challenges, joys, family relationships, social supports and coping strategies they used for dealing with the challenges they experienced in their lives. This study, with a focus on the lived experiences of these parents, provided a platform for these parents to make their needs and coping strategies known to those in positions of educational, mental health and other arenas of societal influence as well as other parents or caregivers for children with PIMD. This chapter describes research design, research questions and provides a discussion of the setting, the participants and my role as the researcher. A discussion of data collection and data analysis, methods to ensure trustworthiness of the study and ethical considerations are also included.

Design

As previously stated, this study was designed with the purpose of achieving a rich description of the lived experiences and coping strategies of parents of children with PIMD. The most appropriate type of design for the research questions was a qualitative, phenomenological, transcendental approach. The details regarding this design follow.

Phenomenology

The phenomenological approach to research was used originally by Husserl in the field of philosophy then built upon by others who integrated the phenomenological view with the fields of psychology and sociology (Heppner et al., 2016). This study qualified as a transcendental qualitative study because it focused on the context of being a parent of children with PIMD

(Heppner et al., 2016) in developing an understanding of the phenomenon of the mental and emotional challenges and joys, as well as the perspectives and coping strategies associated with the experience of being a parent of children with PIMD (Caicedo, 2014). A qualitative study was chosen because qualitative research is described as a field that involves tensions and contradictions (Gall et al., 2007); parents of children with PIMD experience contrasting emotions, tensions and experiences ranging from joy to despair and from stress and depression to peace and adjustment. A phenomenological research design was also chosen because the goal of the phenomenological approach is to study a phenomenon from the perspective of those who have experienced it (Creswell, 2013; MacKenzie, 2018; van Manen, 1990).

Phenomenological research describes what the participants all have in common when experiencing the same phenomenon, to describe the universal experience in the individual experience (Creswell, 2013; MacKenzie, 2018). By asking the participants what the essence of the phenomenon was, this phenomenological research sought to understand the meanings made as human beings experienced the phenomenon (MacKenzie, 2018; van Manen, 1990). By discovering the meaning of a common experience, the phenomenological study uncovered some of the meaning of the phenomenon (Moustakas, 1994), resulting in a retrospective appraisal of the phenomenon, retrospectively focused on experiences that already occurred (MacKenzie, 2018; van Manen, 1990).

Phenomenological research is founded on constructivist theory and is guided by the specifically structured lived experiences of the participants. In this instance, the phenomena studied are the lived experiences and the constructed reality (experiences in and perspectives) of parents of children with PIMD. Phenomenological research investigates what it means to be human (van Manen, 1990). For many parents of children with PIMD, the contradictory emotions

of the joy of parenting along with the emotional, physical and psychological stresses brought on by parenting children with PIMD, was revealed in their lived experiences. These unique experiences contributed to the phenomenology of what it is like to be a parent of a child with PIMD, thereby increasing the body of knowledge regarding the lives of parents of children with PIMD and hopefully improving their lives and their children's lives. Phenomenology was an appropriate design for this study because the research questions explored the depth of what it means to be the parent of children with PIMD.

Transcendental versus Hermeneutical Approaches

There are two separate types of phenomenological approaches available for me to choose from, the transcendental and hermeneutical approaches (MacKenzie, 2018), which are essentially different in both in philosophy and methodology. In a hermeneutical approach, the researcher is considered a participant in the study who is interpreting the meanings of the lived experiences of other participants (Creswell, 2013; MacKenzie, 2018). In contrast, in a transcendental phenomenological study, every experience is "considered, perceived and described in its totality, in a fresh and open way" (Moustakas, 1994, p. 34). In the transcendental approach, the researcher is to perceive her reality through the lens of the other participants by withholding her own judgments and preconceived ideas (Moustakas, 1994), which calls for the researcher to "bracket" or suspend the researcher's own judgments and biases regarding the phenomenon being studied by putting aside one's own understandings so that all phenomena are seen in a fresh, open and new way (Moustakas, 1994). According to Moustakas (1994), a key concept of transcendental research is the researcher's intuition, described as the ability of the researcher to know herself through the capability of her mind to assess knowledge and experiences.

Transcendental Approach

I have chosen the phenomenological transcendental approach and have bracketed my perspectives, responses, thoughts and feelings throughout the entirety of the study through the use of a research journal, because I am the mother of a child with PIMD and have experienced the phenomenon of being a parent of a child with PIMD. Since the goal of the study was to describe the experiences of the participants, I chose a transcendental approach so that I was able to make plain my own perceptions, biases and judgments in a research journal while continuing to expand my knowledge of the phenomenon through the experiences of the participants (Moustakas, 1994). I attempted to recognize and journal my biased perspectives regarding the phenomena being studied and used global research questions based on the literature to explore and understand the lived experiences of the participants (Heppner, Wampold, Owen, Thompson, & Wang, 2016). In addition, there was a two-part criterion for the inclusion of the participants (Heppner et al., 2016), the shared experience of being a parent of children with PIMD and the participants' ability to share their experiences in an understandable way.

This phenomenological study was well-suited to explore and interpret the specific types of thoughts and feelings of the confusion, joys and frustrations encountered and the specific coping strategies used in the unique position and lived experiences of parents of children with PIMD. The purpose of the study was to investigate, categorize and document the experiences of parents of children with PIMD in order to develop opportunities and resources to be implemented by helping professionals, families of children with PIMD and those in other helping roles to support these parents and their families to effectively cope with the challenges specific to caring for children with PIMD. Such opportunities and resources will enable these special parents to achieve a higher quality of life in the context of their roles as parents of children with PIMD.

The use of semi-structured interviews allowed me to fully observe, discover and document the lived experiences of the participants by posing different types of open questions to the participants to provide the participants with the opportunity to expound upon their experiences (Cohen & Crabtree, 2008). In this way the interviewees had the opportunity to relate, express and richly describe their experiences. The content of the interviews served me in understanding the relationships between parents' positive and negative experiences and related stress and coping as they relate to their overall perspectives as human beings in the role of a parent of children with PIMD. In this approach to this phenomenological study, it must be understood that the researcher was an instrument in the study and was described as such. I have made every effort to set aside biases and preconceived ideas about the possible responses of interviewees (Heppner et al., 2016) for the purpose of not influencing the participants' responses and therefore tainting the data itself and the analyses or interpretation of the data (Yin, 2011).

Research Questions

Research questions were formulated to define the purpose of the research, identify the gap in the literature, determine the method to best answer the questions, guide the planning of the study and help frame the analysis and findings (Curry, 2018). The questions revealed the complex familial, social, spiritual, emotional and mental processes involved in the parents' experiences of parenting children with PIMD as well as any felt needs of the parents (met or unmet) and their thoughts regarding the individual, familial and social impact of being parents of children with PIMD.

The design of the study was an attempt to approach the research questions, interviews, focus groups and cognitive representations from an inductive and exploratory perspective. In addition, I established questions based on interest regarding a single phenomenon (being the

parent of children with PIMD) using verbs and not alluding to preconceived outcomes (Curry, 2018). The purpose of this study was to richly describe the lived experiences of parents of children with PIMD. More specifically, I desired to gather information from the participants regarding their experiences as parents of children with PIMD with a central research question and four more specific research questions.

Central Research Question: How do parents of children with PIMD in Central Virginia describe their experiences as a parent of children with PIMD?

RQ1: How does the participant describe how the experience of being a parent of a child with PIMD affects the participant's mental and emotional well-being?

RQ2: How do participants describe the coping strategies they have used to deal with their experiences as parents of children with PIMD?

RQ3: How do participants describe their existential understanding of and spiritual perspectives regarding their children's disabilities?

RQ4: How do participants describe the impact of having children with PIMD on their families and outside of family social and other interactions (Vélez-Agosto et al., 2017)?

Setting

This study focused on the lived experiences of parents of children with PIMD in Central Virginia. The participants came from personal contacts as well as the local YMCA as well as acquaintances of originally contacted potential participants in Central Virginia. The interviews for the study took place at the participants' homes (five), at a public library (one) or over the phone (one). The participants and the setting in which the interviews, cognitive representations and focus groups were conducted provided the researcher with access to an adequate population

of parents of children with PIMD in Central Virginia and provided a comfortable, neutral environment in which the participants were able to express themselves freely.

Participants

The method of sampling for this study was purposeful, criterion-based, homogeneous sampling, as, a homogeneous sample is appropriate when research questions are specific to the group of interest, and is then explored in greater detail (Center for Innovation in Research and Teaching, 2018). This sample consisted of key informants who had knowledge of being parents of children with PIMD and who were willing to talk about their experiences (Curry, 2018). According to Curry (2018), the sample size cannot be determined in advance, but by the principle of theoretical saturation, or the point at which no unique concepts arise from the interviews (Curry, 2018). It was estimated that saturation would occur at around eight participants, but the researcher felt that saturation was reached at six participants.

The participants in the sample for the study were selected from a subset of the target of the research, parents of children with PIMD (inclusion criterion). The participants were solicited from local organizations including the YMCA, the Regional School for the severely and profoundly ID, local county schools and the local day center for individuals over 18 years old with special needs. I collaborated with the administrators and directors of these organizations in face-to-face meetings or by email to explain the purpose of the study and to recruit the appropriate participants.

The two-hour semi-structured interviews, the cognitive representations and the focus groups with these eight participants more than saturated the information being collected (Center for Innovation in Research and Teaching, 2018). This sampling technique effectively represented the demographics of the larger population of people with PIMD and their parents, whether

biological or adoptive, as demonstrated by their parents' initial responses to the screening questionnaire regarding the severity of their child's ID.

Procedures

I attained approval from Liberty University's Institutional Review Board (IRB) before initiating the study (Appendix A). After obtaining IRB approval, I initiated contact with the participants, some of whom I knew by acquaintance from my son's school for severely and profoundly ID students, and others via acquaintances through my personal life, including directors of the other agencies and organizations, such as the YMCA and the Adult Day Center. In addition, three of the eight participants contacted me after hearing about the study from a friend whose child also has PIMD and who had participated in the study. The potential participants' contact information was obtained in person, although in several cases, I left my contact information with a mutual acquaintance, and then the participant contacted me. After initial contact, a recruitment letter (Appendix B) and screening questionnaire (Appendix C) was sent to the potential participants by email, explaining the purpose and requirements for participation in the study and a screening questionnaire (Appendix C) to ascertain if the potential participant met the criteria for the study and to be certain that the potential participant was indeed living in Central Virginia.

The interested parents sent the questionnaire back to me by email. I then contacted the qualified participants by text message or phone call to schedule an interview. Before beginning the first interview, I wrote in my research journal (Appendix D) how I felt about the first interview. Once I was with the participant, I had the participant sign the confidentiality papers and explained to them that I would not be acting as a counselor or friend during the interview, but as an information-gatherer only.

The interviews and descriptions of the cognitive representations were audio recorded, face-to-face, with the interviewee and me seated in chairs where we could see and hear each other well, or by telephone (on speaker) with me seated in a room by myself so no one could overhear the conversation, but so that the recorder could easily pick up the sound. The recorder was tested before the interviews began. During the interviews, at times I had to pause the interview so the participant could take their child to the rest room, make sure he or she did not need attention or so that the participant could greet a spouse who was arriving home. Other than those occasions, the recorder stayed on record mode the entire time. Once the interview was complete, I explained to the participant what a cognitive representation was, then provided paper and colored pencils for them to write or draw their cognitive representations. When they were finished, I recorded their narrative describing the picture they had drawn or what they had written.

After the data was collected from the interviews and cognitive representations, I sent the participants a link to the GroupMe app by text message and asked them to join our group. After the first three interviews, I engaged the group (on GroupMe) with a guide question to stimulate additional descriptions of their lived experiences. After each interview and cognitive representation, I transcribed the recording and wrote in my research journal. Every few days, after two or three comments had been posted on GroupMe, I added another guide question. I continued this process over the five weeks during which I conducted the interviews.

A two-hour recorded interview was predicted from the number of questions, and was also chosen for the following reasons: two hours is a long enough period of time to complete the questions, but not so long that people would be hesitant to participate due to time constraints. Any follow-up thoughts or questions by the participants were handled via the focus group. Two

hours was enough time to gather sufficient data for the first analysis; recordings enabled me to listen and re-listen at various intervals to be sure to observe and document all inferences, including tone and volume of voice, speed of speech, hesitations, emotional expressions such as crying, becoming tearful or laughing, and pauses that may relate meaning not expressed verbally.

Additionally, two-hour time slots enabled convenient scheduling for both the participants and me and protected the participant from becoming emotionally or mentally overwhelmed with the interview questions and the expression of answers to the interview questions. The participants seemed to feel very comfortable with me and were quite descriptive with the answers to the interview questions and cognitive representation descriptions.

The focus group was initiated after the first three interviews had been transcribed and preliminarily analyzed, both to allow participants to have time to mull things over and jot down any ideas or additions they would like to share during the focus group as well as to provide an opportunity for me to deepen or further explore any questions asked during the interviews. The transcriptions of the interviews and cognitive representation descriptions also noted any nonverbally communicated information, which was documented during transcription. I used the GroupMe app in order to avoid interfering with the participants' busy schedules. This app enabled the participants to make comments at their convenience.

During the interviews, I asked the interview questions without offering emotional support or feedback of any kind except to say, "Thank you" and then proceed to the next question. The recordings were then transcribed; seeing the words of interviewees written provided additional insights into their lived experiences as well as prompts for the focus group. Once the interviews had been transcribed and analyzed using Nvivo, the last guide questions for the focus group were posted, and the data from the focus group was collected and analyzed, also using Nvivo. Several

central themes were developed, then the Dissertation Chair suggested that I take another look and possibly limit the number of themes and include them as subthemes, which I did. Then my interpretations of the analysis were documented, and the results presented to my Dissertation Committee.

Interview questions (Appendix E) were designed to solicit vibrant and detailed descriptions of the experiences of the sample population to reveal the joys, challenges, perspectives and coping techniques experienced that they associated with their role of a parent of children with PIMD. These questions provided enough data regarding the parents' narratives to help me understand the phenomena of the participants' experiences as well as their emotional and mental perceptions and existential perspectives as parents of children with PIMD. Additionally, I kept a journal of my reactions, responses, feelings and thoughts regarding each interview and cognitive representation with the participants (Appendix D). This journal is now part of the research data.

The Researcher's Role

In existential phenomenological research, the researcher is the instrument (Yin, 2011). It was understood that by conducting the study, both my personal interpretations of the information gathered and the influence of my personal context and pre-research understanding would influence the overall interpretation of the information gathered (Thompson, 2018). Therefore, in accordance with transcendental approach, I bracketed myself by keeping a research journal (Appendix D), recording my thoughts, feelings and responses to the interactions with the participants. It is further understood that the researcher's interpretations were a dynamic and live part of the building of meaning throughout the research (Thompson, 2018). As the mother of a son with PIMD, I have experienced the joys, pains, sorrows and stressors that come with

parenting a child with PIMD. I knew my own perspective on my son's PIMD but wanted to know if different existential perspectives or spiritual beliefs had affected or influenced the participants' experiences. I also wondered if the experiences of other parents of children with PIMD were similar to mine with the same emotional outcomes I have experienced or if they were able to overcome the stressors with specific coping strategies.

I hold a social constructivist perspective, believing that there is a close link between parent well-being and child well-being and that specifically, my own son's lack of well-being affected not only my well-being, but that of my other children as well. As a Christian mother, my children have always been a top priority for me. Keeping my son alive and healthy over 18 years was the most difficult life experience I have had to this point. The stress I experienced led to detrimental emotional and psychological effects and negatively affected the rest of our family. I discovered that other parents have had some similar experiences and emotional effects, but others have had very different outcomes. I am an old acquaintance of one of the participants (Elizabeth) and knew the son of two other participants from my son's school. I had met another participant through a friend at the YMCA. Another participant and I had a common acquaintance through my son's school, another was an acquaintance of my husband's, and the last two were acquaintances of two of the first six participants.

Data Collection

Data was collected in three ways. A pilot study was conducted to test the validity and relevance of the interview questions. After the pilot study, the interview questions, focus groups and method of cognitive representation were reviewed (Creswell & Poth, 2018). Once the interview questions were formalized and the review conducted and approved, semi-structured interviews began. Cognitive representations and their interpretation by the participant were

conducted at the end of the semi-structured interviews. Thirdly, a focus group was conducted using GroupMe to add depth to the understanding of the participants' experiences.

Interviews

Phenomenological interviews are informal and interactive, much like a social conversation, and produced a thorough understanding regarding the phenomenon studied (Moustakas, 1994). Gall et al. (2007) suggested that at least one long semi-structured interview be conducted to ensure that all aspects of the participants' experiences are included. The interviews were semi-structured and included open-ended questions leading to rich descriptions of the participants' experiences. Before the interviews, the purpose of the study was explained, the procedures of the study were explained, and the confidentiality of the interviews and the importance of participant's being candid and focused were shared with the participants. I said, "Some of these questions could be a bit difficult for you. If at any time this is too much for you, please just let me know, and we will take a break or get a drink of water."

Interview Questions

The following questions were asked of the participants:

Self-Identification and Family Description:

- (1) Please introduce yourself to me, as if we are meeting for the first time.
- (2) Please describe your experience as the mom or dad of children with PIMD.
- (3) What is the first thing that pops into your mind when someone asks you about your child?

Highs and Lows:

- (4) Which aspects of caring for your son or daughter with PIMD are the most rewarding?
- (5) Please describe some of the joyful or happy memories that come to mind.

(6) Please describe some of the important milestones in your child's life.

(7) Which aspects of caring for your son or daughter with PIMD are the most challenging?

(8) Think back to when you discovered that your child had special needs. What was it like to learn that your child had special needs?

(9) What *events* or experiences have been the most difficult for you as the mom or dad of children with special needs?

(10) Why do you think that was and is the most challenging for you? (This question may or may not be asked depending on the respondent's answer to the previous two questions.)

Emotional and Psychological Outcomes:

(11) What do you feel are some of the emotional or psychological effects or results of having to face challenges like these?

(12) Describe how you have thought about and felt about your child's overall condition, including his/her health.

(13) Please tell me about any symptoms of depression you may have, (as needed, I described some such symptoms) such as sleeplessness or sleeping too much, sadness, being negative, having low levels of energy, being easily irritated, feeling hopeless, experiencing less pleasure in life than usual, finding it hard to focus, eating more than usual or less than usual, feeling restless, drinking more alcohol or caffeine than usual, feeling anxious, or feeling worried or nervous.

Coping:

(14) Sometimes depression or anxiety can be decreased or avoided when a person uses coping skills such as having a positive attitude, getting regular exercise, having the support of a

spouse, having social support and doing something enjoyable like a hobby. Do you find any of these things helpful in relieving stress? How about something else?

Support:

(15) What do you do to get a break from the responsibilities of caring for your child?

(16) Can you please tell me about the people and organizations who make up your personal support system, such as respite workers, family members, spiritual resources, friends or teachers?

Adjustment:

(17) How would you change the way you have learned to cope with having a child with PIMD?

(18) What recommendations or advice would you give to the parent of a newborn that has just been diagnosed with an ID?

Marriage and Family Relationships:

(19) Please describe your relationship with your spouse (if married).

(20) How about your relationships with your other, non-disabled children?

(21) How do your other children get along with your child with special needs?

(22) Please describe how your child's disability has affected your family?

(23) How do you imagine your life would be different if your child were typically developing?

Conclusion:

(24) Thank you so much for being willing to participate in this interview and in this study. You have given me a lot of information, and I appreciate it. I have one more question

before we finish today: Do you have anything that you want to add so that I have a pretty complete picture of your experience as a parent of children with PIMD?

Question one was intended to introduce myself to the participant while enabling the participant to understand the intentions of the interview and to make her comfortable. It also provided me with a sense of the informant's context while establishing a sense of comfort in the interviewer-interviewee relationship while maintaining professionalism. Question two gave the participant the opportunity to cover a broad range of experiences. Based on her response to the question, whether succinct or more extensive, the interviewer decided whether to proceed with the next question or possibly to skip to other questions.

Parents of children with PIMD often experience various types of feelings regarding their child and his disabilities (O'Connell, O'Halloran & Doody, 2013). Questions two and three give the participant the opportunity to share the most prevalent feelings and cognitions about their child and his condition. I was able to observe prominent themes (emotions described, thoughts about the child) that seemed to be most important to the participants based on this question.

Questions three through fourteen helped me to establish some neutrality for the participant, to avoid focusing on either just the negative or just the positive aspects of being the parent of children with PIMD (Gallagher, et al., 2008). The same authors also asserted that caregiving burden is related to symptoms of depression and anxiety for parents of children with ID (Gallagher et al., 2008). These questions gave the participant the opportunity to bring up her own struggles or challenges related to caregiving burden without putting words or ideas in her mouth. In addition, Slattery, et al. (2017) found that an optimistic perspective predicted a higher level of positive reappraisal and social support, which led to the parents' finding greater benefits from their circumstances.

Questions five, six, seven and ten elicited descriptions of any difficulties or challenges experienced by the participants regarding their child with PIMD. Ndengeyingoma and Ruel (2016) asserted that nurses find it challenging to identify and meet the complex needs of patients with ID. In addition, medical clinicians are often inexperienced when it comes to children with ID (Eddy, 2013) and may be untrained in the understanding, assessing and treating the multiple comorbidities of children with PIMD. Additionally, primary care providers (PCPs) may not have the time, resources or training to practically meet the complex healthcare needs of children with PIMD with multiple comorbidities (Foster, et al., 2017). These same questions provided a stimulus for participants to describe other challenges such as finding support, having to intervene as an advocate in both medical and educational settings, as well as experiences of anxiety, depression, grieving, isolation and loneliness. These same questions also prompted responses regarding the participants' experiences with having to invest a lot of time and energy into learning about their child's condition as well as discovering any supports and services available to help them care for their child with PIMD.

Hedov, Wikblad and Anneren (2002) report that those parents who have a strong sense of their own strength and ability (self-assessed empowerment) to handle their child's disability were less stressed and more able to self-regulate emotions and able to solicit social support (Pisula & Kossakowska, 2010). Hastings, Allen, McDermott and Still (2002) also found that there was a significant relationship between parents' positive perceptions and coping. Questions eight and 12 set a stage for the participants to describe their overall perspective on their experiences of parenting children with PIMD and how they have responded to or coped with the challenges they have had to face.

In addition, questions four five and six contributed to the neutrality of both me as the interviewer and the study itself, taking the focus off of the negative aspects of having children with PIMD (which as a parent of a child with PIMD I tend to focus on) and allowing the participant to share the positive experiences associated with having children with PIMD (Blacher & Baker, 2007; Grant & Ramcharan, 2001; Little & Clark, 2006). Additionally, these questions, guided by research by Slattery, et al. (2017), allowed the participants to reveal their primary perspective, as Slattery, et al. (2017) asserted that parents' perspectives on their child's disability can be a moderator of parental stress and that optimistic perspectives predict higher levels of positive reappraisal and social supports.

Question six is intended to explore the possibility that the absence of accomplished milestones throughout the child's life may be part of the never-ending cycle of grieving and the ensuing depression that parents of children with PIMD often experience (O'Connell, O'Halloran & Doody, 2013; Patrick-Ott & Ladd, 2010). There was a gap in the research in this specific area regarding missed milestones and associated cognitions and emotions, which the participants' answers helped to fill.

Barnett, et al. (2003) discovered the diagnosis of children with PIMD or ID can be extremely difficult for the parents to accept. Heiman (2002) describes the parental experience of children's diagnosis with a DD as a crisis. Question eight, in some cases, revealed the interviewee's initial mental and emotional response to their child's diagnosis, which may have more to do with the parents' personality and support system than other considerations. Barnett et al. (2003) a parent's initial response to her child's diagnosis can set the stage for either positive or negative outlooks on having children with ID, which can then in turn affect the parent's ability to cope with the challenges associated with having children with ID (Barnett, et al. (2003).

Nelson Goff et al. (2013) stated that initially, upon diagnosis of children with DS, parents experienced intense grief and loss and adjusted at varying lengths of time and degrees and that the parents' experiences was somewhat related to the amount of information regarding the disability that was presented, the way in which it was presented by medical practitioners and the parents' spiritual beliefs.

Questions seven, nine and ten allowed the participants to describe the most challenging events that they have experienced as the parent of children with PIMD. Children with PIMD often have multiple comorbidities. Some parents may experience the initial diagnosis as the most challenging of their experiences while others may feel that the hospitalizations of their child have been the most difficult (Seliner et al., 2016). Still other participants may experience chronic sorrow, missed milestones (Patrick-Ott, & Ladd, 2010), social stigma (Park & Seo, 2016), or social isolation (O'Byrne & Muldoon, 2019) as their most challenging experiences.

The answers to questions 13, 14, 17 and 18 were intended to reveal the state of the participant's self-awareness as to her perspectives (positive or negative or ambiguous) regarding having children with PIMD, without leading the participant to specifically mention depression, anxiety (O'Connell, O'Halloran & Doody, 2013), or other potentially negative emotional and psychological responses. Caicedo (2014) stated that parents of special needs children were often frustrated, angry and anxious and often felt hopeless and helpless. Masulani-Mwale, Kauye, Gladstone and Mathanga (2018) stated that psychological distress is strong and common among parents of children with ID in Malawi. Additionally, Tsai and Wang's (2009) research concluded that the stress of their responsibilities as parents diminishes their ability to adequately care for their children and negatively affects the whole family.

Questions 14, 15 and 16 are intended to reveal what coping skills the participants find helpful and not helpful in dealing with the stress of parenting a child with PIMD. Dos Santos and Pereira-Maria (2016) suggest that the parental stress associated with caring for children with PIMD is high and can produce changes in family dynamics and coping approaches. They also asserted that social support strengthens the family unit (Dos Santos & Pereira-Maria, 2016).

It has been confirmed through multiple studies that social support, especially from spouses, grandparents and other family members helps parents of children with disabilities to adjust and cope (Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2015; Todd, Blomley, & Loannon, 2010; Wallender et al., 1989; Wang et al., 2013). Additionally, Jackson, et al. (2018) and Young et al. (2019) found that parent support groups can help parents of children with ID to cope with the stressors of their parenting roles. White and Hastings (2004) asserted that social support is inversely related to anxiety and depression in parents of children with ID's. Question 16 elicited responses from the participants regarding their social support systems to help me understand the roles and influences of various types of social supports. Questions 14, 15, 16 and 17 confirmed previous studies' findings regarding parents' perceived helpful coping strategies

Question 18 allowed the participant the opportunity to voice his or her lessons learned and gave the opportunity to be introspective and express existential considerations regarding his or her experiences as the parent of a child with PIMD. When their child is newly diagnosed with PIMD, parents are often not familiar with, trained or prepared to face the challenges that having a severely disabled child can present. This can give parents a sense of helplessness (Caicedo, 2014). However, along the way, parents of children with PIMD learn the educational, social, medical and other systems, i.e. what resources are available, what they need to do to cope, etc.

Question 18 provided the opportunity for parents to share the experiences, knowledge and wisdom they have gained with their experiences.

Question 19 assisted the researcher in understanding the effects of parenting children with PIMD on her marriage relationship (if any). Gertstein, et al. (2009) asserted that marital satisfaction is linked to emotional well-being in parents. Norton, et al. (2016) further asserted that marital satisfaction among parents of children with developmental disabilities is much lower than marital satisfaction among TD children and even children with DS.

Questions 20, 21 and 22 gave the participant the opportunity to describe the perceived effects of having a child with PIMD on other family relationships. Luijkx et al. (2017) posit that siblings of children with PIMD had some positive and some negative experiences with and perceptions of their sibling with PIMD and that the interactions between the TD sibling and the sibling with PIMD could be difficult and awkward socially.

Question 23 gave participants (especially if they are the biological parents of the child) the opportunity to think and express any “what if” thoughts or any dreams that may have been grieved over. Grief experiences were termed common among parents whose children were newly diagnosed with ASD; additionally, grief-related emotions such as shock, negation, fear, sadness, guilt and anger were expressed by parents of children with ASD (Fernandez-Alcantara et al., 2016). Interestingly, some parents are able to resolve their grief while others encounter more difficulties and obstacles to overcoming the grief associated with being the parent of children with ASD (Fernandez-Alcantara et al., 2016).

Question 24 assisted me to begin winding up the interview while gaining insight into any life lessons the participant may have learned through her experiences as the parent of children with PIMD that they may at some point in the future want to share with the new parent of

children with PIMD. This question also set the stage for the focus group prompts. Young et al. (2019) asserted that when parents of children with disabilities assist other parents in a peer group, both parties are better able to move forward in their journey as a parent from feeling emotionally lost to flourishing. Question 24 opened the door to the participant to disclose any such opportunities or experiences and to express her overall lessons learned as a parent of children with PIMD.

After receiving approval from the IRB to collect the data for this study, I asked the assistance of my Chair and Reader as well as my pilot interview participant to be sure that the questions were well-written for clarity, understanding and appropriateness, also ensuring that none of the questions were likely to cause intense negative emotions from the participants, causing harm and violating ethical standards of research.

Cognitive Representation

At the end of the interview, participants were asked to create a cognitive representation of their thoughts and feelings about being the parent of children with PIMD. Participants were provided a piece of white copy paper and some colored pencils and were asked to create an image or images, with or without words, to capture their emotions and thoughts about being the parent of children with PIMD, to present their concepts and perceptions of experiences as parents of children with PIMD (Frederiksen, 2001). This was done at the end of the interview to offer a way to express anything that they may have not been able to express verbally during the interviews. After about ten minutes, or when the participant told me she was finished, she was asked to describe and explain her creations. Their comments were also recorded.

Focus Groups

A focus group of three to eight participants (the number of participants increased as the interviews were conducted) was conducted after the individual interviews take place. The group was used to expound on thoughts, feelings or themes that emerged from the interviews. Participants were asked to comment, clarify or further explain or describe things that they said in the interviews. The focus group was conducted via GroupMe, a link to which participants were given after the interviews and cognitive representations. The focus group prompts, responses and comments were posted on the app, and all participants were able to see each other's responses. The prompts evolved from the themes that were developing throughout the interview, transcription and analysis process. The prompts were as follows:

1. How did the interview affect you personally?
2. Some of you mentioned the grief cycle. Please comment on what that means to you as a parent of a child with PIMD.
3. What do you think would be important for others to know about your experiences as the parent of a child with PIMD?

The GroupMe app allowed the participants to participate at their convenience, which was intended to increase the amount and quantity of input from the participants. However, the focus group participation was sparse and did not provide as much data as I had hoped. The focus group responses were transcribed and coded (using Nvivo).

Data Analysis

The goals of data analysis are to make sense out of each data collection, find patterns, themes and relationships within each collection as well as repeated patterns and relationships across collections and to uncover new understanding about the lived experiences of parents of

children with PIMD (Data Analysis: Analyzing Data in Qualitative Research, n.d.). The same author contends that sorting and coding data can result in distortions or misunderstandings:

A serious problem is sometimes created by the very fact of organizing the material through coding or breaking it up into segments in that this destroys the totality of philosophy as expressed by the interviewee-which is closely related to the major goal of the study that informs the data analysis (Data Analysis: Analyzing Data in Qualitative Research, n.d., p.1).

After personally transcribing the interviews, I used the complete transcripts from the interviews and relevant expressions of each participant. Any statements related to being the parent of children with PIMD were considered significant. According to Yin (2011), qualitative data analysis involves five phases: compiling data into a database, which in this case involved recording and transcribing the interviews, cognitive representations and focus groups, disassembling or coding the data, or finding themes, (using Nvivo) and reassembling the data as patterns were discovered (using myself and Excel as tools). Curry (2018) writes that data analysis is an iterative process of both individual and multidisciplinary group review and interpretation of the researcher's collected narrative data. I reduced the data to meanings that are arrived at with an open mind to the experience of the phenomenon (DeFelice & Janesick, 2015). I used content analysis to categorize the collected data to "classify, summarize and tabulate the data" (Qualitative Data Analysis, n.d.).

The steps outlined by Qualitative Data Analysis (n.d.) are as follows: first, identify word and phrase repetitions, observing those most used and those used with intensity of emotion; second, compare the findings of the current data with the findings of previous literature and discuss any differences; third, search for any information that may be missing (either from

specific individuals or based on what I may have expected based on previous literature); fourth, compare any metaphors with phenomena from a different area.

To follow the above steps, I transcribed and re-read the transcripts from the interviews and cognitive representations, then used Nvivo to identify repetitions of words and phrases, coded the words and phrases and counted the number of times the words and phrases (or meanings of words or phrases that were the same) and were used both by an individual and across the group. An integrated approach to coding was used: first, each line of the transcript was coded while I was constantly looking for new (de novo) themes that may have emerged as the code structure evolved (Curry, 2018). The codes used were both one-word codes or short phrases that represent the essence or key characteristics of the gathered transcribed verbal information, used to categorize the data into similar categories (Curry, 2018). The codes were then put into a code structure, which is a compilation of the codes that were emerging, developing and evolving and which included brief definitions or properties for each code (Curry, 2018). There were instructions for guidance regarding the use of the codes and possibly illustrative quotations to explain the codes (Curry, 2018).

There were multiple versions of the codes as they evolved; I started with as many as 36 codes across the eight groups of data from the eight participants. Additionally, a somewhat deductive (intuitive) approach based on my expertise was to the line-by-line approach, but I attempted to be self-aware and document my own responses, reactions and relevant biases. The initial codes were developed from the deductive approach while the secondary (sub) codes were developed from the emerging data (Curry, 2018). The code structure was adjusted as the recorded and transcribed interview data was analyzed and re-analyzed. Then I compared the data with previous literature, discussed any differences and any information that seemed to be missing

with my Chair. The themes observed are unifying concepts that helped me to identify the patterns of thoughts, feelings and behaviors of the participants in their specific situation as they experience(d) the phenomenon of being a parent of children with PMID, which is the heart of this study.

Epoche

By conducting the process of epoche, I attempted to set aside my preconceived ideas and biases to see the phenomena of the lived experiences of parents of children with PIMD with a fresh perspective (Moustakas, 1994). In phenomenology, epoche brackets or sets aside one's own experience and thoughts in attempt to see the phenomena under study in a fresh way (Moustakas, 1994). As I conducted the interviews and provided the opportunities for the cognitive representations and the prompts for the focus group, I kept an ongoing journal of my own thoughts, feelings and reactions to the interviews, participants' narratives and responses to questions, prompts and drawings. I took time before each interview to relax my mind, focus on my thoughts and feelings, pray and mediated and prepare for the interview, especially reminding myself to attempt to be a reporter and not a counselor. I believe this enabled me to be an observer in the process of data collection (Moustakas, 1994).

Phenomenological Reduction

The next phase in developing understanding of the meanings of the phenomenon being studied was the reduction, the phase in which the researcher's seeing things as they seem to be were described (Moustakas, 1994). The interview, cognitive representation and focus group experiences were reduced to language that describes both actions and inward consciousness (Moustakas, 1994). This reduction required "graded prereflection, reflection, and reduction" (Moustakas, 1994, p. 91) with the goal of getting to the essential essence of the experience

(MacKenzie, 2018). To accomplish reduction, I journaled as a way to record and reflect on my own reactions, responses to, thoughts and feelings regarding the process of, experience within and reflections after the interviews, cognitive representation process and focus group.

Variation and Synthesis of Meanings

The last steps were to use “imaginative variation and synthesis of meanings” (MacKenzie, 2018) to consider the various possible meanings of the experiences and to synthesize the data to produce a cohesive statement that captures the essence of the phenomenon (Moustakas, 1994). In this stage, I considered the possible meanings of the statements, common phrases and consistent themes within the transcripts that expressed universal concepts experienced by the participants. The final step was to synthesize the meanings and essences of the participants’ experiences, with the realization that these meanings and essences are only part of the full picture. The analysis was finalized using re-reflection of the data, including my journal and transcriptions from the interviews, cognitive representations and focus groups, and NVivo.

Trustworthiness

Trustworthiness deals with the credibility, dependability, transferability, and confirmability of the research; each of these topics is addressed individually in the following sections. Nutt, Williams and Morrow (2008) suggest three categories of trustworthiness to be pursued in qualitative analysis: integrity of data, balance between subjectivity and reflexivity and clear communication of results. Thomas and Magilvy (2008) describe four traits of trustworthiness for qualitative research: truth or value, also known as credibility, applicability or transferability, consistency or dependability and neutrality or confirmability. The current study achieved credibility through the use of a pilot study, methodically recorded interviews following

a specific protocol, cognitive representations and focus groups. Multiple sources of data have enabled triangulation of the data for confirmability and dependability (Creswell, 2013).

Interviews took place in a consistent setting with the same interviewer, in most cases in the participants' homes. I took a consistent approach to the interviews with all the participants. Additionally, the data gathered is confirmable by any person in the public who may choose to investigate the accuracy of the data gathered. In order to accomplish trustworthiness, I employed the use of (1) triangulation to collect converging data from various sources, (2) the search for discrepant data to test conflicting explanations, and (3) comparison of results to compare the results between participants' responses (Yin, 2011). Additionally, I submitted the transcripts to the participants after each individual interview to confirm its accuracy and to allow the participants to suggest any edits to the transcripts and to clarify any meanings being derived from the data.

Credibility

Thomas and Magilvy (2011) stated that credibility is ascertaining the degree to which the data is representative of the larger population of similar participants as a whole. Furthermore, credibility depends on the depth of the data collected and the researcher's analytical abilities. Credibility was achieved by reviewing individual recordings and transcripts to be sure they were accurate, by finding similarities both within each individual participant and across all the participants of the sample, by ensuring proficient interviewer techniques, by checking the accuracy of the transcripts and by using actual quotations from participants (Thomas & Magilvy, 2011). Having multiple means of collecting data assisted me to add credibility to this study (Creswell, 2013). Additionally, peer review and participant checking were used to ensure

accurate interpretation of the data and NVivo software was used to analyze the data and correlate the findings.

Validity

Quantitative research seeks to achieve project credibility by ensuring the validity and reliability of a study; credibility in qualitative research really depends on the effort and ability of the researcher(s) (Golafshani, 2003). There are inherent limitations of the qualitative method of research (Curry, 2018). I have made an attempt to ensure that saturation of data was accomplished regarding the phenomena of experienced challenges, joys, perspectives, emotions and coping skills of parents of children with PIMD. I kept a journal of my thoughts and feelings regarding my interviews and interviewees as well as my responses and reactions to the cognitive representations and the focus groups. Additionally, along the research journey I attempted to phrase the interview questions, cognitive representation prompt and guide questions for the focus groups in a way that was non-leading and neutral. Additionally, an interview guide is included in the final document as an appendix, and the conduction of data analysis (coding and coding structure) was done with great care and attention to my own bias. In addition, I used qualitative software (NVivo) to assist in the coding and analysis of the data.

Another potential assault on a qualitative study's validity is disconfirming data. I did not discover any disconfirming data in the analysis (Yin, 2011), so I did not need to review the interviews again or conduct a follow-up interview.

Golafshani (2003) stated that "Reliability and validity are conceptualized as trustworthiness, rigor and quality in qualitative paradigm" (p. 604). I believe that I exercised due diligence to ensure the trustworthiness, rigor and quality in this study through the use of well-developed interview questions and repeated research analysis. Additionally, documentation of

each step taken during the course of the study is available to the board and to the public so that there is transparency in the research (Yin, 2011). After the reduction and analyses of the interviews, I described in writing (Chapters Four and Five), from a deep understanding of the participants' lived experiences, my new understanding of the phenomena and have shared this with my Chair. In Chapters Four and Five, I have offered my insights, intuitions and understanding as well as evaluated and determined themes and conclusions. Yin (2011) cautions me to ensure rigor through double checking or triple checking the data's accuracy, ensuring that the analysis is both complete and thorough. Yin (2011) adds that I should continually self-evaluate my own bias as analysis is being conducted. I must be slow-paced and humble enough to be open to changing any initial research conclusions in order to accomplish the highest level of validity possible during all phases of analysis, including data checking, theme development and conclusion drawing.

Dependability and Confirmability

Dependability and confirmability reflect the consistency of the study and are based on the depth of the details regarding the participants' context and the setting of the study. To be dependable, I have provided an audit trail that describes the purpose of the study, discusses the selection of the participants of the study, describes the process of data collection, explains the reduction of the data for analysis and discusses the techniques used to establish the credibility of the data (Thomas & Magilvy, 2011). To establish dependability, peers were invited to participate (Thomas & Magilvy, 2011) in the analysis stage of the study, and a detailed description of the methods used was provided (Thomas & Magilvy, 2011).

A confirmable study is reflective and flexible in the sense of my maintaining self-awareness of potential preconceptions and biases and her willingness to adapt the findings as

they evolve throughout the research process (Thomas & Magilvy, 2011). To ensure confirmability, I recorded my observations in my research journal regarding each interview within 24 hours after the interview and cognitive representation. The notes and journal entries (observations) included the observed emotional responses, biases and insights regarding the interviews (Thomas & Magilvy, 2011) as well as my own responses and insights. Additionally, I attempted to allow the participant to lead the direction in which the interview flowed and encouraged responses to interview questions and asked for clarification as appropriate (Thomas & Magilvy, 2011). All interview transcripts, cognitive representation transcripts and focus group transcripts have been reviewed multiple times to discern the common themes in the participants' perceptions and lived experiences (Moustakas, 1994). Finally, I tried to encourage the participants use their own words as much as possible, rather than the words used in the questions, to capture the depth of the descriptions of their lived experiences (Thomas & Magilvy, 2011).

Transferability

Thomas and Magilvy (2011) define transferability as “how one determines the extent to which the findings of a particular inquiry have applicability in other contexts or with other subjects/participants” (p. 154). Thomas and Magilvy (2011) further state that by providing a dense description of the demographic information and geographic boundaries of the research as well as the use of the same data collection procedures and methods and the same inclusion criteria, one is able to achieve a high degree of transferability. I complied with these suggestions and believe, therefore that this study is transferable.

Ethical Considerations

I used due diligence to fully abide by the ethical codes set forth by the American Counseling Association (ACA). Specifically, the guidelines for ensuring confidentiality, privacy,

beneficence, justice, fidelity, professionalism, nonmaleficence, justice, fidelity, and autonomy were honored in every way feasible (ACA, 2014). To accomplish these ethical goals, the researcher obtained permission from the Institutional Review Board (IRB) prior to initiating contact with the participants; the participants were advised regarding the potential emotionality of the topics to be explored and were made aware that they had the right to leave or discontinue their participation at any time. In addition, the participants read, signed and reviewed with me a confidentiality agreement and discussed the limits of confidentiality. The participants' privacy was protected by using pseudonyms for their names, and by using “_” in place of the names of the towns in which they live, the names of any local organizations, hospitals, persons or entities mentioned in the interviews and by guarding the recorded data on a protected thumb drive in a locked drawer in my locked office, keeping transcriptions, journal, coding and demographical information on a password-protected file on my laptop. The name of the locations of the interviews were not disclosed, as all of the interviews took place in the participants' homes, in the local university library or over the phone.

Summary

This study was a transcendental phenomenological study regarding the lived experiences of parents of children with PIMD. Multiple means of data collection were used including semi-structured interviews, cognitive representations and focus groups. My role as a researcher participant was recorded via a research journal. The data was reviewed in an effort to find common themes and experiences of parents of children with PIMD. The data was analyzed in several ways, including the researcher's personally doing the transcription, re-reading the transcriptions, and using NVivo software. The transcriptions were reviewed with participants to ensure their accuracy. This chapter provided details regarding the design and rationale,

participant selection process, research questions, site description and rationale, procedures for the study, the role of the researcher as a tool in the study, as well as the data collection and analysis techniques for the study.

All the specific portions of the study mentioned above were selected specifically to achieve the goal of acquiring a fuller understanding of the lived experiences of parents of children with PIMD. The above-described transcendental phenomenological approach provided participants with opportunities to describe their experiences with depth and richness and also provided a fuller understanding for the readers of the lived experiences of parents with children with PIMD so that compassion, understanding and assistance can be offered to this special population.

CHAPTER FOUR: FINDINGS

Overview

This chapter contains the details of the findings resulting from the study regarding the lived experiences of parents of children with PIMD. As previously stated, research questions include: How do parents of children with PIMD describe their experiences as parents of children with PIMD? How do the parents of children with PIMD describe the impact of their experiences on their well-being? How do the parents of children with PIMD describe their understanding of and perspectives regarding their children's disabilities? How do parents of children with PIMD describe the impact of having children with PIMD on their families and outside of family social and other interactions? Additionally, the theories that have guided this study are Bronfenbrenner's bioecological theory of human development (expanded by Vélez-Agosto, Soto-Crespo, Vizcarrondo-Oppenheimer, Vega-Molina, and García, 2017) and White and Bregman's (2011) family systems theory, as together they explain the inter-relational aspects of micro, meso and macro systems, resilience, and coping within specific contexts.

The impact of personal resilience was not included in this study. However, the existential perspective of the parents interviewed was described as the participants revealed their individual mental and emotional processes and experiences (intrapersonal processes) along with the effects of their external environments. Environment in this study refers to both the family of which the participant is a part as well as the society in which they live.

In this chapter, results are presented that incorporate the narrative (from the interviews and focus group) as well as the drawn descriptions (cognitive representations) of the participants in both group descriptions and individual portraits. From the data gathered, themes were developed by coding and clustering meanings that resulted from the interviews, focus group and

cognitive representation drawings and their corresponding verbal then transcribed descriptions. This chapter concludes with discussions on how the research questions were addressed, how the themes were developed and finally a chapter summary.

Participants

This section presents the eight individuals, Andy, Becky, Callie, Debbie, Elizabeth, Francine, Georgia and Isabelle (all pseudonyms) whose narratives and cognitive representations provide the stories from which the data for this study are drawn. First, a group description is provided to identify the participants' similarities. Second, individual descriptions or portraits are provided, based on my interactions with the participants. It must be stated, however, that while an attempt has been made by me to suspend my own judgment or subjectivity regarding the study, it is impossible to either interact with or observe the participants objectively. Therefore, a copy of the research journal (Appendix D) is provided so that the reader may have insight into the potential effects of my subjective perspectives and experiences on the research process and themes developed.

The participants for the study were found through contacting the local school for children with severe and profound disabilities (Debbie), through acquaintances from the local Young Men's Christian Association (Callie), and through acquaintances of people I know personally (Andy, Elizabeth, Francine and Georgia). In addition, two participants were contacted by initial potential participants: Andy recruited Becky, and a potential participant (excluded from the study because she did not meet the screening criteria) recruited Isabelle (who did meet the criteria).

The following table outlines some of the participants' commonalities and individualities.

Table 3

Characteristics of Participants

Pseudonym	Gender	Married/Remarried	Separated/Divorced	Biological or Adopted	Gender (Child)	Age (Child)	Number of Siblings/Stepsiblings
Andy	Male	Remarried		Biological	Male	21	3
Becky	Female	Remarried		Biological	Male	21	3
Callie	Female	Married		Biological	Female	6	3
Debbie	Female		Divorced	Biological	Male	15	1
Elizabeth	Female	Married		Biological	Female	21	3
Francine	Female		Separated	Adopted	Female	21	2
Georgia	Female	Married		Biological	Female	18	0
Isabelle	Female	Remarried		Biological	Male	21	3

The participants were one man and seven women from Central Virginia who met the screening requirements of the study as being the parent of a child with PIMD in Central Virginia. Each participant completed the screening questionnaire (Appendix C), and although nine potential participants were interviewed, one of the participants later disclosed to me that her child did not completely meet the criteria for profound intellectual disabilities because her level of communication and apparent intellectual capacity met criteria for severe ID, so she was excluded from the findings. The interviews, cognitive representations and focus groups by which the data were collected were conducted in February and March of 2020 in Central Virginia.

Before each interview, it was explained to each participant that during the interview, the researcher would have the role of an information-gatherer and not a counselor, friend or fellow-parent of a child with PIMD. Then a test of the recording device was made, and the interview was begun. After the interview, the participant was instructed regarding the cognitive representation activity (Appendix F), then the researcher recorded the participant's verbal description of the drawing he or she had made. After the interview, participants were given instructions on how to access the GroupMe app and join the focus group. Guide questions for the focus group were posted every few days, the next guide question being posted after at least one

or two participants had responded to the previous guide question. Actual guide questions for the focus group are in Appendix F. The participation in the focus group was not heavy; only five of the eight participants (Andy, Becky, Callie, Elizabeth and Georgia) contributed to the focus group.

Once the transcriptions of the interviews and cognitive representation descriptions were completed, participants were emailed a copy of the transcription to verify their accuracy. The participants did not note any errors in content in the transcriptions. As themes were discovered, these themes were shared with the focus group to verify accuracy and to gain additional descriptions of the participants' experiences. The following are group and individual descriptions of the participants.

The Group

These eight individuals share some features not included in the screening criteria. They are all Caucasians; all eight participants have all had multiple encounters with more than one hospital and have multiple specialty physicians employed in the care of their son or daughter with PIMD. In addition, all have had multiple visits to emergency rooms or urgent care clinics for their child with PIMD. Six of the eight participants' children have seizure disorders as part of their PIMD. Some of the participants have had difficulties with their experiences with medical personnel, but most related that they are appreciative of their doctors' willingness to learn from them as the experts on their child.

Based on the data gathered, all the group members seemed very involved with their children's lives. Four of the eight participants stay at home with their child with PIMD and do not work outside the home (Andy, Callie, Debbie and Elizabeth); two of the participants' husbands stay at home to care for their child with PIMD (Becky and Georgia). Three participants

worked full-time outside the home (Becky, Georgia and Isabelle), and one participant worked part-time outside the home (Francine).

All the parents seemed extremely devoted to their son or daughter with PIMD, to the extent that one of them (Becky) commented that her son is, “the love of my life... what I look forward to at the end of the day.” In addition, all the eight participants are their child’s strongest and most informed advocate. Francine shared, “I go head- to- head with doctors because at times, I have to be her voice. She doesn’t have one.”

It was also observed that each participant mentioned that participation in church had had some role in his or her life. For example, Georgia said, “our church has been wonderful. Ever since she’s been born, ___ has been a part of our choir.” Becky shared Georgia’s positive church experiences, but Elizabeth described her experience with church a bit differently:

Church has been very, very difficult too. I used to be able to take her when she was younger and there would be people to volunteer to stay with her and so forth. But I found out that they weren’t necessarily watching her the way they were supposed to be and she... ended up at the back of the church and these kids were trying to give her hard candy and that’s a choking hazard for her. So, after she had pneumonia in 2015, I just stopped going... it was more anxious for me to even take her ...

Each participant also seemed forthright and eager to share his or her experiences so that others would know or understand not only their challenges, but also their joys, their love, and their dedication to their children as well as understand the nature of their child’s disability. Other commonalities shared by all eight of the participants include that they were all born in the United States. Additionally, six of the participants were very open and willing to have the researcher in their homes for the interviews. The remaining two participants found it more convenient to

conduct the interview by phone. All of them expressed that they would like for the researcher to meet their son or daughter, and the researcher did meet six of the eight children with PIMD. It was apparent in all the interviews with the participants that their child with PIMD is their primary consideration and concern in everyday life and decision-making in the family.

Perhaps the most prominent commonality of the eight participants is that each of them, in some way or another, described their life as a roller coaster or having lots of highs and lows, or having good seasons and bad seasons (see Theme One below). It seemed like all had been able to survive the difficulties of their lives as parents of children with PIMD, but four of them (Andy, Becky, Callie and Georgia) seemed to be counter-balancing their challenges with healthy perspectives and effective coping strategies, enjoying their journey while the other half seemed to employ some coping strategies but be just surviving (Theme Two below). Andy shared:

I can tell you I enjoy every moment of the day with him. I mean there's days when he's done ticked you off, but you get over them real quick when he lights up that smile... But I enjoy it. I actually look forward to it. I'm with him basically seven days a week, sunup to sundown and then some.

Isabelle, however, stated:

___ (My son) wants, craves, vies for your undivided attention every, literally every waking moment ... when he is awake, he is pulling on you, he wants your attention, yet he doesn't really play, and that is difficult. That is difficult. Like if he would sit down and I could read him a book, or if he would sit down and I could roll the ball with him or roll trucks or put Legos together, anything, but he doesn't play, so you end up just being dragged in circles. He's non-verbal, so you don't understand him, so he gets frustrated

and then you get frustrated, so I think his constant need and just never being able to breathe... is difficult.

It is important to mention here that specific data regarding individual personal characteristics of the participants such as personality, socio-economic status, number of children in the family or individual resilience can have an effect on the individual's level of balancing their lives in order to thrive. However, the effects of those variables on the participants' experiences was not included in this investigation and appear in the section *Topics for Future Study* in Chapter Five. From the data that was gathered in this study regarding the lived experiences of parents of children with PIMD, the following themes and subthemes were derived.

Individual Portraits

The following portraits of the participants, listed alphabetically by their pseudonyms, describe each participant, based on information gathered during the interviews, cognitive representations and focus group.

Andy

Andy and his wife live with their son with PIMD in a middle- class home in a small, close-knit community in Central Virginia. Andy is the father of a 21-year-old son with PIMD. The couple cares for their son at home and has opted for him to not participate in any kind of adult day care since he graduated from a special school for severely and profoundly disabled students.

Andy is a heavy-set man, probably in his early sixties, who has a good sense of humor. During the interview, he told several funny stories about his child with PIMD. Andy's wife was present during the interview and took their son to the next room to watch television during the

interview, though both were listening, with his wife contributing a comment every now and then. They seemed like a caring family that got along well together.

Andy's son is able to walk and smile but cannot communicate or assist in any self-care activities, including toileting. In addition, Andy's son has a seizure disorder that can be life-threatening. Andy recently retired from his job and is now his son's stay-at-home parent. He loves his new job and spends most of his days with his son watching television, going out to Walmart "to watch the girls" or doing crafts at home. On occasion, friends of the family come to take their son on an outing or the whole family goes on outings with friends. The family attends church each week, though Andy says he must sit in the back where he will not get anyone in trouble with his clowning around.

Becky

Becky lives with her husband and 21-year-old son with PIMD. Becky seemed to be a rather quiet person; my interview with her was quite short as she was crying during many of her answers to the interview questions and did not go into detail in response to the questions she was asked because of her crying. However, the answers she gave were very descriptive. Becky's comment that seemed to have captured the emotional essence of the lived experiences of parents of children with PIMD was that it is like an "emotional rollercoaster; emotions all over the place." In describing her experience upon discovering that her child had an intellectual disability, she said that it was, "Tough. It felt like your heart was stolen. A roller coaster ride again. Alone. Scared. That's pretty much it."

Becky works full-time outside her home, about an hour away from home and attends a local church. She is very close to the people she works with and participates in some of the activities of the church, sometimes taking her son with her, "We have a women's group at

church. There's like five of us that are on the fellowship committee and we usually get together about once a month and do things at the church..."

Becky's son has a genetic syndrome that includes seizures and ID. She dislikes working so far from home, especially if her son is experiencing seizures. Becky loves being at home with her husband and son. She mentioned that being with her son "and husband and just having family time is de-stressing for me."

Callie

Callie is the mother of three daughters. Her daughter with PIMD is the oldest at six years old, and her younger two children were two years old and under one year old at the time of the interview. Her other two children are TD. Callie and her husband live on a farm in a rural area. Despite the challenges Callie and her husband face, she felt very blessed to be able to live the life she lives. Callie was quite eloquent in her answers to the interview questions, and very honest about her sometimes- distressing feelings.

Callie seemed very knowledgeable about the resources available to her to help her care for her child with PIMD. Callie has a degree in special education and worked in the mental health field before her daughter was born. However, soon after her daughter's birth, it became necessary for Callie to leave her career in education to care for her child. Callie takes her job of parenting her children seriously. She described when her daughter with PIMD was first born:

We weren't confident that her seizures were under control... we weren't exactly gonna hand her over to somebody and get a second-hand account of what her day looked like and what she may or may not have been acting like (referring to detecting seizures). I also never wanna have to sit in front of the doctor and say, I don't know, let me ask

whoever was taking care of her that day. I wanted to be the most knowledgeable about my daughter.

Callie is a very active and determined 30-year-old who is proud that despite the challenges of adjusting to having a child with PIMD, she has been able to continue living out her and her husband's dream on the farm with her husband and children, as her cognitive representation reveals.

Figure 1. *Callie's Cognitive Representation*



Debbie

Debbie is the single mother of two boys, the older boy with PIMD. She is in a doctoral educational program and has her parents close by to care for her son with PIMD when she cannot

be available. Debbie is a vivacious person and has been caring for her two sons mostly by herself since her husband left the family. Debbie's son with PIMD is 15 years old and in addition to the ID, has autism as one of his other diagnoses. He can speak some words, but Debbie says that he is very difficult to understand and many things he says make no sense at all in the moment.

Debbie states that her son is very funny and does a lot of things that make her laugh. She shared a few stories during the interview, one of which she told, laughing through the entirety, about her son defecating all over the floor in the middle of the night as he walked around the house talking to himself. It is evident that a sense of humor helps Debbie to get through some unpleasant situations and that as the single mother of a child with PIMD, she is very tired.

During the interview, the see-saw of emotions that Debbie experienced regarding her son and his condition was visible and audible. At times she laughed about her son's unpredictable, sometimes messy, sometimes loud behaviors, while at other times she cried, and at one time it was uncertain whether she was laughing or crying. She is, however, determined to finish her doctorate and be able to provide for her two sons.

Elizabeth

Elizabeth is a middle-aged woman who is married and had four children as well as several grandchildren. Her daughter with PIMD was her second child. She lived in a comfortable, middle-class home in a middle-class area of Central Virginia. Her husband changed jobs within the last few years and now works at home and is available to help his wife Elizabeth care for their daughter, who is 25 years old, and who is ambulatory but non-verbal and is chronically underweight.

Elizabeth's affect seemed a bit flat, as if she were very tired. Throughout most of the interview, she was feeding applesauce to her daughter with PIMD or helping her acquire a toy

she wanted. The daughter obviously wanted her mother's undivided attention, but the interview interfered with that attention. I asked if she wanted to take a break to attend to her daughter at two different times, but she simply paused, assisted her daughter and continued.

One of the memorable things about the interview with Elizabeth was her comment about her difficulty with the medical community, which had not been very helpful to her over the years. She recounted:

The medical, just the medical alone for our daughter is just overwhelming at times and the experiences that we have there (feeding her daughter applesauce), we have had some really, really good doctors for our daughter, but we've also had some really lousy doctors that have come right out and said, "I don't wanna bother."

Elizabeth also expressed disappointment with the church's lack of help or checking in on their family but very thankful for her husband's support and her other children's efforts to include her, albeit virtually, in family gatherings. Elizabeth shared her thoughts about her experience as the mother of a child with PIMD, "It's an experience that I don't wish on other people. Because it's hard. It changed our life dramatically..."

Francine

Francine is the adoptive mother of a daughter with PIMD. Francine is a nurse and explained:

We adopted her at eight months was, ... well it's very ... difficult ... I was in a case and because I am a nurse, they had called about this child, and I was already doing foster care, and they wanted to know, could we maybe come look at this child, at Charlottesville, Kluge, because they were getting ready to put her at King's Daughter down at Fishersville and she was getting ready to be institutionalized. They just wanted

to get her out of the hospital because her affect was so flat... I said I would come and just see how it was. See if this might be a possibility that we might be able to take her. I mean, she was 8 pounds, and she had an enormous amount of stuff, you know, a list of stuff... and I just, and when I saw her, I knew we just had to help save her.

Although her husband still lives with her, they are in the process of separating with the intent to divorce. She seemed very anxious and quite hypervigilant during our interview. She obviously cares deeply for her daughter with PIMD and explained that the noises her daughter was making were happy noises. Francine described her daughter as sweet and happy. Sometimes her daughter's noises were quite loud, but they did not interfere with our interview.

Francine was observed to be very anxious and emotional and said she was "exhausted." She related that she has just pushed on to do what needs to be done for her family regardless of the cost to herself. She explained, "I hardly sleep at all. Literally, having to make myself sleep because I still get up and check on her two or three times a night, I mean eyeballs on her, on the camera, on her, where we can see her..."

Francine was a professional nurse but states that she lost multiple jobs due to having to take time off for her "daughter's appointments; I kind of thought that she would grow out of that because I worked in the field, but for ___ (my daughter), she seems to be requiring more" so now Francine only works part-time in another business to help a friend. Otherwise, her full-time job is caring for her daughter with PIMD who has a seizure disorder and both a G-tube and a PICC line, and "She gets a cold, and she gets pneumonia and we're now in the hospital for seven days." Francine's daughter's medical fragility has caused multiple, near-death experiences resulting in both her anxiety and exhaustion. Her response to these situations is usually, "I don't

know, I usually have a good cry and then I break out in shingles. I've had shingles seven times. It's almost a joke now."

Georgia

Georgia is the friendly and cheerful mother of a daughter with PIMD who 18 years old. Georgia lives with her husband and their daughter who is the couple's only child. Georgia and her husband decided not to have more children after their daughter with PIMD was born, even though Georgia had dreamed, "I would have six children and they would all come home for Christmas, and they were all gonna sit around the table like a Norman Rockwell painting."

Georgia was excited about the opportunity to have the interview and loves her online support group for other parents with children with the same disorder as her daughter. She referred to the other children with the same disorder as her child, whose parents are in her support group as "our children." Georgia was very enthusiastic about her online support group.

Georgia's husband stayed in the room during the interview; their daughter was lying on the floor on cushions in front of us and did not make many sounds. Georgia described her daughter as happy, content, "non-verbal, non-ambulatory, can do nothing for herself, has skills scattered from about 3 months to 6 months on the fine motor skills." Georgia stated that she was very happy that her daughter has not had seizures, as the majority of those with her specific diagnosis have a comorbid seizure disorder.

Georgia stated that her husband and she struggle to lift and transfer her daughter to and from the floor, chairs, tub, shower, and car because she is getting heavier and stiffer as she gets older. Georgia and her husband live in a middle- class neighborhood in Central Virginia. Georgia is a music teacher at a local school, and her husband is recently retired so that he can care for their daughter full-time at home.

Isabelle

Isabelle's interview took place over the phone for convenience. Her schedule was too busy to accommodate an in-person interview. She had been a law enforcement officer and served in the military but is out of the law enforcement and military. Isabelle continues to teach autism and Crisis Intervention Training to first responders. Isabelle seemed like a cheerful mother of an almost 21-year-old son with PIMD. She had a lot of energy and a wealth of information to share about her situation as the mother of a child with PIMD.

Isabelle stated that she continues to work because her son is still able to attend school, a local school for children with autism, which is one of her son's diagnoses. Her son's disabilities include severe behavioral challenges that make him especially difficult to care for. She shared that she has had thoughts of suicide but would not act on them because there would be no one to care for her son:

I have cut his hair for years. I have gotten it down to a science. Because he doesn't sit still and so we go into the walk-in shower and ___ (my son) moves his head and he yells and he bites, but we, I manage to get it done, and patting myself on the back, I've learned to do a really good job. But I think, who's gonna do this? I clip his toenails, I clip his fingernails, I clean his ears. Who is going to be able to do this when I'm not here?

Isabelle was the only participant who gave details about the role of her faith, even before I asked the interview question about any spiritual resources. She explained that:

I think had it not been for God and for my faith, I probably would have gone ahead and checked out, but absolutely, my faith and not necessarily even the church. The church hasn't really rallied around. It's just been my relationship with God.

Isabelle has been married, divorced and remarried and, like Debbie, attributed her first marriage's failure to her son's condition. She has three other children, two biological and one stepdaughter who live with her and her second husband. Isabelle stated that she was especially concerned for the future as her son will age out of school at age 22, and there will be nowhere for him to go during the day for social interaction or to be cared for. She mentioned that she had had numerous negative experiences with schools, and agencies and school administrations:

There has been, yeah, has been fights and people will call it advocacy; I call it fights.

There's been the learning that no one really has your best interest of your child at their heart as you thought they did, especially in the public school system, not nearly the way that you do, so you have to fight for everything.

Results

The Central Research Question for this study was: How do parents of children with PIMD in Central Virginia describe their experiences as a parent of children with PIMD? The participants answered the interview questions, which were based on the research questions, and revealed two major themes: "My Life With My Child With PIMD Is Like a Roller Coaster Ride," which connected to research questions one and four. The second theme that emerged was "Balancing the Stressors: From Surviving to Thriving," which connected to research questions three, two and four. In addition, the challenges or burdens of parenting a child with PIMD appear in both themes, very specifically and with subthemes in Theme One as the "Uphill Climb," and in Theme Two more generally and as the left side of the scale as "The Weight of the Challenges."

Theme Development

As previously mentioned in chapters three and four, the participants were recruited through a local school for the severely and profoundly disabled, through the local YMCA, through the local adult day center for disabled adults and through personal contacts. Once potential participants were identified, I emailed them the invitation letter and screening questionnaire. The potential participants read the invitation letter which explained the purpose and process of the intended study and filled out and returned the screening questionnaire to me by email. Once I received the completed questionnaire from a participant, I reviewed it to ensure that the screening qualifications were met. Once I confirmed that the qualifications were met, I called the participant to schedule an interview.

The first participant was initially reluctant to participate but when I emailed him and explained the study further, he decided to participate after all. The first three interviews took place at the participants' homes; the fourth interview took place at the university's library in a public room, the fifth and sixth interviews took place at the participants' homes, the seventh interview took place at her home, the eighth interview took place over the phone, and the ninth interview took place over the phone. After the eighth interview, the participant emailed me a few days later and explained that her daughter was able to read and write, which disqualified her from the study. Therefore, the participant "Helen" has been removed from the study, and no data is included from that interview.

Before the first interview and after every interview (along with the cognitive representation description that took place at the same time as the interview), I wrote my thoughts and feelings in my research journal (Appendix D) to record my own responses to the interviews and cognitive representation descriptions. Also, within two days of the interviews and cognitive representation descriptions, I transcribed them. Thirdly, after the interviews and cognitive

representation descriptions were completed, I added the participant's phone number to the study's private group on the GroupMe app so that each participant, after having completed the interview and cognitive representation, could participate in the focus group by responding to the guide questions and the responses or replies of other participants. After each transcription was finished, I imported the transcribed data into Nvivo where I began to conduct the analysis. After three weeks of prompts for the focus group via GroupMe, I transferred that data to Nvivo.

To follow the steps outlined in chapter three of this study, I transcribed and re-read the transcripts from the interviews and cognitive representations then used Nvivo to identify repetitions of words and phrases, code the words and phrases and count the number of times the words and phrases were used both by an individual and across the group. An integrated approach to coding was used: first, each line of the transcript was coded while I was constantly looking for new (de novo) themes that may have emerged as the code structure evolved (Curry, 2018). The codes were both one-word codes and short phrases that represented the essence or key characteristics of the data gathered (Curry, 2018).

The codes were then put into a code structure in an outline of the emerging, developing and evolving code and included brief descriptions for each code (Curry, 2018). Tables three and four explain the most frequently occurring codes, which were converted to sub-themes as well as the corresponding number of occurrences of those sub-themes (Curry, 2018). There have been multiple versions of the codes because the organization of the data changed as major themes emerged and subthemes fit within them.

An intuitive, logical approach to coding was used, but I was self-aware of the potential for my bias, which was documented in the research journal. The initial codes were developed from the thematic, relational aspects of the data, and as mentioned, coded data that fit "under"

the major themes that were emerging became sub-themes. The code structure was outlined in two separate documents as it was adjusted according to analysis and re-analysis with the assistance of the Chair. I then compared the data with previous literature and did not find any information contrary to what the literature had supported. Any additional sub-themes that arose were included in the analysis, results and interpretation.

Themes

After reading, transcribing and re-reading the transcripts and cognitive representations, then looking at the responses in the focus group, then listening to the recordings again, I was able to code repeated words, phrases, perspectives and topics, and found that there were two major themes across the participants. The following are the two primary themes that emerged: “My Life with My Child with PIMD Is Like a Roller Coaster Ride” and “Balancing the Stressors: From Surviving to Thriving.”

Theme One: My Life with My Child with PIMD is Like a Roller Coaster Ride

The life of a parent of a child with PIMD is “incredibly difficult but also incredibly rewarding. We have found a lot of gifts and grief” (Callie). The participants in this study confirmed this theme, many of them stating that it had been a “roller coaster ride,” (Becky, Callie, Elizabeth and Isabelle), and others describing a similar journey of ups and downs or bad seasons and good seasons. I have stayed with the theme of the roller coaster ride, describing as “Uphill,” the climb that the roller coaster must take as it works toward the top of a steep incline, inching its way toward the top at which point the journey becomes less difficult.

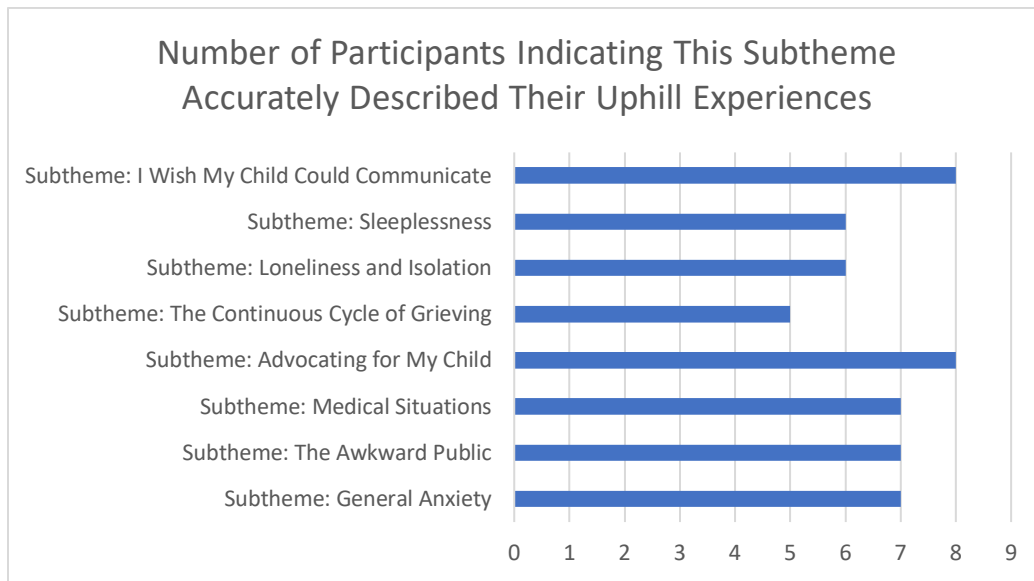
The Uphill. The “Uphill” represents the seemingly cyclical challenges that the participants faced. The sub-theme “Uphill” was further divided into additional sub-themes which describe the specific challenges described by the participants. The sub-theme “Downhill” was

also divided into additional sub-themes to reflect the joys and good seasons experienced by the participants.

Elizabeth described the roller coaster effect by stating in the focus group that, “Life in general has ups and downs, but when your life is complicated by a challenging special needs child, it seems the ride is magnified ten times. Life is just harder.” The following chart provides a visualization of the number of participants out of eight who indicated that the specific uphill sub-theme items accurately portrayed their lives as the parents of a child with PIMD. Further, the uphill or difficult aspects of being the parent of a child with PIMD are placed into subthemes below according to the type of challenge (uphill climb) the participants described.

Table 4.

Number of Participants Who Related to the Uphill Experience



General Anxiety. Most of the participants discussed many anxiety-provoking, stressful and difficult situations and circumstances. Francine shared that her daughter, “...For my journey (crying), I wish at times I would have thought more about how it was going to affect the stress of the family since we adopted her. But I didn’t.” In response to the interview question regarding

the emotional or psychological effects of the challenges of her parenting role, Becky answered that, “stress, heart ache (crying), worry, sometimes confusion because you don’t know what to do.” Callie shared that, “You cry, I mean I’m on the brink of tears pretty much at all times.” Callie added, “We definitely experienced trauma with her birth and everything and I think that there probably is some post-traumatic stress disorder from that” and “I think the anxiety is ... comes from both the past and the stress of looking into the future.”

Callie explained that the situation of being the mother of a child with PIMD made her anxious, but “I didn’t know what anxiety was for a long time. I knew I was experiencing it for a long time, but I didn’t have a name for it...” Some of the sources of anxiety for parents of children with PIMD include but are not limited to their child’s seizure disorder and their child’s inability to communicate, especially concerning pain. Several of the participants (Andy, Becky, Callie, Debbie, Francine) described the seizures as the most difficult challenge as well. Andy stated that the most difficult aspect of parenting his son was “the seizures. I would have to say ... it is the worst because there is really nothing you can do. You know you can give him his rescue meds and just hope and pray that they work.” In addition, some parents shared that they experienced anxiety when their child was hospitalized or even just in preparation for doctor visits. Georgia described how worrying about her child kept her awake at night:

I ... wake up , and my mind is gonna race, and it’s all gonna be worst case scenarios, it’s all gonna be what if, what if that had happened, well, what if... And sometimes ... I’m lying in bed, and I’m thinking the worst, and like she’s not breathing, but yet I can’t get up and go check on her. And we have a camera right in our room, and I can see right there, but she’s, like you just, you feel frozen to your bed...

The Awkward Public. Five participants described their experiences of anxiety, irritation or frustration as a result of negative interactions with the public, which several of them (Andy, Callie, Debbie, Elizabeth, and Georgia) described as, “People just don’t understand.” Debbie related one incident regarding awkward situations in public:

He would hold his ear and make this loud squawking, we called it squawking, loud squawking noise. You know I could pull up to drive-thru, and he’d be doing that in the back seat, and somebody would say, “Do you have a duck with you? Are you carrying a duck?” or “Is that a monkey? What is that noise?”

Elizabeth added that she does not take her daughter to restaurants because once her daughter finishes her meal, she will want to leave, making it nearly impossible for anyone else to eat their meal. She says about going to restaurants and other outings, “We have to pick and choose. And those are the hard things, picking and choosing what you’re going to do, when you’re going to do it and how you’re going to do it. That’s the hard things.” Andy described a situation that occurred with his family in a restaurant:

The worst we’ve ever had was with restaurants ... People wanna stare. And it’s adults. And me, I get kind of temperamental and wanna go say something. And my wife will do something like, “You sit over here,” and ___ (son with PIMD) would eat with food coming out of his mouth. Then she (my wife) would eat with food coming out of her mouth and look right at them. They quit looking.

Becky also stated that she dislikes it when people in public stare at her son and stated that she wished they would just ask questions about her son so she could educate them, instead of just staring at him. Callie confirmed this sentiment, saying, if other parents instruct their children not to look at her child with PIMD, it’s like they are, “... shooing your child away from my child as

if she has leprosy or something, that's what hurts and that's what I wish people knew." Georgia added that that the comments made to her out of ignorance did not just originate from the general public, but at times, even her family seemed to not treat her daughter as well as they did her cousins and they do not seem to be sensitive to her daughter's inability to measure up to their cousins' accomplishments.

Additionally, the topic of guilt was mentioned by both Isabelle and Debbie in the interviews, and in response to a focus group prompt. Callie said she felt guilty leaving her daughter with PIMD behind when the rest of the family went out. She described:

It just always feels like a piece of us is missing when she isn't there. We walked into my baby shower last summer and she immediately started crying... it was too overwhelming for her so she went home with our aide where she was much more content... but I still couldn't even bring myself to take a picture with my husband and my other daughter to mark the occasion because it just hurt too much to not have her in the picture with us. I guess the guilt stems from an inability to adapt EVERY situation for her or to make her comfortable in every situation.

Additionally, Debbie mentioned that she also had experienced guilt and found that in order to survive, she had to begin:

Releasing the guilt, working through the guilt of whatever... knowing that there was something that caused me to go into labor, I absorbed a lot of guilt from that. What did I do, why was what in my life was I doing that wasn't, that had put this baby's life in danger... releasing the guilt is what I would say if I could look back and say what can, how can I help you get through this? The first thing I would say to myself is release the guilt.

Medical Situations, Including Seizures, Hospitalizations and Doctor Visits. Andy expressed in the Focus group that he experienced anxiety as related to his son's seizure disorder, "Dealing with the seizures is a roller coaster. When he's good, we're good. When he's having seizures, my world is shot." In the interview, Andy added, "...when he goes into a seizure, you just want to scream, but you don't. You do what you gotta do. When he's back on his feet and he's better, you go outside, and you scream, and you punch a wall or whatever."

Becky related that her son's lack of ability to communicate contributed to her fears, mostly experienced because she works an hour from home, and with her son's seizures, even though she trusts her husband who cares for her son while she is at work, she likes to be there with him when he is having seizures, so she gets anxious, scared and feels hopeless. Becky stated that, "His seizures again are a big thing. The main thing is my fear that something is gonna be wrong with him and I'm gonna miss picking up on what's wrong with him... Something bad is gonna come out of that, so it's a fear."

Becky explained further by stating that a TD child could complain of a stomachache or something else, but her son cannot, so "it's all guesswork." She said that communication is key to everything, and if you are unable to communicate, then you cannot do much of anything. Georgia's experience with the difficulties of having a child who cannot communicate lasted two years, when her daughter with PIMD was in a lot of pain, and no one could tell what the problem was:

She has never been a crier, but February 2018, she started with these episodes of self-injuring and screaming and we knew something was wrong... something physically that was hurting her. And ... nobody could figure it out, of course because she can't tell us, so ... we start from the toes up, what's going on, is it her wisdom teeth? The dentist checked

wisdom teeth to see if there's wisdom teeth coming in. and we're going through all that and we had some family members who then felt that she was just being behavioral and so that was hard on us. So, we were like, no, we know our child, she's in pain, there's something going on. So, we were able to narrow it down to this area (pointing to belly) ... So, after 2 years, we finally had all the surgeries and we're doing good (laughing).

Georgia added that because her daughter had deteriorated so much over so long a period of time, the parents thought she might be dying for some undiscovered reason. Francine echoed Becky's feelings when she said, "That's my biggest fear, that you know, it (her death) may happen (crying) one of these days, ... when she has a seizure, I always say, God, don't let her go like this."

Georgia related that although many children with the genetic disorder that her child has often also have seizures, she is grateful that up to now, her daughter has not had any seizures, though, she adds, "it is not off the table." Again, Andy spoke about the worry related to his son's seizures, "Usually if he's in the hospital or in an ambulance ride for a seizure that I can't get him out of, I get worried. I've been told that the seizures are what's gonna kill him so you get kind of worried when you can't get him out of them."

Callie described the difficulty of hospitalizations for surgeries, stating that through her daughter's hospitalizations, she learned that whenever her daughter with PIMD is in the hospital, she runs on adrenaline, but when she gets home, she describes, "I feel like I have been hit by a Mack truck and it typically takes me like three days to recover." Callie also shared that just taking her child with PIMD to see the doctor evoked anxiety. She said that when her daughter was younger, even the weeks and days before a doctor's appointment made her anxious because

she was asking herself, “are they gonna give us a new diagnosis, are we gonna find out that she’s dying ... it’s a very real possibility.”

Regarding anxiety related to medical interactions, Georgia added, “I just feel like I wanna crawl out of my skin, ... especially if I’m waiting for answers, like if I’m waiting for doctors to get back to me with something.” Debbie described her son with PIMD’s first months of life in the Neonatal Intensive Care Unit (NICU) and how it changed her as a person, saying that she changed from a “very fun-loving, ... outgoing person to very secluded, very reserved and protective of him.” She adds that, “the 4 months that we lived at the hospital, it changed who I was because I became this caretaker for this little being... and he still needs me. He will always need me.”

Each participant except Isabelle described at least one situation in which their child was having a medical crisis. Most of the crises were seizures (as with Andy, Becky, Callie, Elizabeth), accidents related to the child’s disability (as with Debbie and Francine) or near-death experiences (as in Francine’s case). Two of the participants who related to me that they had experienced anxiety related to their child’s condition also shared that they attended psychotherapy for help with their anxiety (Callie and Francine) and some revealed taking antidepressants or anti-anxiolytics. Francine was very transparent when she shared that because of the level of stress she experienced, being a stress eater and having gained a lot of weight, she ended up having gastric bypass surgery to lose weight.

Several of the participants also described the isolation they could feel as a result of their child’s condition. Francine described, “I would love for her to be in school because she loves it, loves people, loves it. But she was staying so sick, that’s what happened in 2009, she was staying so sick ...” Elizabeth’s daughter, when younger, had a similar experience:

When she was brought home from the NICU, they told us she can't get RSV, she can't get that, you're gonna have to be kept on homebound isolation and keep her away from other sick people and things like that because her respiratory problems at that time, if she were to get sick, would probably kill her.

Advocating for My Child. In addition to the topics above, most of the parents mentioned having to perform the role of advocate for their child in unexpected ways. Callie, Debbie, Elizabeth, Francine and Georgia stated that they were responsible for knowing more about their child's medical condition than the doctors. The pressure was on them to figure out what was happening with their children when unforeseen illnesses arose. Some of the participants related having to be outright pushy to get what their children needed medically (Francine). Callie related it this way, I have to "... stand up to the doctors (laughing). I always tell them I'm really happy for you and all the letters that are behind your name, but I am the expert on ___ (my daughter)." She added that she has to, "do what I gotta do at the moment and just pray a lot and advocate for her if it's, particularly if it's medical, do a lot of advocacy and just be prepared." Isabelle unabashedly using the word "fight" rather than "advocate" when referring to her need to be a voice for her son.

When asked what advice she would give to the parent of a newborn with PIMD, Isabelle responded that she would advise them to get resources and be their advocate. Francine added that she would advise a parent of a newly diagnosed child to make "sure you're an advocate, ... just, I mean staying on top of it, but also making sure you've got some caseworkers, some people who will have a voice for you." Debbie also mentioned that she has had to become her son's advocate, and Georgia explained that her role as advocate extended to the school as well, saying, "at school she has a one-on-one aide, which we fought for, because they did not want to do that."

The tension of the conflictive situation when the participants had to “fight” (Isabelle) for their child to get what he or she needed produced stress and sometimes anxiety. When Callie’s daughter “was younger, it was, the weeks and days leading up to big doctor’s appointments, I would get very anxious and ... are they gonna give us a new diagnosis? Are we gonna find out that she’s dying?”

The Continuous Cycle of Grieving. In response to one of the interview questions regarding challenges and joys, Callie said:

We kind of just live in the cycle of grief, you know, there’s – it’s just so much different than somebody dying because you... That person dies and you grieve their death and then you move on with life. Whereas with this situation with every new diagnosis or ... kids that were born the same time she was are playing soccer now and when all those kids you know go to prom,... get their driver’s license, go off to college, get married, have babies, all those new milestones, life events that we will inevitably miss out on, ... I think ... the grief cycle will start all over again... Those kinds of things are all ... catalysts, to the grief cycle so we’re always kind of living in it.

Georgia echoed Callie’s description of the continuous grief cycle by saying that she also experienced the grief cycle, and:

It’s there and then you’re fine, and it’s there... it can be the smallest little things that triggers it, it can be big things that trigger it ... like it’s for it’s supposed to be your (child’s) senior year, things that are significant.

Elizabeth contributed to Georgia’s sentiment, saying, “It’s just a grieving for what you thought you would have and what you didn’t get.” Later in the Focus group, Elizabeth expounded on her interview comment, adding that:

I watch her grow and mature into a beautiful young woman, but knowing that she will never experience close friendship, play a sport, high school graduation, the excitement and independence of driving a car, a romance, a wedding or children...a feeling of being left hind or left out.

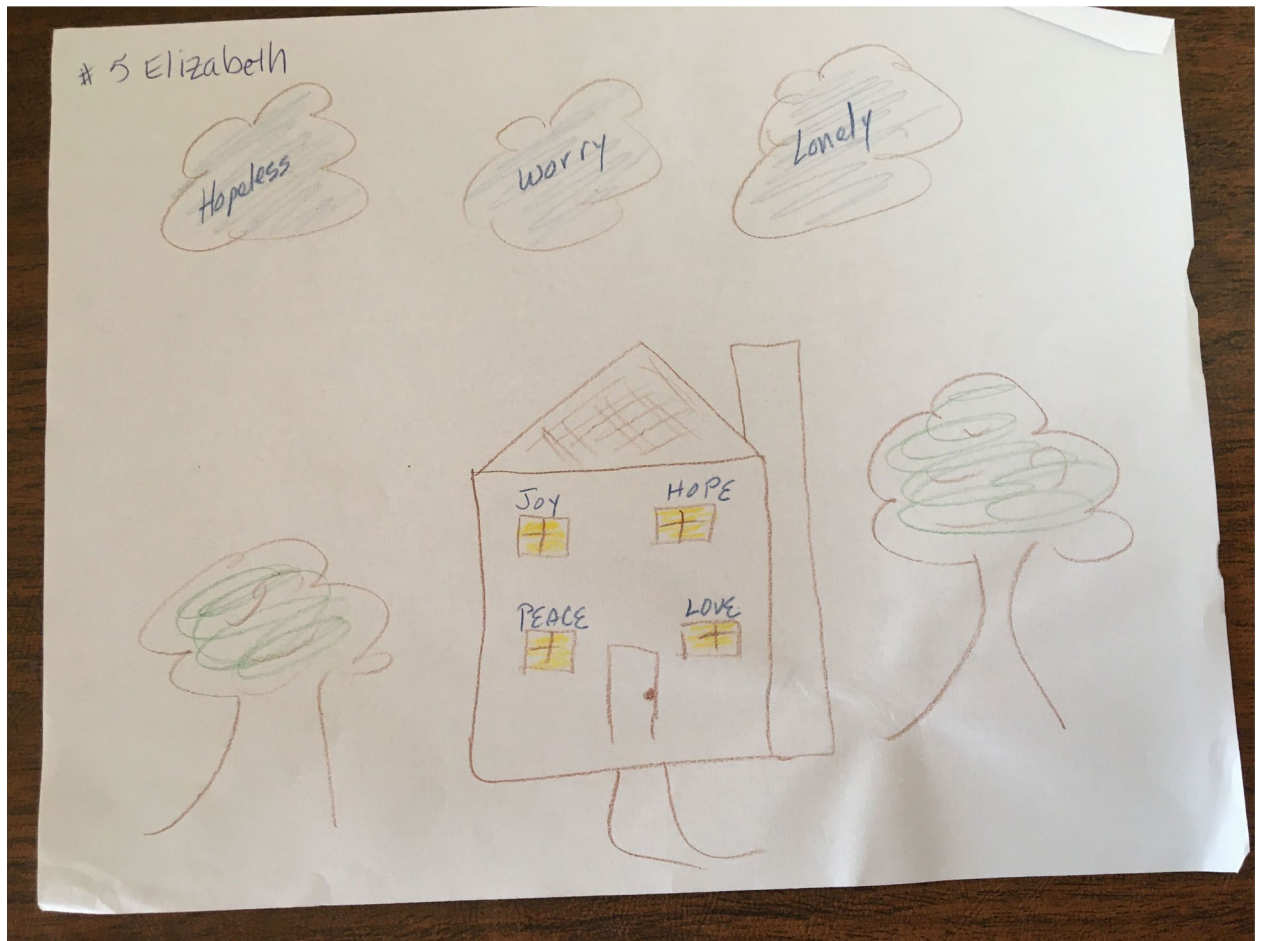
Loneliness and Isolation. Two of the participants mentioned loneliness and isolation as sources of difficulty. Those who had experienced isolation for certain periods of time remember those times as being very difficult. Elizabeth described it this way:

There's this feeling of being left out sometimes. Not just with friends, but even with family. There's sometimes a feeling of loneliness, isolation. After a while you kind of get used to that. You just don't dwell on it very much...

The loneliness and isolation often resulted from (1) not being invited to events because people had assumed that the parents would not come because of their child with PIMD (Elizabeth) and (2) not attending events because having their child with PIMD with them was too difficult (Elizabeth, Francine, Debbie, Callie and Isabelle). Elizabeth's description of her cognitive representation expressed this isolation while describing a house with some dark clouds over it, "and they are dark clouds because they are always lingering in the background of hopeless, worry and lonely."

Figure 2.

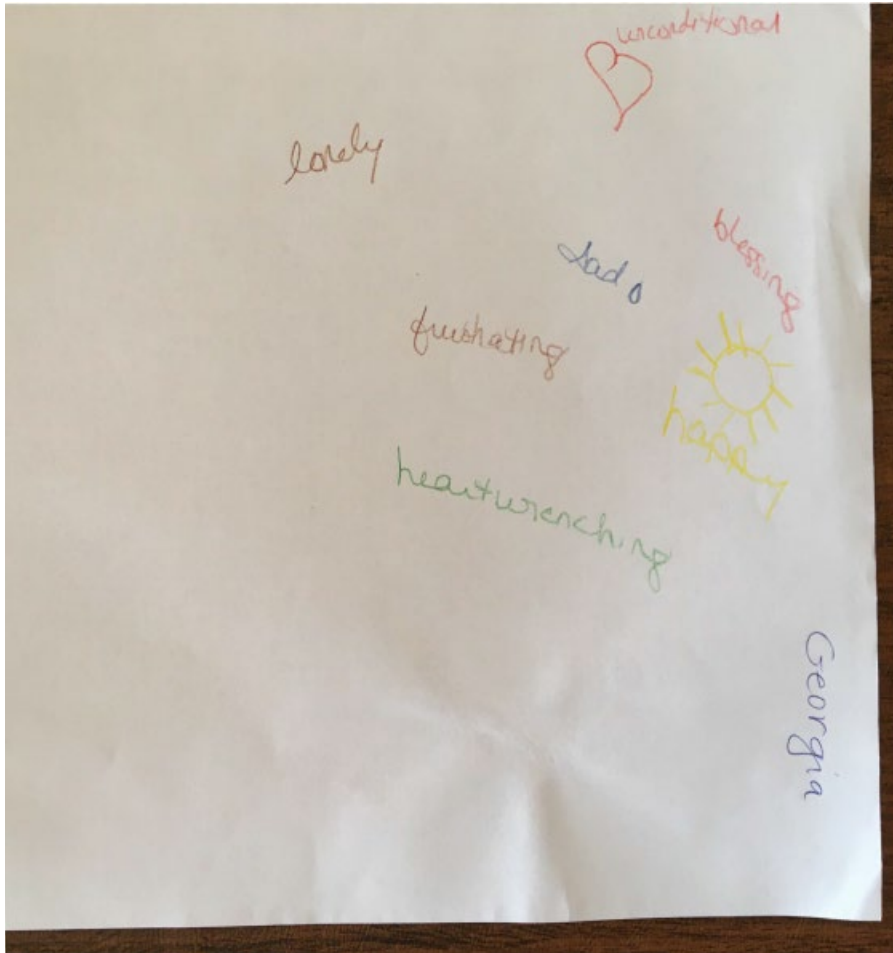
Elizabeth's Cognitive Representation



Georgia's description of her cognitive representation echoed Elizabeth's, "Lonely because sometimes it's, you feel isolated from your peers because what they're going through in their stage of life is different than what they're going through" and "I get into that, into a thing of just feeling like I'm ... feeling like I'm alone, that no one is understanding what I'm going through or things like that."

Figure 4

Georgia's Cognitive Representation



Sleeplessness. Becky related that her son with PIMD sleeps only a couple hours per night, and that at first it was hard, but she got used to it:

When he goes through 5 or 6 days of two hours of sleep (per night). (Laughing) other than that I'm fine. I think when I had him and he didn't require sleep, at first it was really hard and now sometimes when he sleeps ... 4 hours, or whatever which is his normal day whatever 4 to 5 hours ... I guess my body's just gotten accustomed to it ...

Debbie described a specific episode when her 15-year-old son kept her up one night recently:

I had moved to my room ..., but I heard him... getting up and he was walking through the house and talking really loudly ... And I walked to check on him and I smelled poop

(laughs). He had taken off his diaper and he had pooped on the floor in several different places. So, that's challenging. You know, when you're, I mean it was like almost 1:00 in the morning (laughing) and you're tired and this life doesn't allow us to get sleep.

Callie explained that whenever her daughter is hospitalized, she does not get to sleep, as hospitals are notorious for not allowing anyone to sleep. Elizabeth described the effect of sleeplessness on her family, saying that sleepless nights are the most challenging thing about her daughter's PIMD and that "going without sleep is really hard on everybody- the whole family, not just mom and dad, but the child and siblings that are in the house."

I Wish My Child Could Communicate. Each of the parents interviewed expressed their desire for the child with PIMD to be able to communicate, but most children with PIMD are non-verbal. In this study, two of the children could say a few words, one could say many words, but they did not make sense, and the other six were considered non-verbal. It is especially difficult when a child has specific medical issues arise but is unable to communicate what is wrong. Francine described it as having to be her child's voice because she does not have one. Becky described it this way:

A "normal child" could say my stomach hurts or my throat hurts or my head hurts, he can't tell you that, so it's all guesswork. When you can tell something's not right with him, you start guessing. Ok, I wonder do you have pain here? ... So, it's a big deal to me. Communication, I think, is the key to everything. If you can't communicate, you can't do much of anything.

Elizabeth echoed Becky's sentiments regarding having to guess what was happening with her daughter:

Also think trying to figure out what the medical problem is. You know something's wrong and she can't communicate to me, "I have a headache or my tummy hurts, I just don't feel good" or whatever, she could not even communicate to me that she had a broken bone if she had something like that. Other than seeing changes in behavior or a fever or and then it's a guessing game, constantly, what is it, is it the flu, is it strep, is it just a virus? And that's very, very difficult because she is totally nonverbal and cannot tell me where it hurts or how she feels at that moment.

Georgia described other impacts of her daughter's inability to communicate:

I'm never gonna hear the word "mom" or I'm never gonna hear "I love you." And I think that is where the isolation can sometimes fit in when I just sit there and go, ok, this is, that is not a thing I'm gonna hear. And when I hear parents be like, "oh, my child won't stop talking," I just wanna be like, be thankful! Just be thankful because they're talking, at least they're expressing something to you, and you know what they want. But with us, it's more of a, we had a doctor say to us one time that we're probably more in tune with our child than a typical parent would be, because we just, we have to know..."

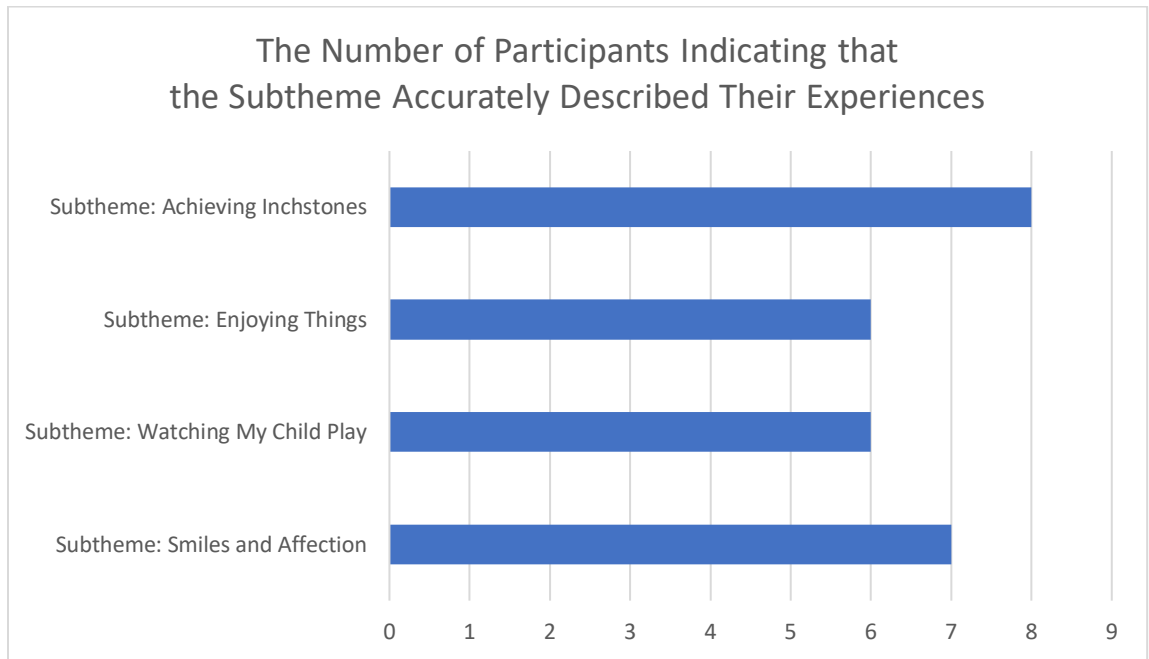
Isabelle described a situation where another child with special needs and her own son had been physically abused by an aide on the school bus:

Because the aide would sit down and then would pinch my son or smack my son, but there wasn't enough video because it magically... disappeared, ... but the hardest part was watching the few videos when I was getting my son off the bus, and you can hear my voice, and they're laughing and joking with me as they're letting my son get off the bus, and I had no idea that just a few minutes before, my son was being hurt (crying a bit), and he could not tell me. That was awful.

The Downhill. Following the uphill, there is the downhill or coasting of the roller coaster ride, during which participants described “easier seasons” (Callie). The downhill describes the various joys and periods of relative calm that the participants experienced in their lives as parents of children with PIMD. In response to the interview questions, cognitive representations and focus group guide questions, the participants described their downhill rides as finding joy in their child’s smiles and affection, watching their child play and enjoying things and witnessing their child achieve “inch-stones.” Each of these sources of joy experienced by the participants is further described below in subthemes, and the following chart is provided to give a visualization of the number of participants out of eight (X-Axis) whose responses to interview questions revealed their inclusion in the joyful events or activities (Y- Axis).

Table 5.

Participants and Their Downhill Experiences



Smiles and Affection. All but one of the participants (Elizabeth), stated that their child’s smile just lit up their day. During the interview, Elizabeth’s daughter with PIMD was not

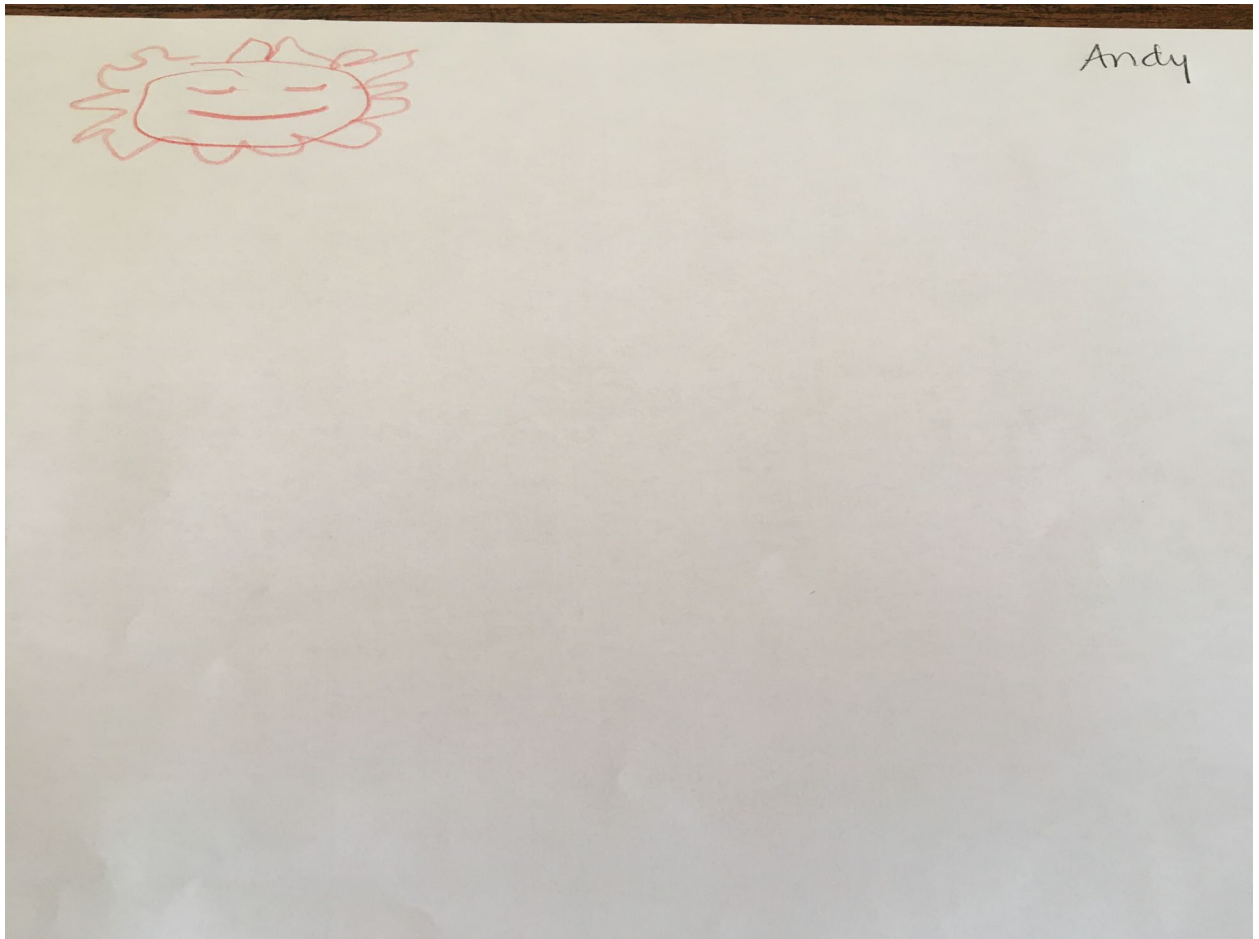
observed to smile or express any emotion. Becky described the joy she experienced daily when she returned home from work to see her son's smile and get his hugs; it was something she looked forward to at the end of each day. Likewise, Debbie described the joy from just being her son's mommy, and shared her experience of joy when her son arrives home after school:

They pull up on the bus, I look up and there he (her son with PIMD) is and he's just smiling at me with these little jagged, crooked little teeth, ya know, and he has this big smile on his face, ... life is just really good, even though it sucks really bad.

In the focus group, Becky stated that "his smile can brighten any cloudy day." Isabelle said that the first thing that comes to her mind when she thinks of her son with PIMD is his "infectious smile." In the focus group, Andy added that his son's smiles "make my worries go away." As if for emphasis, given the instructions of drawing something that would represent the entirety of what his life is like as the father of a child with PIMD, Andy's cognitive representation (Figure 4) was a picture of a smiling sun in the color red. When asked if he wanted to comment on the picture or add anything, he said no.

Figure 3

Andy's Cognitive Representation



Francine added that one of the rewards of being the mother of her daughter is, “She’s still able to give hugs and wave and acknowledge mom, dad, ... know, her siblings...” Along the same lines, Andy stated that one of the rewarding aspects of caring for his child with PIMD is that his son, “... just loves to hug and kiss and gives a smile. He’s full of laughter.” Andy added that, “He’s got a shirt that says, ‘Hugging is my business,’ and, on the back, it says, ‘and business is good’ and ... we bought him that shirt for Christmas.”

Watching My Child Play, Enjoy Things and Achieve Inch-Stones. Francine tearfully described how happy it made her when she saw her 18-year-old daughter with PIMD just enjoying simple things like playing with her toy duck and making happy noises, “When she

plays with her duck and she wants her duck to do some stuff. It's that little stuff that just means something." Callie described their experiences as follows:

So, we're always kind of holding our breath whenever we go and do certain things as a family and when she enjoys them and when we know that she's having a good time. And the effort of getting her there and preparing for everything leading up to it is worth it. That is incredibly rewarding. Or finding just anything new that she enjoys that puts a smile on her face. Her emotions are kind of the way that she speaks so to have that confirmation from her that oh, ok, you are happy right now and you are enjoying this moment that you're in. That's really rewarding.

Elizabeth described the joy she experienced when watching her daughter participate in hippotherapy:

When she got on the horse, she was just smiling and beaming the whole time. And there were several workers that volunteer for the horse program that had seen her participating and they knew what it was like, and they know how difficult it was for her. And there was one gentleman, and he was just standing there crying (mom crying) because he was so excited about what she was doing. So, there's lots of happy things.

Callie related the same sentiment in a different way when she described not milestones, but "inch-stones," a measure used by many parents of children with PIMD to measure any tiny bit of progress their child makes. Callie seemed to have summarized the thoughts and feelings of most of the other participants when she said, "And just little things bring us an immense amount of joy." Debbie added to this sentiment saying that, "Well, watching him eat (brings her joy). It's one of the big things because he's so tiny, he's now finally on the chart for size and even brain size because he does have microcephaly so he's in the 2% range on the charts now." In addition,

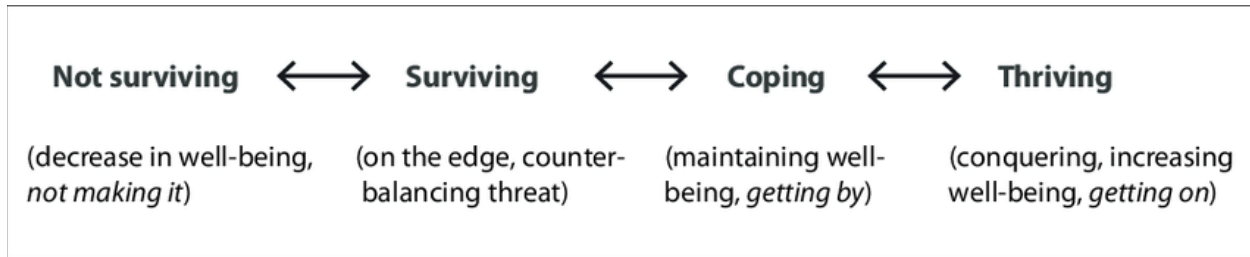
Becky happily, but crying, commented on the joyful moments when her son achieved some milestones such as taking his first step, sitting up for the first time (which she described as an exuberant family event) and the first time her son said, “I love you.”

Theme Two. Balancing the Stressors: From Just Surviving to Thriving

Grey, Totsika and Hastings (2017) found that mounting stressors experienced by families make them progressively less able to handle those stressors. The same authors found that a continued imbalance between the family’s stressors and resources is a threat to the parents’ well-being (Grey, Totsika & Hastings, 2017). In Theme One, the participants described the many stressors they faced as the uphill climb of a roller coaster, and in Theme Two, these stressors are seen on the left side of the scale in Figure 6. In Theme Two, the challenges or stressors faced by participants are described in broader categories as medical needs, physical burdens, emotional burdens, other children’s needs, spouse’s needs, career demands and social isolation.

The scale in Figure 6 depicts these stressors as being counterbalanced by the helpful perspectives and coping strategies of the participants. Further, in this study, it became evident that the degree to which the participants adopted helpful perspectives and employed their coping strategies determined their degree of well-being, which ranged from :”Not surviving” to “Successfully thriving” (Figure 5). Both *helpful perspectives* (subtheme one) and *coping factors* (subtheme two) contributed to the right side of the scale which in turn, helped balance out the stressors on the left side (Figure 6).

Figure 5.

The Continuum of Not Surviving to Thriving

(Efendić, Cvetičanin, & Kumalić, 2017).

The participants' answers to interview questions and focus group questions, along with their cognitive representations showed that if they had helpful existential perspectives, and if effective coping factors and strategies were regularly present, then they had higher levels of thriving. Callie, for example, described these changes in levels of thriving as "seasons" during which she sometimes felt overwhelmed and exhausted (meaning the scale would tip to the left) or better seasons in which she felt well-balanced and very good about her life (i.e., the scale was more balanced or possibly tipped to the right). Isabelle stated that at one time, she had wanted to end her life because she was unable to balance the challenges with helpful perspectives (overly weighted to the left) and did not have the spousal or social support or other coping strategies needed to thrive; thus she was close to the other end of the continuum, "Not surviving."

Figure 6.

*Balancing the Stressors for Parents of Children with PIMD***The Weight of the Challenges**

- Medical Needs
- Physical Burdens
- Emotional Burdens
- Other Children's Needs
- Spouse's Needs
- Career
- Social Isolation

**The Counterweights- Helpful Perspectives and Coping Factors*****Helpful Perspectives***

- Realistic Expectations
- Finding Joy Daily
- Accepting the Disability
- Willing to Learn

Coping

- Spousal and Social Support
- Other Coping Factors/Techniques

Since the left side of the scale is described in detail in Theme One, the primary focus in this section is on the right side of the scale and includes the subthemes of helpful perspectives and coping factors.

Subtheme One: Helpful Perspectives. Perspectives on life's circumstances can affect emotional and mental health. Hassall, Rose and McDonald (2005) asserted that parental cognitions regarding their child's disabilities affected their levels of stress. Family systems theory purports that each person in a family, along with his personality, background and perspective, affects the other members of the family. Hill and Rose (2009) assert that parental cognitions regarding the child's disabilities can affect parental mental health outcomes. John and Montgomery (2015) state that spiritual or existential perspectives affect parental well-being. In this section, spiritual or existential perspectives are simply referred to as "perspective," and the participants' helpful perspectives are described.

Throughout this study, it became apparent that various participants had differing perspectives regarding their child's disabilities, which in turn affected how the participants dealt with the challenges and stressors they faced. The participants' responses to interview questions gave them the opportunity to describe their existential or spiritual perspectives. Research by Beighton and Wills (2019) concluded that many parents of children with ID attribute positive intrapersonal gains and growth to their role as parents of children with ID. The participants in this study confirmed these research findings that parents' positive perspectives affect emotional well-being. The specific perspectives described by the participants in this study include having realistic expectations, learning to accept the child's as he or she is, finding the positive in each day, experiencing growth as a result of the experiences and having a hopeful outlook.

Realistic Expectations. The term, "positive perspective" is purposefully avoided here because as Callie said:

... eventually, you kind of just – it's not giving up- you learn to just stop setting expectations because you're continually setting yourself up for disappointment. You know my husband at times thinks I'm pessimistic. I don't think I'm pessimistic. I think I'm realistic. I can only take so much disappointment. So, if I don't set expectations, I can't be disappointed and everything else is just a positive, it's a game if we don't expect it and then it happens, then we will throw a party. Positive is not necessarily reality...

The parents of children with PIMD must fight unrealistic expectations and be prepared for medical or other crises at any given moment as well as for developmental setbacks (Callie, Francine, Georgia). It is, especially in the early years (Callie, Elizabeth, Georgia), grievous, to

expect your child to meet a certain milestone only to be disappointed, over and over. However, out of the eight participants, Isabelle was the only one who said that if:

I could give my son the things that normal boys have, I would in a heartbeat change it. My son to have dates, my son to play a sport ... or could go to a prom, if I could have a mother-son dance at his wedding, if I could see him be a father, man I would change his disabilities in a heartbeat. So, I guess maybe I understand the concept of what people are saying, the lessons they have learned through their child's disability, and learning how to love their child. I get it, I understand all of it, but if I could give ___ (my son) ... some normalcy, not being treated like he's contagious, hands down, I would change it, absolutely would change it.

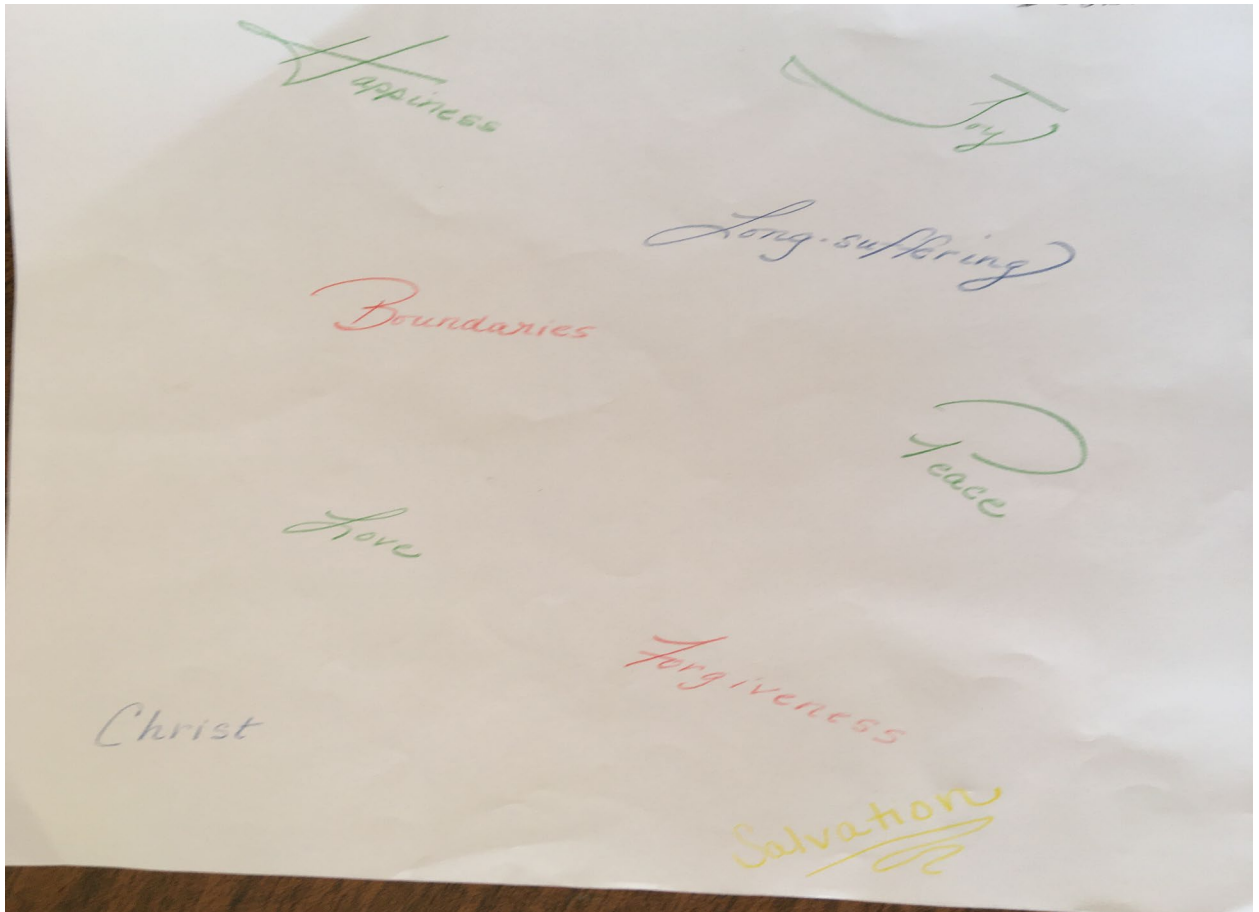
Finding Joy in Each Day. Despite the setbacks and disappointments, in her cognitive representation (Figure 7), Debbie described her way of having a positive outlook, choosing to find joy in moments throughout her day in this way:

Words I feel in my everyday life: happiness, joy , peace, forgiveness, long-suffering, boundaries, love, Christ, salvation. Those are all words that I think of every day. These are words that I have also written and put around my desk. I have I think of a positive word every day or it doesn't have to be really positive, it's just a word that I'm thinking of that I can look to and say, ... "I had real peace in this moment" or "there was so much joy,"... or "in this moment we had this happiness." I always have my salvation. I always have Christ, ...

Those were the things she chose to focus on. Elizabeth confirmed this, saying: "So, we pick and choose our battles on what we're gonna think about that day (laughing) and how we're going to live that day based on everything else."

Figure 7

Debbie's Cognitive Representation



Accepting My Child, the Way He or She Is. The remaining seven participants had different perspectives indicating that they were content with their child with PIMD just as he or she was (is). Andy explained:

I am very, very proud of _____. And the man he has become. (Crying gently), if I had it to do over again, I'd want it to be the exact same way. I wouldn't want him to be pshhht, normal because it wouldn't be him.

Debbie, looking back to the brighter side of her son's birth, added:

I didn't ask God why (her son had been born this way) because I saw the blessings from it. I saw people pouring together and pouring into us love and support from churches everywhere. And so, we had all of these people from all around the world praying for him and for us too because we were in this situation...

Isabelle stated:

It gets tough because I am somebody who likes to fix. I like to find solutions, and the first thing that I had to learn is that I don't have control and I can't fix it and that took me a lot of years.

Debbie added that:

If someone were to give me the option to give him a shot and cure his autism and fix his brain, would I do that? No, I would not. I love this child just as he is... He's just this little perfect broken child... But he loves who he is!

A perspective that was portrayed by Francine when asked the question, "How do you imagine your life would be different if your child were TD?" responded, "I don't know. I honestly cannot fathom that. I mean I want her to be... She would have a car. (Crying) she will turn 21, she'd be, it's hard for me to fathom that." Andy stated that he enjoyed every bit of his role as the father of a child with PIMD, "and I'd do it all over again as long as I had his mother helping me." On the surviving to thriving scale (Figure 5), at the time of the interview, Francine would be further to the left toward surviving rather than thriving.

On the other hand, Callie said that she had to, "learn to just stop setting expectations because you're continually setting yourself up for disappointment." Debbie stated that at times she was sad, thinking, "What was it going to look like? What was the future gonna hold? How could we survive every day? How could we just wake up and get through this day?" Francine,

with a more accepting perspective added, “I think every day when I wake up and she wakes up (is alive), oh good day, God’s good.” Her way of accepting her child the way she is and looking for the positive in each moment has helped her to move along the surviving to thriving continuum (Figure 5).

Finding the Positive. A basic tenet of positive psychology is that people with positive perspectives cultivate greater levels of emotional well-being (Fredrickson, 2000). Callie explained that her current satisfaction with her life is tied to her perspective:

The perspective that we’ve been given, is one that I don’t take for granted at all, ... I know how difficult it is for her to do every little thing she does throughout the day, for any typical child. Not difficult, but just how many different things have to go right within their brains, I mean the right messages being sent to the right appendages, it’s just I don’t take anything for granted. And I find so much excitement, we both do (Callie and her husband), in just the little things.

Additionally, the participants who seemed to be thriving at the time of the interviews found positive things to focus on and positive, hopeful outlooks that they would “get through it” (Debbie), that “a better season was right around the corner” (Callie).

Seeing Personal Growth. John and Montgomery (2015) asserted that parents’ perspectives on their children’s disabilities may be associated with outcomes related to parental well-being. One facet of some of the participants’ perspectives was that all of them felt that their son or daughter with PIMD had changed them for the better, that the child’s disability had a purpose in their lives. Andy stated, “So more than likely if he was normal, I’d have been divorced by now,” and Becky and Elizabeth both stated that they would not have become the caring persons they are now.

Becky stated that if her son did not have his disabilities, they (the parents) would not be as good as they are, nor would they be as strong as they are, and that their son with PIMD has made them what they are. Similarly, Debbie shared that her son with PIMD:

He kind of, well, it changes who you are. It changes, it has changed everything about me... but it's... I had to learn that whatever is going to happen is going to happen. This is all part of God's plan. This was something that God put into my life to change me, to grow me ...

Isabelle added that "... learning that unconditional love, learning that in me, learning that I can do the things that I have done. That's been eye-opening."

In some cases, the participants would realize that their emotions or cognitions were leading down a negative track and changed them so that they would not get sad. Above, Francine cried thinking about the milestones her daughter would not meet, then to me, and to herself, stated that, "I know that she's more of a blessing to me than we are to her. I know her life has meaning."

Willingness to Learn. Andy, Becky, Callie, Elizabeth and Georgia explained that when their child was born, there was a "learning curve" (Isabelle, Callie, Isabelle) and that they spent a lot of time self-educating regarding their child's condition(s) by Internet and support groups, therapists, nurses or others with similar experiences, before their medical appointments and then teach the doctors about their child's (sometimes rare) disorder so that they were able to advise and educate the doctor. Andy related his learning experiences this way:

We just started just canvassing the Internet and books and we found out everything we could find out. And every time the doctors tell us this is wrong with him or that is wrong with him, when with the seizures with ___ ___ (name of syndrome), we researched, and we

found out what was what... And most of the time we know more than what the neurologists are telling us... So, when we go to the doctor's now, they ask us, what is he doing, and why is he doing this? And we can tell them because we know what to look for.

Becky advised parents of children newly diagnosed with ID to learn "Everything you can about the disability to see what you can do to push them along and get them further along in life." Debbie added, "You have to balance it. You know, he's broken here (pointing to brain) but not broken here (pointing to heart) and you have to find a way to balance that out."

Another thing that several parents had to learn was how to treat seizures at home using an emergency seizure plan (Andy, Becky and Francine). In addition, other participants (Callie and Francine) had to learn to change G-tube buttons and figure out how to meet the nutritional needs of their children to keep them alive. As described above, the parents' learning experiences with their child with PIMD may never end as the child's condition may worsen with time, as Georgia experienced:

When she was younger, ... it was always, oh, well, it'll be easier when she gets older, ... Don't wait for oh, this is gonna get easier, this is gonna get better, because in reality, the older she gets, the harder it's getting because of the physical needs.

Subtheme Two: Coping Factors and Strategies. The distinction is made here between coping *factors* and *strategies* because certain *factors* that assisted the participants in coping were not planned or even within their control, such as having spousal and social support. The coping *strategies*, on the other hand, are specific things that the participants could control and implement. The coping factors and strategies that the participants in this study described as being more helpful than others were elicited from the participants by specific interview questions and focus group questions. This section describes those coping factors that affected the participants'

ability to manage and which, along with subtheme one, having a helpful perspective, placed them somewhere on the spectrum of “just surviving” to “thriving” (Figure 5). Each participant had to find some way to manage the abundant stressors they faced. The degree to which their spouses and others were supportive affected their ability to cope, and additionally, each participant found his or her own individual coping strategies, things that helped them relieve stress. Sometimes the coping strategies that worked were discovered by trial and error (Elizabeth).

Elizabeth described times when she was not thriving; she expressed having had a lot of anxiety and frustration at times, “Because I was trying to do so much on my own with very little help. I had given up a lot of my hobbies, had given up a lot of things.” When she realized that she could not go on as she had been, she:

... Gave up helping out with the youth on Sunday nights and made that our date night and had personal time on Sunday nights. And we do have someone who faithfully comes and stays with her just about every Sunday so those were the positive changes I had to make, and that’s made life a little bit easier.”

It appears that Elizabeth made the transition from not balancing (just surviving) to balancing well (thriving) in 2015 when she made those changes.

Spousal and Social Support. As previously stated, Saini et al. (2015) stated that spousal support and social support are two of the variables that contribute to marriage satisfaction of parents of children with disabilities. Family systems theory asserts that when the spouses have higher marriage satisfaction, family well-being can be improved. Based on the findings in this study, it was confirmed that spousal support and social support contributed to parental perception of both marital satisfaction and parental emotional well-being.

Spouses. All eight participants described the importance of spousal and social support in their lives as parents of children with PIMD. When asked, “Which of all of those things that we just talked about (coping strategies) do you feel is the most helpful?” Georgia replied, “Having a supportive spouse.” The support that the married participants (Andy, Becky, Callie, Elizabeth, Georgia and Isabelle) received from their spouses was spoken of as the most important or most beneficial coping mechanism the participants had. Andy described his wife’s support, “I just do what I normally do and if it gets to be too much, mom takes over and I just go sit in the other room.” As an ex-military person, Isabelle described her spouse’s support this way:

In the Army, they used to call it battle buddies. You don’t just leave your battle buddy. You go in together; you go out together. That’s how it is with ___ (her husband). You laugh together. He’s the only one who knows the depth of my depression and still loves me anyway.

Isabelle talked about specific ways in which her husband and she support each other, saying:

We argue, not really argue, over who is going to serve whom, like, no I’ll do the dishes tonight, you’ve had a hard night, or no, you know what, I’ll do ___ (son), you just go. Tonight when I came home, I knew that ___ had been with (son) for a few hours and I could see that he was a little bit tired, so I was like, “go, just go, go in the room and hang out” so I made him dinner and brought him dinner in the room. And no, I am not this amazing wife, God knows, but he will do the same thing for me. It’s a partnership.

Three participants who were not achieving a healthy balance and were just surviving each day (Debbie, Francine and Isabelle) were either divorced (Debbie), in the process of divorce (Francine), and/or had children with behavioral issues (Debbie and Isabelle). Two of the divorced participants had not had a high level of support from their ex-husbands (Debbie and

Isabelle). It was noted that those who appeared to be thriving (Andy, Becky, Callie and Georgia) had spouses who were very involved in the care of the child with PIMD and very helpful to the spouse who was the main caregiver for the child with PIMD. One anomaly to this pattern was Francine, whose husband was very involved with their daughter with PIMD, but whose personal problems and mental health issues seemed to cause marital problems, to which the participant attributed their upcoming divorce.

Social Support from Others. Beyond spouses, other participants discussed the importance of getting out with friends for social support. Becky described her attendance at a women's group in her church as vital. She said, "We have a women's group at church. There's like five of us that are on the fellowship committee and we usually get together about once a month and do things at the church ... and that's my de-stress." Becky added another source of social support that helped her cope, "My co-manager and my assistant, we're like family so they can sense if something is going on with me, and I can sense if something's going on with them and we talk it out." Debbie described how great it was, after years of being socially isolated, to finally get out and socialize a bit. She shared:

Really (we were) just learning to live for this little kid. We don't, I don't get to have a social life. Going to Bible study is a big deal for me (crying) because I get to get out and meet people and see people and finally socialize, but under normal circumstances, you don't get to do that.

Georgia also had a very supportive church that has been key in her ability to thrive amid the challenges she faces. Becky added that her entire church, her neighbors and her relatives have been very supportive of her daughter with PIMD and their family. She shared:

My cousin ... is like a huge supporter. Our neighbor next door if I'm at work and something happens and I'm on my way home, she comes here. I have an uncle down the street. If something happens, he's here. So , we have them all around us (chuckling).”

The participants who had good marriages with supportive spouses and who were socially active (Andy, Becky, Callie, Georgia) were generally more positive than negative and seemed to cope better and be thriving; those who had neither a supportive spouse nor an active social life seemed to coping less well and be just surviving rather than thriving.

Other Resources for Coping. The participants shared their individual coping strategies that worked to relieve the stress in their lives. Again, once the participants who had been either previously or currently not balancing well (thriving), learned to do something different by adopting additional or different coping strategies to move along the continuum from barely surviving to thriving. It was observed that the coping strategies presented by the participants were mostly unique to the individual. Two of the participants said that making crafts at home was a good coping mechanism for them (Andy and Becky); two participants stated that taking a drive while their spouse was watching the child(ren) was helpful to them (Callie and Debbie). One participant mentioned that she had some alone time that she badly needed when her husband took her daughter for a drive, and two participants mentioned going to therapy (Callie and Francine) to help them with their emotional stress.

One participant also mentioned that reading for pleasure and playing the piano and worshipping were great ways for her to de-stress (Georgia) and another (Francine) said that laughing helped her to cope with her challenging circumstances. Additionally, although Andy did not say it in words, it appeared that a good sense of humor was also an important coping

strategy for him, as he took time to relate several funny and sweet stories about his son's antics.

This also echoed Francine's coping technique of laughter, about which she said:

When it's (the crisis with her child with PIMD) all over with, I'm probably gonna break out in shingles and I'm gonna have a good cry; or I'll call my girlfriend and we'll have a good laugh. Ya know, laughter is great for us. I mean if I don't speak to her once a day, do seven chuckles, you know... I actually probably could take my life on the road (laughing, both laughing). Seriously, my girlfriends say, you probably could take that on the road. I probably could, no joke (both chuckling).

Summary

In this chapter, the findings from the lived experiences of parents of children with PIMD were discussed. The participants were described both as a group and individually. Theme One, "My Life With My Child with PIMD is Like a Roller Coaster Ride," answered the following research questions: RQ1: How does the participant describe how the experience of being a parent of a child with PIMD affects the participant's mental and emotional well-being? RQ4: How do the participants describe the specific joys and challenges that relate to their role as a parent of children with PIMD? RQ 5: How do participants describe the impact of having children with PIMD on their families and outside of family social and other interactions? Theme Two, "Balancing the Stressors: From Just Surviving to Thriving" answered the following research questions: RQ2: How do participants describe the coping strategies they have used to deal with their experiences as parents of children with PIMD? RQ3: How do participants describe their existential and spiritual understanding and perspectives regarding their children's disabilities? Chapter Five explains how the data in the study answered each research question.

The data gathered from the participants through semi-structured interviews, cognitive representations and focus groups revealed two major themes. First is the theme of the participants' experiences being like a "roller coaster" as the participants "ride" the uphill challenges and enjoy the downhill joys of being a parent of a child with PIMD. Second is the theme of "Balancing the Stressors: From Just Surviving to Thriving," which draws from data regarding the stressors or challenges faced by the participants in general terms, and gives the added essence of the continuous nature of these stressors as the participants attempt to balance meeting the needs of all their family members, including their child with PIMD and other obligations. The participants' narratives revealed that as they experienced or discovered helpful perspectives and effective ways to cope with the challenges they faced, their lives were better balanced. Those who were not keeping the right side of the scale weighted with helpful perspectives and effective coping experienced varying degrees of anxiety, depression (Isabelle, Francine, Georgia, Callie and Debbie) and sometimes relationship difficulties (Isabelle, Francine and Debbie).

In summary, all eight participants were distinct individuals with very different lives, but all shared similar experiences as the parents of children with PIMD. All the participants have had to face an uphill climb that included dealing with public ignorance, handling sometimes- intense medical situations, being their child's advocate, being in a continual grieving cycle, and experiencing loneliness, isolation, fatigue and frustration, which are specifically described in Theme One, Subtheme One as "The Uphill Climb," and generally described in in Theme Two as the left side of the scale. All those challenges produced varying levels of stress and anxiety in the participants' lives. In addition, all eight of the participants considered the coasting or downhill portion of their journey to include their child's smiles and affection, the joy of watching their

child play and enjoy simple things and times of celebration when their child achieved inch-stones.

Additionally, all eight participants had perspectives regarding their child's disabilities that were described as either helpful, counteracting the weight of the stressors, or not helpful. In addition to the consideration of the participants' perspectives, each participant had to figure out ways to balance the challenges of their lives as parents of children with PIMD with individual ways of coping, from screaming when alone (Andy and Callie) to exercising (Callie, Elizabeth and Isabelle), to reading (Georgia), to playing the piano and worshiping God (Georgia) and most importantly to all eight, relying on spousal support (six of the eight) or other family support (two of the eight) as well as outside-of-family social support. All eight of the participants loved their child with PIMD deeply and had found ways to "just do it" (Debbie), some having found great joy in caring for their child with PIMD (Andy, Becky, Callie, Debbie, Francine, Georgia) and able to employ effective coping strategies, and some struggling to survive emotionally at times (Isabelle Callie, Debbie, Elizabeth, Francine and Isabelle) with the many challenges that were part of their lived experiences as the parents of children with PIMD. Chapter Five describes the results of the study in terms of the specific ways in which the data addressed each research question as well as the implications of the study.

CHAPTER FIVE: CONCLUSION

Overview

The purpose of this study was to describe the lived experiences of parents of children with PIMD in Central Virginia. This chapter consists of a summary of the findings, a discussion, implications, delimitations and limitations and topics for future study. Additionally, this chapter describes how the results of the study fit into the existing research, how the findings can be helpful to stakeholders and how the study confirms or disputes previous findings in the extant literature. Lastly, this chapter contains topics for future study based on questions that were evoked while conducting the study.

Summary of Findings

This phenomenological investigation into the lived experiences and coping strategies of parents of children with PIMD revealed two major themes, “My Life with My Child with PIMD is Like a Roller Coaster” and “Balancing the Stressors: From Just Surviving to Thriving.” The contents of both themes thoroughly answered the central research question as well as the four additional research questions. The results of this study also exposed a number of areas that are open for future research.

Research Questions Addressed

The primary research question of this study was: How do parents of children with PIMD in Central Virginia describe their experiences as a parent of children with PIMD? The participants stated that they faced a higher number of and perhaps more intense stressors than parents of TD children such as chronic medical problems and around-the-clock caregiving. As Callie shared, children with PIMD need constant supervision and care, need assistance with all daily self-care tasks and typically need frequent medical visits. Additionally, children with PIMD

sometimes require surgeries and hospitalizations, and often experience seizures, which as Francine, Andy and Becky pointed out, can be life-threatening. Each of these aspects of caring for a child with PIMD adds a certain amount of labor as well as stress, anxiety or worry to the parent's life, and as Callie stated, can put her "on the verge of tears at any time."

Research Question One. How does the participant describe how the experience of being a parent of a child with PIMD affects the participant's mental and emotional well-being?

This research question regarding the emotional and psychological effects of having a child with PIMD was answered by the participants' descriptions in the several ways, mostly in the descriptions of the participants' "Uphill" and "Downhill" rides of Theme One. Theme Two, "Balancing the Stressors: From Just Surviving to Thriving" also contributed data to address this question in both Subtheme One as it described the helpful perspectives that contribute to or detract from "Helpful Perspectives," and Subtheme Two, which described the participants' effective "Coping Factors" related to their mental and emotional well-being. Four of the participants (Becky, Debbie, Georgia and Isabelle) described their experiences as an emotional roller-coaster due to the many downhill rides of, as Callie stated, "good seasons" and the uphill rides of "difficult seasons," all the while knowing that whichever season she was in, the other one was just around the corner.

Others, including Andy, Elizabeth and Francine, described the same concept a bit differently, saying that they had their happy times and their sad times. All eight of the participants stated that their sad times were mostly related to their children's medical crises (including seizures and surgeries) or behavioral problems (Debbie and Isabelle) but that their happy times were related to the joy their child brings them just with his or her smile, affection, play, seeing them reach an inch-stone, or their child's being funny.

Some of the participants (Debbie, Elizabeth, Francine, Georgia and Isabelle) mentioned depression or symptoms of depression, which were investigated through interview questions 11, 12 and 13 (Appendix E). Participants Becky, Callie, Debbie, Elizabeth, Francine and Georgia also talked about the sadness and grief that comes when they think about the milestones their child will never accomplish or the experiences their child will likely never experience that TD children normally experience. In the focus group, Elizabeth shared:

First, it was the diagnosis and prognosis of what her life is expected to be, then – the feeling of loss for “life stages” that will not happen... she will never experience a close friendship, play a sport, high school graduation, the excitement and independence of driving a car, a romance, a wedding or children.

All eight of the participants became tearful at different times throughout the interviews. Becky, Debbie, Isabelle and Francine openly wept at different times in the interviews. Most of the participants, excluding Andy, expressed their sadness or grief that accompanied missed milestones or missed experiences. It was also interesting to note that Callie derived most of her joy from her two TD children. She explained that after having been disappointed at her first child’s (with PIMD) not being able to meet normal milestones, when her two younger children reach those milestones, she becomes ecstatic.

Andy, Becky, Callie, Debbie and Francine were perhaps the most emotionally expressive, becoming tearful when discussing how much they love their child with PIMD and how much joy he or she gives them. All the parents described the intense joy of any positive accomplishment and celebrated what both Callie and Georgia termed, a very small inch-stone, such as picking up a spoon or saying a word after years of hoping, working and waiting for these things to happen. Francine has large celebrations whenever her daughter with PIMD has a “big birthday” such as

her 16th or 21st. They celebrated, as Debbie mentioned, just that their child had made it through another year. As Debbie, Elizabeth and Isabelle described, having a child with PIMD changes how you view life, “the little things” become more important and are not taken for granted.

The participants with children who were more medically fragile and could not often go outside the home to socialize expressed difficulties with anxiety and depression more than the others (Callie, Debbie, Elizabeth, Francine, Isabelle). Several of them were comfortable enough with me to share that they go to psychotherapy (Callie, Debbie and Francine) and/or are taking anti-depressant or anti-anxiolytic medication (Callie, Debbie, Francine and Georgia). In addition, Callie stated, “You know, I just need a vacation from my brain, not from life really, just I want my brain to shut up and stop worrying me and stop stressing me out all the time.”

The participants who seemed to have the most emotional struggles were Isabelle and Debbie, both of whom mentioned guilt and self-blame regarding their role as the mother of a child with PIMD as a reality in their lives. The only participant who seemed to openly express wishful thinking was Isabelle, who was also the participant who had been deeply depressed and suicidal at one time and who stated that she would love it if her child were TD and able to have “normal” experiences like other children.

Research Question Two. How do participants describe the coping strategies they have used to deal with their experiences as parents of children with PIMD?

This research question is primarily answered in Theme Two, “Balancing the Stressors: From Just Surviving to Thriving,” specifically in Subtheme Two: “Coping Factors and Strategies.” All the participants referred to feeling stressed, anxious, worried or depressed due to their role as a parent of a child with PIMD. Andy, Callie and Isabelle described times of frustration, anxiety or sadness in which they just wanted to scream or cry but would usually find

another way to cope. Becky said that just being with her family was a way of coping; Francine mentioned that she would just “break out in shingles again and cry.” Andy said that he watched television and enjoyed his son. (Andy also had a good sense of humor). Callie said that when things were extremely difficult to handle, she would exercise, go for a drive and cry or scream or just drive. Francine, Becky, Callie, Debbie and Elizabeth stated that getting out with girlfriends was an important way for them to de-stress.

Research Question Three. How do the participants describe their existential understanding of and spiritual perspectives regarding their children’s disabilities?

This research question was answered by Theme Two: “Balancing the Stressors: From Just Surviving to Thriving,” more specifically in Subtheme One: “Helpful Perspectives.” Courtney et al. (2018) asserted that parental perspective regarding a child’s disability influences family outcomes. In addition, Hassall, Rose and McDonald (2005) asserted that the parents’ stress levels were affected by their cognitions regarding their children’s disabilities, including cognitions regarding parental locus of control, parenting satisfaction and child behavior. Although the interview questions in this study (interview questions number two, five, 12, 15 and 16) dealt with coping, spiritual support and parental perspective, the participants did not provide a plethora of data on their existential understanding or spiritual perspectives. The questions seemed to be avoided, perhaps because they were not well worded (limitation of the study) or at least not understood well enough for participants to answer in depth. However, all the participants expressed their existential perspective or philosophy regarding their child’s condition in subtle ways. Andy, Becky, Debbie, Francine and Georgia stated that their child is just the way he or she is supposed to be, and that other than seizures or pain, they would not want their child to be any different. Each participant in some way expressed that their lives had been

changed by their experiences, having made them “a better person,” changing who they were and making them less selfish. Debbie stated that her life as the mother of a child with PIMD, “has changed everything about me.”

Callie, Elizabeth and Georgia stated that it would be great if their children were able to do the things that they cannot do now due their disabilities, but they love their daughters the way they are. Isabelle emotionally expressed how she longed to see her son do things that TD children could do, such as drive, have a spouse, or have children. However, Andy, Becky, Debbie, Francine, Georgia said that they will always have “their baby” with them and choose to consider the fact that their children will never leave home a blessing.

Several participants (Andy, Becky, Elizabeth, Francine) said that their child with PIMD has made them a better person. Francine described her daughter and her own experience, saying her daughter with PIMD is “loving, kind, she’s just an angel from heaven (crying hard). She makes me be a better person.”

All the participants were involved in continuous research regarding their child’s condition because new information can be discovered. Andy, Becky, Callie, Georgia and Debbie conveyed that although society is becoming more educated and more comfortable with children with disabilities, they sometimes are disappointed or even angered (Andy) by public reactions to their child’s behaviors in public.

Research Question Four. How do participants describe the impact of having children with PIMD on their families and outside of family social and other interactions?

The current study answered Research Question Four primarily in the context of Theme One, “My Life with My Child with PIMD is Like a Roller Coaster Ride,” Subtheme One, the “Uphill” portion of the roller coaster ride, which included the challenges of family and other

social interaction for participants. This research question is also answered in Theme Two, “Balancing the Stressors: From Just Surviving to Thriving,” and specifically Subtheme One, under “Helpful Perspectives,” as well as Subtheme Two, under “Coping Factors,” where the importance of spousal and social support was described by the participants.

Courtney et al. (2018) asserted that parental perspective regarding a child’s disability influences family outcomes. Research by Dos Santos and Pereira (2016) found that isolation, self-blame, and wishful thinking were often associated with negative outcomes in parents and families of children with ID. The findings in the current study confirmed Dos Santos and Pereira’s (2016) results; Becky, Callie, Debbie, Elizabeth, Georgia and Isabelle made overt references to isolation or loneliness due to their child’s condition. (As previously mentioned, the isolation factor is due to the limited opportunities for social engagement associated with the parents’ care for their child with PIMD.)

Andy did not allow his son’s condition to hinder his or his family’s social involvement and gave many examples of social events that they attended together as a family. Callie’s social approach was a combination of times of social isolation due to her daughter’s condition, times of full family participation and times of family- minus-her- daughter with PIMD’s participation. Callie stated that when the family participated without her daughter with PIMD, she missed her a lot and sometimes felt guilty for leaving her out of the family activity.

It was evident that the study’s results confirmed conclusions by Dos Santos and Pereira (2016) who asserted that parents of children with ID experience greater stress than parents of TD children and that such stress can foster changes in family dynamics and coping strategies. Based on their study of siblings of children with PIMD, Luijkx, et al. (2017) asserted that siblings of children with PIMD had both positive and negative experiences with their affected

sibling, and that having a sibling with PIMD evoked both positive and negative feelings toward their affected sibling. Additionally, Luijkx, et al. (2017) described difficult and awkward interactions between the child with PIMD, the accompanying family members and the general public or school friends.

The siblings of one daughter with PIMD seemed to have less interaction with their TD siblings once the TD siblings had left home, which the participant (Elizabeth) attributed to the child with PIMD's inability to communicate or socialize normally. Debbie shared that she had lost relationships with two of her sisters due to her son's PIMD. Neither Andy nor Becky spoke about any distancing or changes in their family relationships; their son with PIMD is quite a bit younger than his half-siblings. In the focus group, Andy stated that his relationships with his two other biological children was a nine on a scale of one to ten, with one being very poor and ten indicating excellent. In the focus group, Elizabeth also shared that her relationships with her other three (TD) children were very good.

On the other hand, regarding sibling relationships, it was noted that Callie, the mother of the 6-year-old with PIMD had not (yet) witnessed any relationship changes because her daughter with PIMD was the oldest, and the other two children are very young. In addition, Francine stated that her grown children still have regular contact with their sister with PIMD and that they "adore her." Georgia does not have other children but mentioned feeling on the outside of her extended family at times due to their daughter's condition.

Wilder and Granlund (2015) studied the effects of having children with PIMD on family life and found that having children with PIMD affects the entire family's schedule, interactions and social dynamics. Based on their study of siblings of children with PIMD, Luijkx, et al. (2017) asserted that siblings of children with PIMD had both positive and negative experiences

with their affected sibling, and that having a sibling with PIMD evoked both positive and negative feelings toward their affected sibling.

Most of the participants (except Andy and Becky) described how difficult it was to attend a family gathering, adding that even when their child was well enough to attend, sometimes they could not participate in the fun because their full attention was on their child with PIMD. Again, with Callie's daughter being only six years old, the social limitations may not have affected her as much as the parents of older children with PIMD. Elizabeth stated that it was more stressful to go to church and worry about how a helper might unknowingly harm her child with PIMD than it was to stay at home and "attend" church on television. Andy added that his son went everywhere with him, and that if his son could not go, then he would not go either.

Andy, Becky, Callie, Debbie, Elizabeth, Francine and Isabelle said that taking care of their child with PIMD made social interaction challenging in several ways. First, strangers in public sometimes would stare or ignore the child with PIMD, which either angered or frustrated parents and made them less likely to expose themselves, their family or their child with PIMD to the social awkwardness of those moments (Andy, Becky, Callie, Debbie, Francine, Isabelle).

Contrary to the above negative social and both negative and positive family impact that having a child with PIMD may have, Becky and Georgia stated that when their child with PIMD was born, people in the family, neighborhood and special needs community rallied around them for support. Andy, Becky and Georgia mentioned the positive impact that the online support group for their child's specific disorder had been to them. In addition, Andy stated that his son's condition had probably saved his marriage; Georgia and Elizabeth stated that their children's condition had brought their marriages closer together. It is notable that only one participant

(Isabelle) felt that her stepchild may be closer to her child with PIMD than with other stepsiblings.

Discussion

This section provides an explanation of the ways in which the current study confirms and adds to the pre-study literature regarding the emotional, familial and social challenges related to the participants' lives as parents of children with PIMD as well as the coping factors related to dealing with those challenges.

Confirmation of Previous Empirical Literature

This study on the lived experiences of parents of children with PIMD confirmed findings from previous literature regarding the higher levels of stress they experience (compared to parents of TD children), the importance of spousal and social support, the negative effects of social isolation and the difficulty of having a non-verbal child. Freedman et al. (2012) stated that in a family with children with PIMD or any DD, family functioning can be negatively affected, including strained marital relationships (Freedman, Kalb, Zablotzky, & Stuart, 2012), sibling maladjustment (Manor-Binyamini & Abu-Ajjaj, 2012), parental inefficiency (Karst & Van Hecke, 2012) and increased financial burden (Parish, Rose, Swaine, Dababnah, & Mayra, 2012). Such challenges can lead to increased stress for parents (Minjarez, Mercier, Williams, & Hardan, 2013).

Stress and Emotional Effects

Caicedo (2014) reported that mentally, caregivers (usually parents) of special needs children could be frustrated, angry and anxious and often felt hopeless and helpless. This study confirmed Caicedo's (2014) findings. As previously stated, most of the participants experienced

anxiety and frustration. Two participants commented that they sometimes just needed to scream, and one said she felt like she was “crawling out of her skin.”

Research by Fianco et al. (2015) described the negative consequences on the emotional well-being of parents of children with PIMD. Additionally, Burke and Hodapp (2014) reported that parents of children with ID and DD have high levels of stress, and Luijkx, et al. (2017) asserted that parents of children with PIMD face unique and sometimes grave challenges and stressors (Luijkx, et al., 2017). As previously- stated and cited, parents of children with disabilities typically face extraordinary challenges and stressors (Luijkx, Putten & Vlaskamp, 2017). The participants in this study confirmed Luijkx, Putten and Vlaskamp’s (2017) findings, that that the stressors of serious medical situations, including round-the-clock attention and its accompanying fatigue for the parents, as well as their children’s seizures, frequent illnesses and hospitalizations are related to the anxiety or depression they have experienced.

The current study confirmed that the additional stressors faced by the participants led to psychological and emotional distress but that effective coping factors (described by Gloria & Steinhardt’s, 2016) study, are related to decreases in symptoms of depression and anxiety. This study also confirmed findings by White and Hastings (2008) that social support is inversely related to anxiety and depression in parents of children with ID. The current study supported those assertions, expanding them by the finding that this phenomenon is true for parents of children with PIMD as well, just as it was for parents of children with ID.

Importance of Spousal and Social Support

As previously stated, researchers Dos Santos and Pereira (2016) found that parents’ education about their child’s disability, having social and professional support for their child’s condition and having unity with their spouse were important to parents of children with ID. The

findings of this study confirm those findings for parents of children with PIMD: all participants suggested that any parent with a newly diagnosed child with ID seek out information regarding the disability and services to assist them as soon as possible. In addition, each participant validated the importance of social and spousal support (when present).

Negative Effects of Isolation

Luijkx, et al. (2017) described difficult and awkward interactions between the child with PIMD, the accompanying family members and the general public, or school friends which caused the family discomfort. Andy, Becky, Debbie, Francine and Georgia confirmed Luijkx et al.'s (2017) assertion. In addition, the current study also confirmed Dos Santos and Pereira's (2016) assertion that parents of children with disabilities often feel isolated, which can lead to negative emotional outcomes. Debbie, Elizabeth and Isabelle revealed their experiences of isolation as parents of children with PIMD and described corresponding negative emotional responses. No link was specifically made between these participants' experience of isolation and their corresponding levels of anxiety and depression. However, it was interesting to note that for those participants who referred to isolation more than the others also made less references to or comments regarding the joys of their experiences.

Strain on Family Relationships

Andy, Becky, Callie, Debbie, Elizabeth, Francine and Isabelle said that taking care of their child with PIMD made social interaction challenging in several ways. First, strangers in public sometimes would stare or ignore the child with PIMD, which either angered or frustrated parents and made them less likely to expose themselves, their family or their child with PIMD to the social awkwardness of those moments (Andy, Becky, Callie, Debbie, Francine, Isabelle).

Seliner et al. (2016) stated that some parents may experience their child's initial diagnosis as the most challenging of their experiences as the parent of a child with PIMD and that others may feel that the hospitalizations of their child have been the most challenging. As noted in Chapter Four, participants in this study confirmed that parents of children with PIMD do experience chronic grief, missed milestones (Patrick-Ott, & Ladd, 2010), social stigma (Park & Seo, 2016), or social isolation (O'Byrne & Muldoon, 2019) among their most challenging experiences.

Effects of the Child's Medical Complexities

As previously stated, the incidence of comorbid medical diagnoses with ID was 90.6% in 2003 (Arvio & Sillanpaa, 2003). The medical aspect of children with PIMD requires that parents take their child to frequent doctor visits and experience their child's sometimes multiple surgeries and associated hospitalizations. This study confirmed that these occurrences, as mentioned by Zebracki (2018) and Seliner et al. (2016) have negative effects on the emotional and psychological well-being of the parents and the children with PIMD.

Another study by Jansen, van der Putten and Vlaskamp (2017) investigated what parents of children with PIMD find important in their interactions with medical support personnel, and found that most parents are satisfied with the medical support provided for their children, but that a considerable minority said that they did not receive the support that they consider important. This study confirms those findings: Andy, Becky, Debbie stated that they had had mostly positive experiences with medical personnel. Elizabeth, Callie, Francine and Georgia mentioned some negative experiences with medical personnel who helped care for their child with PIMD. Both Elizabeth and Isabelle spoke about distrust for medical personnel based on their negative experiences.

Expansion of the Literature

Geuze and Goossensen's (2018) narrative review of literature related to parents of children with normal lifespan-threatening disabilities is related to the current study of parents of children with PIMD because the participants in both studies share the characteristics of having children with life-threatening disabilities. In both the Geuze and Goossensen (2018) study and the current study, as well as in studies of parents of children with less profound disabilities, there is an overlap of effects on parents of the increased stress and negative emotional, psychological and relational effects on the family. However, Geuze and Goossensen's (2018) study did not expose *specific reasons* for the increase in participant stress and the resulting negative effects on the families of children with PIMD.

The current study fills this information gap in the sense that it gives specific reasons for the additional stress and the resulting negative effects of that stress. For the participants in the current study, these reasons include the negative emotional effects of the child with PIMD's seizure disorders (which could be a subset of life-threatening disorders) and aggressive behaviors which are related to parental anxiety (Andy, Becky, Callie, Debbie, Francine). In addition, the stress caused by the participants' descriptions of their children's emergent and chronic medical issues and their children's experiences of abuse were not found in the previous literature as specifically associated with parents of children with PIMD or even of parents with ID.

Stress Related to Seizure Disorders of Child with PIMD

What was not found in the pre-existing literature regarding children with ID was the specific, intense challenge of seizure disorders and the corresponding mental anguish that they caused for the participants in this study (Andy, Becky, Callie, Elizabeth and Francine). Any association between PIMD with comorbid epilepsy and the added emotional anguish associated

from both conditions has not been empirically established. Andy, Callie, Debbie, Francine and Becky stated that their child's seizures were the most emotionally difficult part of their child's disabilities and illnesses.

Aggressive Behaviors

Another observation from this study is that in addition to the global diagnosis of PIMD, some participants (Debbie and Isabelle) referred to the difficulty of physically and emotionally managing their child's aggressive behaviors. Although previous research did discuss the presence of difficult behaviors in some children with disabilities, it did not ascribe the characteristic of aggressive behaviors to children with *PIMD*, Debbie and Isabelle's descriptions of their experiences confirmed White and Hastings's (2008) findings that the aggressive behaviors of children with *ID* affect the parents' emotional well-being. Hill et al. (2013) stated that approximately 25% of children with ASD exhibit aggressive behaviors. Since individuals with ID often have many characteristics of and sometimes a secondary diagnosis of ASD, they too may exhibit aggressive behaviors (Dekker, Koot, Ende & Verhulst, 2002), which cause the parents and other family members added stress. Research has been found regarding the existence of challenging behaviors in individuals with PIMD (Poppes, Van der Putten, & Vlaskamp, 2010), but not the effects of those behaviors on the parents.

Difficulty of Finding Competent Respite Care

Another area of new findings was the phenomenon of parental stress caused by the difficulty of finding competent and available respite care for their child with PIMD. Realizing that for many parents of children with PIMD, their job requires round-the-clock attention every day of the year, which means that they need for someone to give them a break from their caregiving from time to time. In the world of disability, respite care is an oft-discussed topic, and

one which arose during the current study. Andy, Callie, Debbie, Elizabeth, Francine and Isabelle stated that it was difficult to find adequate respite care for them as they cared for their child with PIMD. Elizabeth shared that she had a lot of difficulties finding adequate, trustworthy support people to stay with her daughter so that she (Elizabeth) could get out of the house for social purposes. Previous studies discuss the isolation sometimes experienced by parents of children with disabilities (Dos Santos & Pereira, 2016; He, 2017), but do not mention that difficulty of finding competent and available respite workers contributes to their social isolation and its negative emotional repercussions.

Abuse of the Child by Other Care Providers

Flynn (2019) asserts that individuals with disabilities are at higher risk for various types of abuse, and although no literature specifically addressed abuse perpetrated on children with PIMD, one participant (Isabelle) in the study was especially angered, upset and distressed by the discovery of abusive treatment of her son child by an adult who was supposed to be caring for her son.

Effects on Sibling Relationships

Previous studies regarding the effects of a sibling with PIMD on inter-sibling relationships and parent-child relationships revealed that TD siblings of children with PIMD experience both positive and negative feelings toward their disabled sibling. In the current study, participants who had other children in addition to the child with PIMD described a strong positive attachment and no negative feelings between the TD child(ren) and the child with PIMD. For example, Francine related that her other children were involved and adored her daughter with PIMD and knew exactly how to take care of her. In addition, Isabelle related a story about her young daughter (TD) who felt terribly guilty for being embarrassed about her

brother with PIMD in public and said she never wanted to ever feel that way again and in tears apologized to her brother.

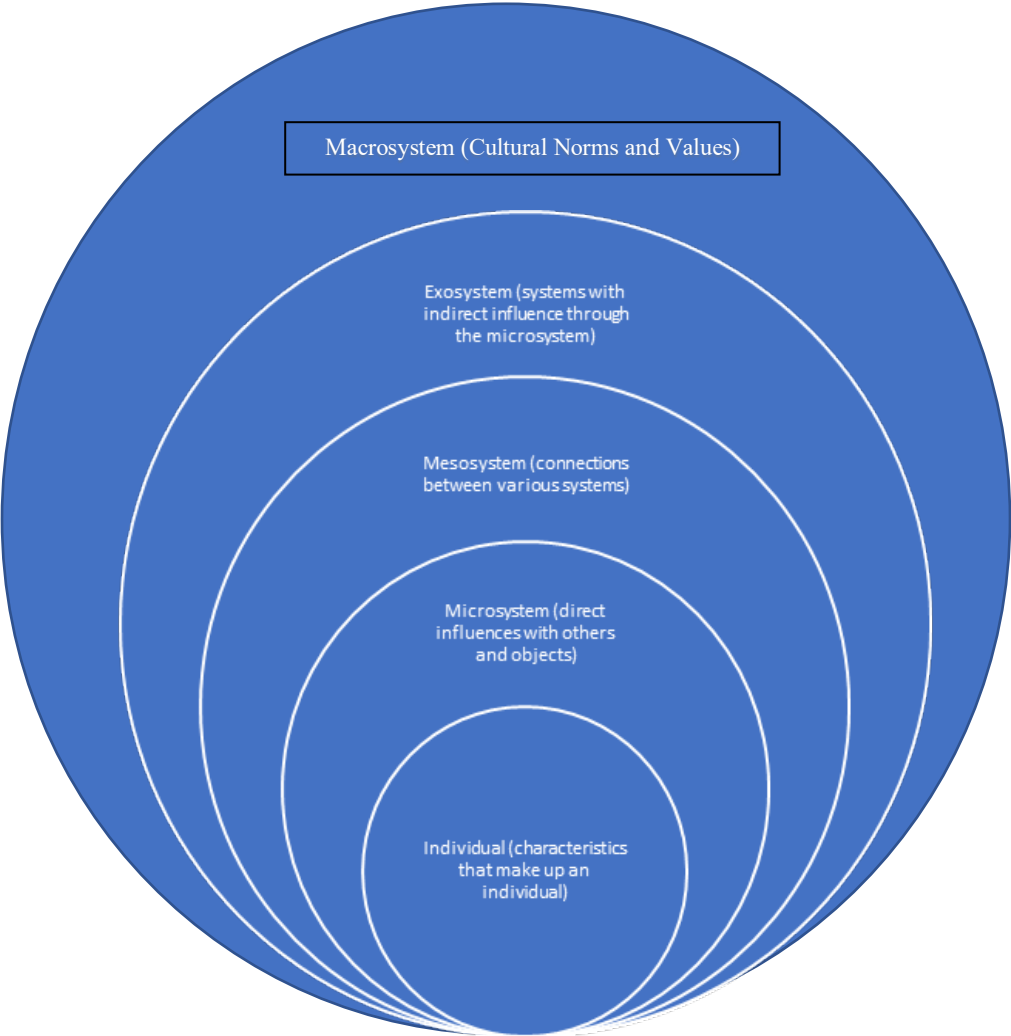
There were very few negative sibling-sibling interactions or feelings mentioned by the participants, although no specific question about negative interactions was asked. In the case of Andy, Becky, Elizabeth and Francine, whose other children are no longer living at home, the quantity of interactions decreased significantly once the adult TD child(ren) left the home. Again, however, no negative interactions or feelings were obvious from the data gathered for this study, in contrast to previous studies.

Theoretical Confirmation

Bronfenbrenner's bioecological theory of human development is represented in Figure 4 (Lichtenberg, 2012) and is further expanded by Vélez-Agosto, et al. (2017), depicted in Figure 5. The second theory upon which this study was based is family systems theory (White & Bregman, 2011) as described by Rosa and Tudge (2015), which states that a person is influenced by the microsystem, mesosystem exosystem, and macrosystem as well as by the proximal processes or systematic interactions between individuals and their environments. The two theories (Velez-Agosto et al.'s (2017) expanded bioecological theory and family systems theory (Rosa & Tudge, 2015) together explain that the culture within which the participants live informs their interpretation of the individual and social practices of their social contexts. For example, the Caucasian, South-eastern, Central Virginian, North American, middle-class, European-based culture of the participants interprets, at least to a degree, the way in which they practice their version of family life, work life, church life, school life, etc.

Figure 8.

Generalized Depiction of Bronfenbrenner's Bioecological Model

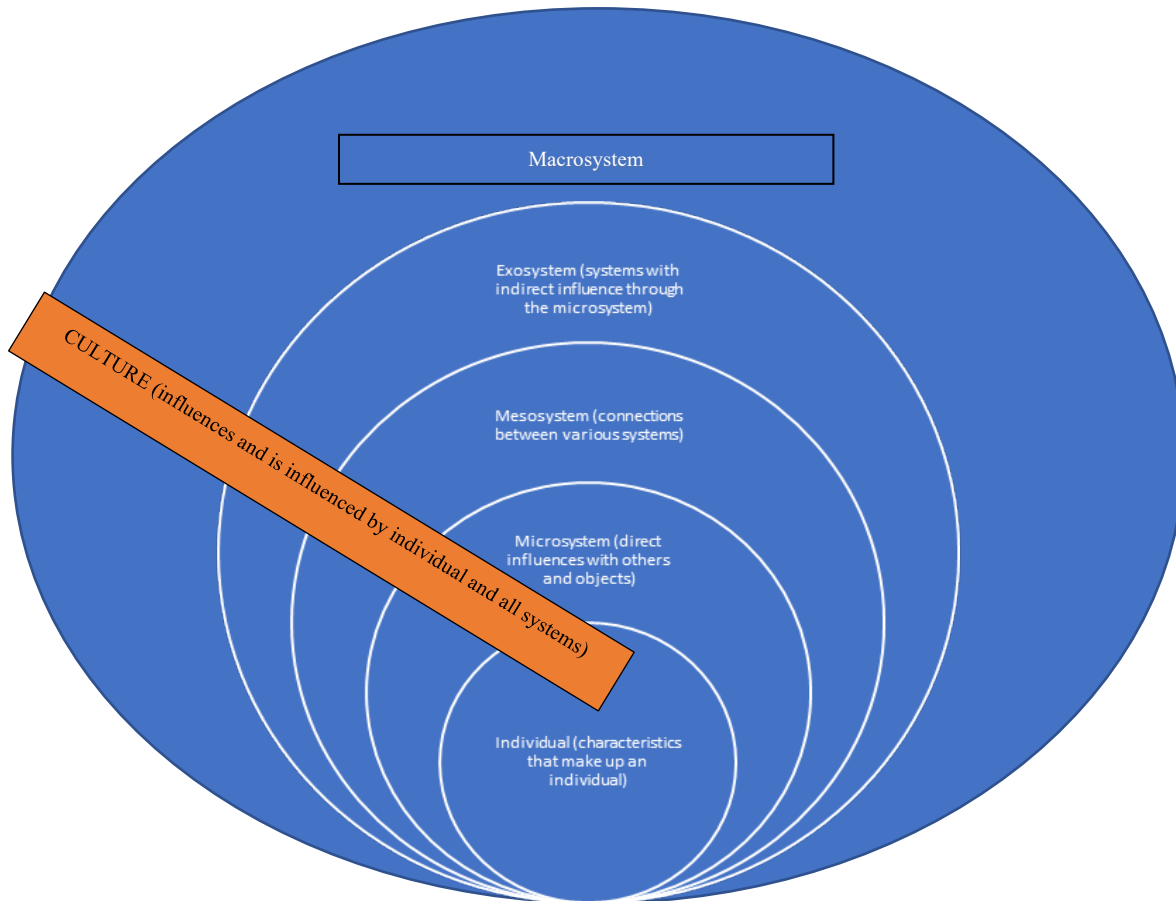


(Lichtenberger, 2018).

The expanded bioecological model (Velez-Agosto et al., 2017) states that culture defines and organizes microsystems, thus becoming central in human development. In the current study, the culture of the participants is consistent in most areas, meaning that the race, ethnicity, language, customs and practices of the participants were similar. Since culture is comprised of social communities such as families, neighborhoods, schools, churches, etc., the practices of those social communities are interpreted through the culture's lens of communication (Velez-Agosto et al., 2017). In large part, individual development within the microsystem is operationalized by a person's culture (Velez-Agosto et al., 2017); social practices are further operationalized by culture. In other words, the influences of an individual's culture and social practices are bi-directional.

Figure 9.

Depiction of Velez- Agosto's Expansion of Bronfenbrenner's Bioecological Theory



In the current study, all the participants were affected by their interactions with each of the systems- micro, meso, exo and macro. Additionally, the participants' shared culture both affected and was affected by social systems. In Becky's case, the cultural aspect of her social support system, such as church and her employment, affected the way in which she interpreted and interacted with her son with PIMD and her husband, and vice versa. In Georgia's case, her husband's support, church support, work support and online support group affected her interpretation of her child's disabilities and then her interpretation (and expression of her interpretation) affected each of those social entities as well. Each participant's description of their experiences supported Velez-Agosto et al.'s (2017) expanded bioecological theory.

Theoretical Expansion

An additional consideration that the two above theories does not include is the influence of an individual's philosophical and spiritual beliefs and experiences, which, based on this study, also influence the culture and then, in accordance with the theories above, affect the way people behave within their micro, meso and macro systems. For example, Andy, Becky, Debbie and Georgia expressed a Christian faith, and are active in their spiritual practices such as prayer and attending church. In Andy, Becky and Georgia's cases, the influence of their spirituality on their lives has been profound as they then influence others around the world whose children have the same syndrome as their child has through their online support group, thus extending their influence through the meso and macro systems.

Andy proclaimed that his son with PIMD is perfect just the way he is. Debbie agreed, saying that if her son were different, he would not be himself, and he loves himself. When asked how she coped with medical emergencies, Becky responded, "pray, pray, pray." These responses by these participants revealed their acceptance of their inability to change their children as well as a dependence on God to help them care for their children in every situation. Even on an individual basis, the participants' spiritual belief systems, within the context of their micro, meso and macro systems, had an interwoven influence, as was described by Georgia:

So, it's just been in an odd way to say, a blessing... even people who are not a part of her special- needs community, just our church- so supportive and what can we do, how is she, how can we pray, what can we do... So, ... it's not a life I would have ever wished, but yet at the same time, I don't know that it's one that I would change.

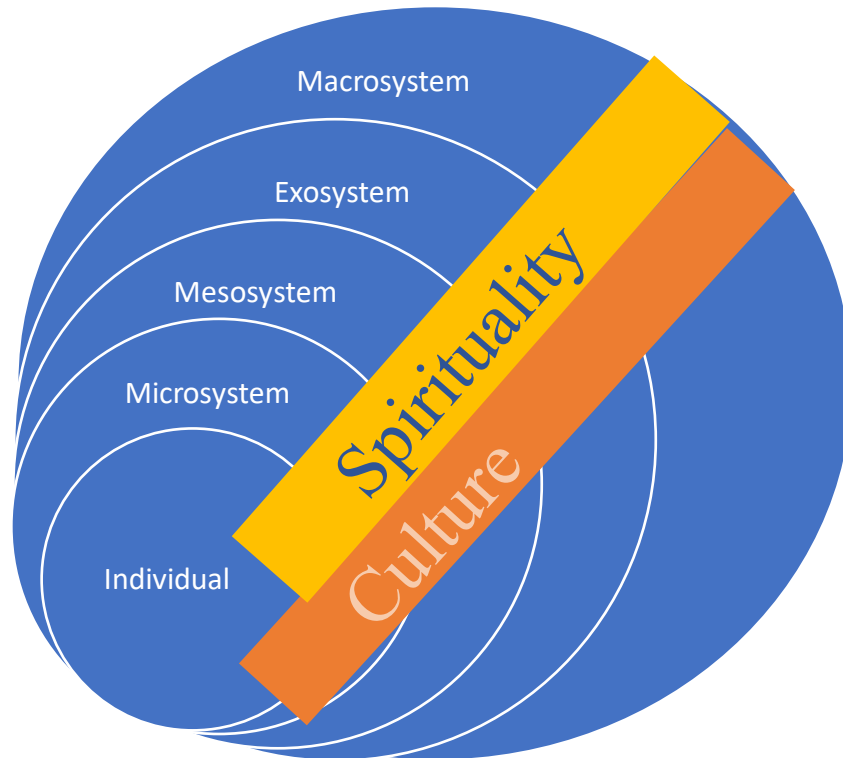
Another example is that of Isabelle, whose spiritual epiphany has brought her to a perspective of trusting God amid the difficulties or “uphill climbs” of being the mother of a son with PIMD. In her cognitive representation, Isabelle described:

You’re going to get it (my experience) through the lens of where I am right now, so, first of all, us talking but also where I am spiritually right now. So, the very first thing that I drew was a heart and then right after that were the words family, love and hope. But then I went back to my heart and I turned it into a broken heart because along with the hope there was a whole lot of hurt... I made like pretend stitches, but those stitches are faith, God, strength and provision because where God has me right now in this season, for the last, probably four months... (she listened to) a testimony, and one thing that they were talking about, it had nothing related to me, but they were talking about God providing manna. Of course, His people were complaining, complaining, complaining, but every day, God was giving them enough provisions to get them through the day, yet it was never quite enough, right? They always wanted more. Then some point in time, even when they had more, it still wasn’t enough. That seems to be the story all along. But that hit me the hardest because I was able to look back, I think it was actually a pinnacle in my spiritual life, I was able to look back and I could see that even on my most difficult days, and even on the days that I didn’t finish out very prettily... There was definitely no mom of the year award being won for that particular day. I still was able to make it through the day, and there was always a new day, because God had gotten me through. He had given me enough provision to make it through the day. Some days He gives me a little bit more than others because some days I need more than others. So, those stitches are kind of like His salve.... to heal that broken heart or mind, knowing that through it

all, He's got us... He's like, hey, you are going to be in the deep waters, but you're not gonna drown, and you're gonna walk through the fire, but you're not gonna be consumed. I am right there. And I really clung to that verse. Because it is so true, I have been in so many times where I thought this is it, I'm done, I can't take this anymore, but yet, here I still am.

Isabelle's spiritual experience changed the way she perceived her past and therefore the way she interprets and will interpret experiences currently and in her future. This change in her spiritual perspective will, according to family systems and bio-ecological theory, effect change on the micro, meso and macro systems in which she lives. The testimony from someone in the meso-system gave her hope, and her hope; her faith and her God gave her a different perspective, which affected her lived experiences. This observation is confirmed in a psycho-spirituality study by Tassell-Matamua and Frewin (2019), it was found that there was a relationship between positive spiritual growth and meaning in life and exceptional human experiences. In conclusion, the addition to the bio-ecological theory and the family systems theory might be termed a spiritual-bio-ecological family systems theory, which is depicted in Figure 6, and considers the bi-directional influence of an individual's spirituality and all the systems' influences of spirituality on the individual.

Figure 10

Spiritual-Bio-Ecological Family Systems Theory

While it can be argued that spirituality is a subset of culture, a Christian-based, biblical perspective would contradict such an argument, as every individual has both the privilege and opportunity to seek God and know Him through Jesus Christ. Once a person is changed by the knowledge of salvation through Jesus Christ, his or her life is affected, which in turn affects the micro, meso, exo and macro systems in which the individual lives. Likewise, entering the concentric circles (Figure 10) from the outside and moving toward the inside, the macrosystem, if it supports biblical truth and gives opportunity for individuals to embrace faith in Christ, will make it more likely that the individual will be influenced by the presence of others from the Christian faith within their macro, meso, exo and microsystems. Thus, this new model that includes the influence of both culture and spirituality in addition to traditional family systems

and the expanded bioecological model (Velez- Agosto et al., 2017), adds an important theoretical distinction.

Implications

The implications of the current study permeate the theories upon which the study was based as well as the pre-study empirical findings and practical applications. All three types of implications are described below.

Theoretical Implications

Based on the new model above, which includes Bronfenbrenner's bioecological theory of human development (expanded by Vélez-Agosto, et al, 2017) and White and Bregman's (2011) family systems theory, as well as the spiritual considerations described above, future research will need to consider the individual spiritual experiences and beliefs of the participants in studies regarding an individual in the context of a family or other social entity as well as the effects of the macro, meso and micro systems' influences on the spirituality of the participants. In this way, researchers will have a richer understanding of the bi-directional influences of spirituality on micro, meso and macro systems. The spiritual considerations in such research is predicted to reveal very interesting and possibly novel outcomes.

Empirical Implications

The current study's empirical findings, based on the two themes discussed in Chapter Four, inform the fields of psychology, pastoral care, sociology, medicine, mental health, ID and specifically the smaller field of science specifically related to PIMD. The implications of those findings are expected to affect the way in which workers in those fields prepare, train and carry out their services to parents of children with PIMD. The following section regarding practical implications will further address these implications.

Practical Implications

The implications of this study reach into many facets of society, including all who serve families and specifically all who serve families with children with PIMD. Those areas of service would include those who work in the fields of social work, medical and mental health work, spiritual care, education and public policy. The implications for each type of stakeholder associated with families with children with PIMD follow.

Implications for the Fields of Family Resources and Church Care

Often, when children are born with disabilities, family members, church members and pastors are unsure of how to help the family adapt to the newborn child with disabilities or the child who is newly diagnosed with ID. As was evident from comments made by Andy, Callie, Elizabeth, Francine, Georgia and Isabelle, parents of children with PIMD need social support and not social stigma or isolation as they embark on a journey with a child with disabilities for which they are not prepared. Andy, Becky, Debbie, Georgia stated that their church had provided an important part of the social and spiritual support they needed. Additionally, regarding social stigma, Andy related that he would much rather that people ask him questions about his son's condition than to ignore the child and the family. He said:

We've had people come up and say, "hey, just what is wrong" and I'll gladly tell you, gladly. There's very little that I don't know about his Syndrome and L---(his other disability) and I could keep you there for hours telling you about it and enjoy every minute of it.

Isabelle added:

Sometimes it's just that people are just ignorant. I'm gonna be honest with you. You have a child with special needs, and they're just waving, and people don't even wave back, or I mean, that's so, I mean, it's a kid. I don't care. It's a child.

Based on both the literature and the current study, parents and families of children with PIMD need support if they are to navigate their journey well. This study informs those who work with families in the context of churches and other social organizations regarding the needs of the parents of children with PIMD.

Implications for the Fields of Psychology, Sociology and Education

Those who study psychology and sociology can benefit from the findings in the current study as well. While additional clinical research is needed in these fields to improve the well-being of parents and families of children with PIMD, based on the current findings, psychologists must be attuned to the toll that the emotional roller coaster takes on these families. In addition, social workers, human services workers and educators in higher education will be able to glean from the current findings and include the empirical and theoretical implications related to this study in their services and instruction, to increase sensitivity to and consideration of the difficulties and needs of parents of children with PIMD.

Implications for the Medical and Mental Health Fields

As was presented in Chapter Four, medical workers, including physicians, nurse practitioners and physician assistants, are often unaware of the sometimes- subtle indications of ID in newborns and toddlers. Callie, Debbie, Elizabeth and Georgia described their experiences with medical professionals who were not able to diagnose or help treat their young child's condition, a situation which caused them emotional stress and anxiety. For Georgia, her experience with her child's pediatrician was frustrating, "I guess she was about 15 months old, (when) we got her in to see a developmental specialist (and got some answers)."

In addition to medical personnel's need to be aware of symptoms of ID, they also need to

be sensitive to the needs of the parents of a child with PIMD, who is on the emotional roller coaster, is likely facing a challenge when taking their child to medical appointments. Counselors and other mental health workers must also be aware that the increased number and intensity of stressors present in the parents' (and families') lives can often be a source of anxiety, depression and other mental health issues. These same workers are also in a position to contribute to or initiate programs for prevention of mental health issues for parents of children with PIMD. Such preventive or support programs include online and in-person support groups and readily accessible information regarding various syndromes as well as important information regarding the services available to children with PIMD to assist the parents in what to many of them is previously unnavigated water.

Implications for the Field of Intellectual Disability and PIMD

Possibly one of the most important implications based on this study is the need for additional research regarding children with PIMD and their families. There is a plethora of information regarding the challenges of parenting children with mild to moderate ID. However, it is evident from the current study that the degree and intensity of challenges of parenting children with profound ID result in a higher probability of emotional distress, accompanying mental health issues and decreased wellbeing for the family. The need for increased support and provision for this population must be recognized by the entities that educate and inform society regarding PIMD and the families of those with PIMD.

Delimitations and Limitations

Delimitations and limitations in research must be exposed in order to gain complete knowledge of the accuracy and dependability of the results of the study. Delimitations can also

provide information to direct future research. The delimitations in this study, which were mostly demographic delimitations, as well as several design limitations in this study are listed below.

Delimitations

Delimitations are purposeful decisions the researcher makes to limit or define the boundaries of the study. A potential weakness of this study is that most demographic characteristics were not controlled. The sample was chosen based on meeting the criteria of the inclusion questionnaire, which was only related to the participant's being the parent of a child (six years or older) with PIMD. The participants happened to be all Caucasians, perhaps because that is the ethnic majority of Central Virginia. Additionally, the study was not controlled for gender, educational level, socioeconomic situation, number or ages of other children, marital status, geographic location (rural versus urban) or proximity to family members. In addition, other variables that could have been controlled or considered, such as the personality type of the participant, the participant's background, the participant's spiritual beliefs, or participant's internal or external locus of control, were not controlled in the current study. The reason for not controlling these demographic characteristics or other variables is that the incidence of profound ID is less than 1%; therefore, finding enough participants in Central Virginia with more of the demographics being controlled would have proven extremely difficult.

Limitations

This study included the participants' perspectives on family relationships, which were gathered only from the parents of children with PIMD and not from the siblings of children with PIMD. Therefore, no conclusions can be accurately drawn regarding any effects, negative or positive, of having a sibling with PIMD on sibling-sibling relationships or regarding the consideration of the perspective of the TD children in the parent-child relationships. Secondly,

participants' spouses were not consulted regarding marital relationships to obtain the perspective of the non-participating spouse. This could result in a lack of accuracy of the health of the marital relationships of the participants.

Another limitation that must be mentioned is that there was only one male in the study as opposed to seven females. Future research could have equal numbers of each gender as participants or have all of one gender and evaluate gender-related results. The same limitation was in place regarding ethnicity, as all participants were Caucasian, which is the majority of residents of Central Virginia. Future research could purpose to have various ethnicities represented in their studies or again, only one specific ethnicity to be able to comment on ethnically based results.

This study design did not control for the age of the child of the participant, but just required that the participant's child be age six or older. According to the PPCT model from Chapter Two, when observing the effects of the micro, meso, exo and macro systems, the researcher must also consider the chronosystem, as individuals and their social and individual characteristics change over time (Bronfenbrenner & Morris, 2006). Throughout the study, it became apparent that the participant who was the mother of a six-year-old with PIMD had not yet experienced as many of the challenges as the participants who were parents of older children (ages 15-25) with PIMD. This participant (Callie, with the six-year-old daughter) was the only one who stated that she had not allowed the child's disabilities to change her family's life. The other participants, having lived through ten to fifteen more years of the roller coaster ride, had a more seasoned perspective and realized that their child had indeed changed their families and their lives.

Recommendations

Based on the data gathered and themes developed, several recommendations can be made for stakeholders. The following recommendations could potentially improve the well-being of the participants and their families, possibly moving them to more of a long-term “thriving” state. Each stakeholder would be called upon to make changes in the roles they fulfill in the lives of the parents of children with PIMD.

Recommendations for Parents

One point of interest that arose in the current study was the pervasive comment across all participant data that if the participants could give advice to the parents of a newly diagnosed child with PIMD, they would suggest that the parents gather as much information as possible as soon as possible. The types of information suggested by the participants was information regarding the child’s specific disorder or diagnosis, support groups for parents of other children with the same diagnoses, and what resources are available locally, state-wide and nationally to assist the parents in caring for their newly diagnosed child.

A second recommendation regarding available resources was from Georgia, who recommended that parents of children with PIMD not become so involved in taking the child to various medical and therapy appointments that the family members do not have time to bond and enjoy each other. In addition, Georgia, Francine, Elizabeth, Callie, Andy and Becky recommended celebrating and being thankful for the smallest accomplishment of the child with PIMD rather than comparing the child to his or her peers. Several of the participants (Andy, Callie, Debbie, Elizabeth, Francine and Georgia all referred to the suggestion of parents with children with PIMD not depending on the medical community to do their research for them or to have the answers, but that the parents need to be prepared to do the research themselves.

Finally, because the difference between just surviving and thriving was associated with the participants' level of spousal and social support, it would be beneficial to all parents of children with PIMD to avoid blaming themselves or their spouses for the child's condition. In addition, it would give the couple a better chance of a happy marriage if they would seek marital and family counseling from the point of the initial diagnosis due to the intensity of the challenges that they will likely face. Additionally, since marital satisfaction affects family cohesion (Mitchell, Szczerepa & Hauser-Cram, 2016), it is important for spouses to see their spouses as a team member and encourage each other to, as Isabelle described of her marriage to her second husband, argue over who gets to serve whom rather than either spouse avoiding the difficult work of caring for a child with PIMD.

Regarding social support, Elizabeth stated that if she had accepted the help that had been offered to her sooner, she may have been able to avoid some of the emotional distress she suffered. Callie also realized after several years of trying to be supermom, she needed outside help and took full advantage of it and is happy she did so. With these findings from the participants, the recommendation is for parents of children with PIMD to accept any help offered from a trustworthy source and to not try to do it alone. In addition, Andy, Becky and Georgia found a wealth of social support from their local churches, so it is recommended that parents of children with PIMD find a close-knit place of worship to become involved with so that such social support can be accessed.

The last recommendation to be mentioned is that each parent of a child with PIMD to find his or her own way of de-stressing, such as crafting, exercise, fun with friends, laughter, playing music, or having a date night with their spouse and for the parent to consider this de-stressing time as essential for the family's well-being. The parents who seemed to have suffered

longer than others took longer to realize that they needed to take care of themselves if they were going to be able to continue taking care of their child with PIMD long-term.

Recommendations for Family Members and Friends

As stated above, social support is a major factor in counterbalancing the weight of the stressors in the life of a parent of a child with PIMD. Adult extended family members must be encouraged to engage with the child with PIMD and her parent, rather than disengage, which leads to social isolation and its associated negative emotional and psychological effects. Beyond just engaging in activities and conversations, Debbie's and parents, Callie's in-laws and Becky's other relatives assisted the participants of this study in caring for the child with PIMD to allow the parents to have a needed respite. All three of those participants found this phenomenon extremely helpful in coping with the stressors associated with caring for their child with PIMD. It is recommended that friends and extended family members become trained and educated in the care needs of the child so that they are able to offer the respite that could mean the difference between surviving and thriving for the parent of a child with PIMD.

Recommendations for Counselors and Social Workers

Mental health workers who work with families caring for an individual with PIMD must also be aware of the phenomenon that caring for a child with PIMD requires an extraordinary amount of time and energy (both physical and emotional) as well as a higher level of support (spousal, social, emotional, mental, physical, financial and possibly spiritual) than parents of TD children or children with less severe disabilities. Based on the current study, participants who were thriving had greater spousal and social support. Counselors and social workers must be prepared to provide information and become a bridge to accessing counseling services, respite services and other accessible resources for the parents who are the child with PIMD's primary

caregivers, their spouses, their children, and those who are involved in meeting the child's medical, educational needs and spiritual needs.

Recommendations for Medical Workers

Medical workers such as physicians, physician assistants, nurse practitioners, nurses, hospital administrators, hospital chaplains, hospital social workers and others in the medical community must better prioritize their own education in the area of PIMD so that they are better prepared to inform, educate and assist the child with PIMD and his or her family. In addition, medical schools and other medically related training programs must include training in the identification and treatment of the various comorbidities typically associated with children with PIMD so that they do not miss important symptoms and diagnoses which may be common for a child with PIMD, but which the child cannot communicate or describe.

Andy, Becky, Callie, Elizabeth, Francine and Georgia and sometimes their spouses experienced anxiety both when they received their child's diagnoses and during the time which there were no known diagnoses for emerging symptoms. Children with PIMD who are nonverbal, since they cannot tell their parents or their medical providers about their symptoms, pain, etc., rely on their parents and caregivers as well as their medical providers to know what to look for regarding symptoms associated with the child's condition. The lack of specific information regarding the symptoms and complications related to a child's specific syndrome (if there was one) or diagnosis that included PIMD caused parents great anxiety and distress. Additional research and related education provided by medical personnel regarding such symptoms and comorbidities would greatly help parents to better prepare for and cope with the anticipated comorbidities. In Elizabeth's case, her daughter did not receive her secondary diagnosis until her daughter was 16 years old. The parents knew something else was going on

medically with their daughter, but did not know the cause, which contributed to the parents' anxiety over the unknown and frustration with the medical community.

Recommendations for Educators

Although educators of students with special needs are typically very well trained to help students achieve their potentials, some educators, school administrators and support personnel are unaware of, and at times insensitive to, the challenges and stressors that parents of children with PIMD face on a daily basis. Educators are in a unique position to remain vigilant regarding the students' well-being, not just in the classroom, but on the bus (where Isabelle's child with PIMD was abused) and at home, being cognizant of the importance of supporting the parents of the children, which in turn supports the children.

Educators can frequently gain insight into the emotional balance of the family of the student with PIMD due to the large amount of time spent with the students. They are then in a position to offer support from the school in which the student with PIMD is enrolled. For example, during hospitalizations or the child's absence from school due to seizures, the school could reach out to the child as well as the parents to offer support, thus becoming another source of social support to counteract the enormous stress of caring for their child in the hospital. Andy, Debbie and Georgia were very positive about their child's school experience and very complimentary of specific individuals at the school who provided support for the family in difficult circumstances related to their child. Unfortunately, in the cases of Francine and Isabelle, this was not always true. The recommendation for educators is to not only receive specialized training for the children with disabilities, but to expand their training to help the families of children with disabilities.

Topics for Future Study

In consideration of the study findings, design limitations, and the delimitations in the study, several recommendations for future studies have emerged. These recommendations would fill additional gaps in the literature regarding individual parents (as in the current study), parent couples, siblings and entire families of children with PIMD. As noted in Chapter One, most of the research in the field of disabilities has been focused on specific syndromes or medical diagnoses such as ID, DD, ASD or DS. Research regarding children with *profound* intellectual disabilities, along with their typical multiple disabilities, is scant.

The first recommendation for future research is to conduct more research regarding individuals with *PIMD* and their families, in addition to general ID, ASD, DS or DD. Coping of parents of children with PIMD could be measured quantitatively with the Coping Health Inventory for Parents (CHIP) (Gothwal, Bharani, & Reddy, 2015). Additionally, although a study was conducted comparing emotional responses and family adjustment of male and female parents of children with health problems (Pelchat, Lefebvre, & Levert, 2007), no research has been found to investigate gender differences in parental emotional responses to their child's diagnosis or ongoing adjustments of parents of children with PIMD specifically. Georgia stated that her husband responded differently to the initial diagnosis of ID than she did. Callie stated that after her husband and she received their child's initial diagnosis, they reacted in two completely different ways:

I immediately started crying, and he looked at me just dumbfounded like, well what are you so upset about and I'm like, did you not just hear what happened? ... He said well yeah, but that is still ___ (our child) ... the diagnosis doesn't change who she is.

Along with that recommendation would be a quantitative study using the *Coping Health Inventory for Parents* (CHIP), which measures coping of parents of chronically ill children,

assessing various coping patterns by measuring three subscales: sustaining family integration, co-operation, and an optimistic perspective of the situation; (b) maintaining self-esteem, social support, and psychological stability; and (c) understanding the healthcare situation via communication with other parents in similar situations and by consultation with the child's healthcare team (Gothwal, Bharani, & Reddy, 2015).

Another recommendation regarding parents of children with PIMD is a quantitative study regarding the effects of socio-economic status and social support on family well-being, perhaps using the Family Quality of Life Scale, which measures five domains: parenting, family interaction, emotional well-being, physical or material well-being and disability-related support (Measurement Instrument Database, n.d.). In the current study, the participants, based on their homes and the types of jobs worked by the non-stay-at-home parent, had similar socio-economic status. However, Parish, et al. (2012) asserted that having a child with disabilities increased the family's financial burden, causing additional stress on the parents. Additionally, single parents, and under-privileged parents with children with PIMD may, as groups, describe differences in their experiences than the participants in the current study.

A study by Ouyang et al. (2014) that evaluated the financial burden of parents of children with Fragile X, ASD and ID, discovered that parents of children with these had to leave their employment to provide the care needed by their children. That finding was confirmed by this study regarding the parents of children with PIMD, as Callie and Francine both left their careers to care for their child with PIMD at home. However, none of the participants was asked about their financial situation nor did they offer information regarding their socio-economic status.

Also related to financial burdens of any parent, perhaps especially with parents of children with PIMD is the occurrence of divorce, which may or may not be higher with a child

with PIMD. In this study, Debbie, who related that her husband left because of the difficulty of caring for their son, added that once her husband left the family, she had to become gainfully employed outside the home and find help to care for her child with PIMD. However, no specific research has been found to compare financial stress on the parents of children with PIMD with financial stress of parents of TD children or children with less severe disabilities, although Seliner, Latal, & Spirig (2016) described the increased strain on mothers of children with PIMD related to the child's hospitalizations, which included financial strain.

Additionally, it must be noted again that the age of the child with PIMD may have made a difference in the outcomes of the study. In the State of Virginia, once a child with severe or profound ID turns 18 years old, the parents can be hired by the state as sponsored placement caregivers and be paid to care for their child in their home through a local agency that administers the Government assistance. This government provision is intended to alleviate a portion of the financial burden that parents of children with severe and profound disabilities face. It is yet unresearched as to whether the families with children with PIMD are affected by any PIMD-related financial burdens. Researchers could gather information regarding the socioeconomic status of the parents of children with PIMD as well as their emotional well-being and their perception of the role of financial considerations on their well-being. A quantitative study using measurements for socioeconomic status at either the societal level, the community or neighborhood level, or the individual level with the use of questionnaires assessing resource-based measures that include education, family income, labor market earnings, wealth and may also include highest level of education attained and the combined income of all family members in a certain year or possibly their assets minus their debt (APA, 2020).

A third recommendation for additional research is a quantitative study regarding the effect of rural living (far from typical resources) for families with children with PIMD. O’Byrne and Muldoon (2019) found that social isolation was regarded by parents of a child with ID as a very challenging part of their experience as parents of a child with ID. It would follow that families who live rurally would have less access to services, assistance and other resources and therefore possibly be more affected by social isolation than families living in urban areas. A quantitative study could determine if there is an association between families living in rural areas, any associated increased social isolation and any effects on parental well-being as compared to families with children with PIMD living in urban areas. The Family Quality of Life Measurement (FQoL), along with the screening questions regarding geographical location (urban, suburban or rural) could be used to investigate any association between geographic location and FQoL.

Another observation based on the current study was that seizures, which are common among children with PIMD, were one of the greatest sources of stress and anxiety for the participants whose children with PIMD had comorbid seizure disorders (epilepsy). In this study, Andy, Becky, Callie and Francine stated that they had to be constantly vigilant for symptoms of seizure activity in their child. Camfield and Camfield (2017) assert that children with ID can be medically predicted to have higher incidence of epilepsy (seizure disorders), and that the more severe the ID, the more likely the child is to have “medication resistant epilepsy” (p. 243). Quantitative research, using FQoL with comparison groups between parents of children with epilepsy only compared to parents of children with epilepsy and PIMD would reveal the effects of the child’s epilepsy on parental stress in children with or without PIMD. A similar type of research is warranted involving comparison groups of parents with children with PIMD and

comorbid challenging behaviors and parents of children with PIMD without challenging behaviors. Again, the FQoL could be used.

A quantitative study on parents' (of children with PIMD) perceptions of helpfulness of medical workers, social workers, early intervention workers and online support groups would be helpful in determining which sources of support are most helpful to parents of children with PIMD. In the current study, Andy, Becky and Georgia were very involved with an online support group and stated that the group had been an immense source of help for them, emotionally, informationally and socially. It is assumed that similar support groups were either unavailable, unwanted for some reason or unknown to the other participants in this study. A literature review involving online support groups for specific diagnoses would be helpful for all stakeholders to have if they are to provide online social support to parents of children with PIMD. Although each participant's child in this study had received assistance through early intervention services and through medical and related services, information was not elicited from the participants regarding the degree of helpfulness of each of these supports.

A case study investigating the multi-dimensional and multi-system experiences of parents and other family members, respite workers, educators, social workers, medical personnel, mental health workers, neighbors, church congregants, insurance case workers who participate in the team approach of caring for a child with PIMD. Such a case study would investigate the many systems involved in accomplishing best mental, emotional, physical and spiritual outcomes for a child with PIMD.

Additionally, Elizabeth, Francine and Isabelle had some negative experiences with some of the medical providers, perhaps due to lack of education or training on the part of the providers. A study regarding the type of and amount of training and education required by

medical workers, mental health workers and social workers in the area of supporting families with children with PIMD would help inform workers in all related fields regarding the need to improve support levels and resources to the parents of the child with PIMD as well as to the child himself. The data from such a study would provide impetus for additional training for medical care workers, mental health workers and social workers.

Finally, research regarding the difference in family experiences between children with mild to moderate ID compared to those with PIMD would also be helpful to determine any differences in stress, anxiety, depression or other mental or physical health problems between the groups. Since children with ID and their families are usually grouped into one of several categories, such as DD, DS, ASD or other specific diagnoses, it would be expedient to evaluate differences in experiences between severities of the ID and perhaps between comorbidities as well.

Summary

This study regarding the lived experiences of parents of children with PIMD brought forth several interesting phenomena. First, parents of children with PIMD stated, “My Life With My Child with PIMD is Like a Roller Coaster Ride” (Theme One), with the uphill portion of the ride being the sometimes intense and frequent challenges such as the participants’ experiences of anxiety, awkward public interactions, stressful and sometimes frustrating interactions with the medical community, having to be a fierce advocate for their child, facing the continuous cycle of grief, and experiencing loneliness and isolation as well as sleeplessness and fatigue. Likewise, the downhill portion of the “roller coaster” ride was described by the participants as sometimes being joyful and having positive experiences, such as watching my child play and enjoy things, watching my child achieve inch-stones and experiencing my child’s smiles and affection.

The second theme that was sifted from the data was that of “Balancing the Stressors: From Surviving to Thriving” and explained that the weight of the stressors mentioned by the participants could be counteracted if the participants had helpful perspectives and effective coping factors and strategies. The difference between those who had the helpful perspectives and who used effective coping strategies reflected the difference between those participants who seemed to be just surviving (Elizabeth, Debbie, Francine and Isabelle) and those who were thriving (Andy, Becky, Callie and Georgia) at the time of the interviews, as related to their lives with their child with PIMD. The continuum of not surviving to thriving was fluid in the participants’ lives and depended to a large degree on the amounts and types of stressors (weights on the left side of the scale) being faced during a given “season” (Callie). The two most frequently mentioned stressors that could quickly weigh down the participants were their child’s seizures and their child’s difficult behaviors. In addition, helpful existential and spiritual perspectives assisted participants to offset the weight of the stressors they experienced, and the coping factors most frequently mentioned and most regarded as significant by the participants were spousal and social support.

The implications of this study encompass a wide array of stakeholders. Counselors, social workers, church members, family members and friends of parents of children with PIMD can use the information gathered in this study to become better equipped to understand and be helpful in addressing the mental health, medical and social support needs of these parents. Those in higher education may use the results from this study to better train future educators, counselors, social workers and ministers regarding the needs of parents of children with PIMD and may take steps toward preventive health and mental health care by providing support, information and

resources, marital support and especially social resources to other parents of children with PIMD.

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Appendix A**Institutional Review Board Application**

January 24, 2020

Anne G. Hubach

IRB Exemption 4172.012420: Exploration of the Lived Experiences of Parents of Children with Profound Intellectual and Multiple Disabilities (PIMD) in Central Virginia

Dear Anne G. Hubach,

The Liberty University Institutional Review Board has reviewed your application in accordance with the Office for Human Research Protections (OHRP) and Food and Drug Administration (FDA) regulations and finds your study to be exempt from further IRB review. This means you may begin your research with the data safeguarding methods mentioned in your approved application, and no further IRB oversight is required.

Your study falls under exemption category 46.101(b)(2), which identifies specific situations in which human participants research is exempt from the policy set forth in 45 CFR 46:101(b): (2) Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:

(iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by §46.111(a)(7).

Please note that this exemption only applies to your current research application, and any

changes to your protocol must be reported to the Liberty IRB for verification of continued exemption status. You may report these changes by submitting a change in protocol form or a new application to the IRB and referencing the above IRB Exemption number.

If you have any questions about this exemption or need assistance in determining whether possible changes to your protocol would change your exemption status, please email us at irb@liberty.edu.

Sincerely,

G. Michele Baker, MA, CIP

Administrative Chair of Institutional Research

Research Ethics Office

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Appendix B
Recruitment Letter

Dear Parent,

My name is Anne Hubach, and I am a doctoral student at Liberty University in the Department of Community Care and Counseling. I am conducting a research project to learn about your experiences as the parent of a child with intellectual disabilities and would like to invite you to participate in one two-hour interview that will include informal questions. We can meet in a place you choose near Bedford or Lynchburg, VA at a time that is convenient for you.

In addition, I will set up a group chat by text on our phones after the interview so that you have the opportunity to chat with other parents of children with intellectual disabilities, including me, to add anything we may not have had a chance to mention in the interview. The information that I gather from you will become part of my doctoral dissertation. You will have access to the transcripts of our interviews and will be invited to correct or change the information regarding your own experiences as we review the outcomes together, either by phone or email. No names will be mentioned, nor will any specific location be mentioned so that all participants remain completely anonymous. In addition, I will be diligent to safeguard your confidences by keeping all data locked on a password-protected external hard drive.

Appendix C**Screening Questionnaire**

Questionnaire Instructions: Please answer each of the following statements with a **YES** or **NO** and return to ahubach2@liberty.edu as soon as possible.

- Yes No Do you live in Central Virginia.
- Yes No Do you have a child with intellectual disabilities.
- Yes No Is your child age 6 or older?
- Yes No Is your child able to feed him/herself.
- Yes No Is your child able to dress him/herself.
- Yes No Is your child able to speak.
- Yes No Does your child have communication limitations?
- Yes No Could your child ever live independently?
- Yes No Does your child require close supervision?
- Yes No Does your child require help with self-care activities?
- Yes No Does your child have any physical limitations?

These questions are based on the *Classifications of Intellectual Disability Severity*, published by the National Academies of Science and Engineering, 2015 found at <https://www.ncbi.nlm.nih.gov/books/NBK332877/>.

Thank you so much for your willingness to help me with this study. I really appreciate it.

Sincerely,

Anne Hubach

Appendix D

Research Journal Excerpts

Below are several entries made into the research journal to support the researcher's attempts at bracketing, in conformity to transcendental phenomenological qualitative research practices.

February 3, 2020

... I am a little anxious about conducting the interviews, as they may be emotionally difficult for both the participants and me. My son was with us all weekend, and it was a great reminder of the difficulties of caring for him 24/7. I am so thankful for his full-time caregiver! I am praying that nothing impedes her ability to continue to care for him.

February 5, 2020

I am a bit frustrated because my first interview was canceled by the participant. She sounded very stressed on the phone. I really do understand how stressful it is to try to work and care for a child with PIMD...

February 9, 2020

...Before the interview, I was very nervous, afraid I would do something wrong or forget to do something or that my recorder wouldn't work right. I was also anxious because I know others who know this family, and although I want to be a good researcher, I also don't want to earn a reputation for being cold or unfriendly toward the participants.

... As I was conducting the interview, I was amazed at how positive this parent was. He did not complain about any hardships or burdens associated with caring for the child with PIMD. He is the stay at home dad for the 23-year-old son and loves his job. Says he enjoys every minute with his son and wouldn't have it any other way. He said that even if he could, he would not

choose to have his son be typically developing or “normal” because then he just would not be who he is. That made me feel guilty because I have often wished our son were “normal” so that he could communicate, play, interact and tell us what he likes and doesn’t like, etc. I tend to bemoan the things he can’t do rather than focus on who he is- my son. So, their perspective was wonderful and made me feel guilty for mine. Another thing that made me feel bad is that he said that when the opportunity came for his child to be cared for by another family when he turned 18, he said, “no way.” I want him here with me. This also makes me feel bad- selfish- because I had not been able to do much for 18 years other than care for our son and after adjusting to having him live elsewhere, I have enjoyed the freedom to take a vacation or participate in an activity with friends or family members. I feel like a bad mom because I enjoy the time when he is with his full-time caregiver, knowing he is well loved and cared for, but being able to relax a bit, which for some reason I am unable to do when Josiah is home with us.

February 12, 2020

... When she said that her son is her life and her love, I felt guilty that I have not ever really wanted Josiah to be my whole life. I have always wanted him to be a big part of it but resented (and was angry at God) at times when I have been forced to only be Josiah’s mom- having to put my daughters’ needs on hold, putting my own needs for sleep, for fun and for relationship on hold for a very long time... I feel badly that this mom doesn’t want a vacation unless her son is with her, which means she is still on 24/7 duty. I am a lot more selfish than that. I guess either that or my resilience is lower, and my needs are higher- we are all different. But she doesn’t mind because he is so sweet, affectionate, smiley. I wish Josiah were that way. I feel that if Josiah were affectionate or could communicate at all, or even smile responsively, it would be easier to feel close to him. Although I kiss and hug on him and talk sweetly to him whenever I

am with him, he does not seem to respond at all, except sometimes he will lean in for a kiss when I ask him to... I wonder how much of his lack of emotional expression/affect is from the medicines he has to take for his seizures or how much could be from brain damage from seizures. I guess I won't know until heaven...

It was difficult to not go into either counselor mode or friend mode. Since we have so much in common, I felt an instant camaraderie but had to maintain my professional researcher distance. I did not like doing that!

February 17, 2020

... During the I interview there were several times when I wanted to interrupt and say, "You must be kidding me" such as when she said that she would not wish for anything to change about her daughter with PIMD, but that she is perfect just as she is. When my son was small, and even now that he is 24 years old, I find myself asking God for a miracle so that Josiah would be able to talk and tell me how he feels and what he is thinking, that he could play games with me and give me hugs and feed himself and use the bathroom. I accept him for who he is and love him dearly but would not be as frustrated if he could communicate and participate more in life with our family. I have trouble believing that these parents would not honestly celebrate with great joy to wake up one day and find that their child could do everything a TD child can do! I think they tell themselves that so that they don't live in disappointment. Maybe I have been depressed because I have lived in disappointment.

Today's participant spoke a lot about expectations. She is onto something there. She said something that I have often said to myself throughout my life, "If you have no expectations, you can't be disappointed when they don't get met." My husband has always said that that is

pessimistic. The participant called it realistic, and I agree... especially in the case with a child with PIMD.

February 18, 2020

... I found myself being jealous that her parents actually moved with her to stay close so that they could provide support to her and her son with PIMD... It struck me that grandparents and others can say, well, he's not mine, so I don't need to help. What happened to brother's keeper? Ugh. This makes me feel angry and a bit resentful. Lord, help me to understand that people don't and can't understand and that each person has his or her own limitations. Help me to love them and forgive them and to continue to help others even though they don't help me. I am sad.

... It feels good to hear others talk about their similar struggles and know that they too are doing the best they can with what they have but have also had some negative outcomes beyond their control. Today Debbie mentioned that if she had the opportunity, she would tell the mom of a newborn diagnosed with ID to not blame herself- ever- that this is God's plan for her on planet earth, just accept it and do the best you can to love your child. That was super helpful- would have been more helpful if someone had said that to me 24 years ago!

February 24, 2020

I have been thinking a lot about the last couple of interviews, and I find myself feeling guilty for not being able to "just get over it" and find joy in each day. I found that the continuous cycle of care for my son was not rewarding enough for me personally, and I feel like a bad mom because of that. I wish I were a nurturer and not a "D" personality, and that I derived all of my personal satisfaction and joy in just nurturing children, but I don't. I am a teacher, an educator, an investigator, a counselor. I want to do more than puree food, feed Josiah, change his diapers,

empty his ostomy, watch for seizures, take him to the day center and doctor appointments for the rest of my life. Does this make me a bad person? A bad mom? I love him so much and will do what is necessary to keep him healthy and keep him alive as long as possible. But I want my life to be filled with more than this- to travel, have friends, sing, attend social gatherings, continue to counsel and teach. I believe that is what God wants me to do, and that's why He provided Josiah's caregiver.

I also feel badly about depending too much on my girls to help me with Josiah when the girls lived at home. Kurt was unavailable. It is amazing that we stayed married because I did not have much support. No one took care of me or looked out for me over the years except my daughters, and that burden was too much for young girls to be asked to handle. Of course, I didn't know that at the time... With participant Debbie, I want to warn her about putting that burden on her TD son... she mentions that they are close-knit and that he looks out for her...

February 27, 2020

I met with Francine today. It was a very difficult meeting because she is extremely anxious and a bit hypervigilant. She made me feel a bit nervous. It affected me to hear Francine say, "We have, ___ and I have really struggled. I think at one point he (her husband) would like to have returned her when she was smaller," since that was a viable option with her being adopted. In addition, her daughter was in the room next to where we met and was moaning, which her mom called "talking" most of the time during our interview. I kept wanting to go in and talk to her but had to restrain myself. The other weird thing that happened was that just as I asked the question about her marriage, her husband came in the door. She introduced me to him but was giving me a look like, "don't go there right now." So, I whispered to her, "Do you want me to come back to this question?" and she said, "Yes."

... In addition, I observed that this mom is totally burned out. She can hardly put a sentence together at times. She has a lot of trouble focusing. Also, I did go to meet their daughter, and she is beautiful, and squeezed my hand when I met her, but her mom told me to be careful that she would grab me and pull my hair or bite me. That was interesting but didn't bother me too much since I am used to being around children with disabilities with behaviors like these.

One of the other things that was very sad was that the daughter rarely goes out because they are afraid that she will get germs. I find this very sad for all of them since much of our well-being can be improved by social interaction, even for children with special needs. I wish I could have recommended something to help this mom. She is in pretty bad shape emotionally and mentally. I may follow up with her if Dr. Milacci says it is ok.

March 1, 2020

... I was surprised to see her daughter with PIMD lying on the floor on cushions. I don't let my son stay on the floor when he gets down. I wondered what that was all about. I found out that their daughter with PIMD was their only child and felt sorry that they didn't have other children to love on and have them love back. I will be honest, I was a little judgmental of Georgia and her husband because they were not in good physical condition, and I have problems with people who won't take care of themselves, especially when they know their daughter depends on them to be healthy. One of the things she said in the interview was that they were having increasing difficulties physically transferring their daughter. I know that burden because I have hurt my back on several occasions when I was getting my son out of bed or off of the floor.

Georgia's husband sat in the room with their daughter during the interview. Georgia was very upbeat and positive. I used to get mad when other parents of children with PIMD were

happy. I felt like it wasn't fair for them to be happy when I was so miserable. Thankfully, my counseling courses, and in the process of counseling others, I have taught myself CBT and become a much happier, positive person.

Another thing that I was bothered by in this interview is that I felt jealous of two things, first of all that Georgia had such a supportive and involved husband, and second of all that Georgia and her husband had such a wonderful support system, people from church (which I never had to help me) as well as their online support group (which didn't exist 24 years ago), extended family (who did not help us at all with our son except a dozen times in 24 years), and even neighbors who helped them out on occasion. Their setup was like Andy's and Becky's, and I was a bit jealous and then got irritated with myself for being jealous! I was over my unhealthy feelings by the time I arrived home an hour later and was just thankful that they had each other and were mostly content.

March 17, 2020

I had planned to meet with Isabelle yesterday, but all the weird stuff with the COVID-19 came out, and she called to cancel, saying it wasn't a good time for her. I suggested we do a phone interview this evening. I was anxious to get this interview done, as it was my last one, but made myself not focus on finishing, but rather on gathering excellent data. I was not disappointed. Isabelle reminded me of myself personality-wise and attitude-wise in some ways. I really liked her and would like to meet her someday.

It was a little difficult to do the interview because my own son was very vocal in the background the whole time and my dog would not stop barking. It was a little embarrassing, but it worked out. Isabelle was very good on the phone interview and gave me lots of confirming data. My emotional response to Isabelle was compassion. She was tired; she still has other

children at home with her. I remember what it was like to try to juggle all the needs of all the family members. Maybe juggling is another theme?

Isabelle sounded burned out. I wanted to offer counseling, especially some resources that could help her, but I will not do that until my study is completed and my dissertation written so that no further bias can cloud my thinking and processing the data.

March 20, 2020

I finally finished transcribing my interview with Isabelle- over 20 pages. As I listened to the interview again, I was struck by how alike our experiences were. I am thankful God brought her to me so that a voice similar to mine could also be heard. Her son is a few years younger than mine, and she never got involved or had access to support groups. However, she did have access to caring people who have provided respite for her.

Appendix E

Interview Questions

1. Please introduce yourself to me, as if we are meeting for the first time.
2. Please describe your experience as the mom or dad of a child with PIMD.
3. What is the first thing that pops into your mind when someone asks you about your child?
4. Which aspects of caring for your son or daughter with PIMD are the most rewarding?
5. Which aspects of caring for your son or daughter with PIMD are the most challenging?
6. Think back to when you discovered that your child had special needs. What was it like to learn that your child had special needs?
7. What events or experiences have been the most difficult for you as the mom or dad of a child with special needs?
8. Why do you think that was and is the most challenging for you? (This question may or may not be asked depending on the respondent's answer to the previous two questions.)
9. What do you feel are some of the emotional or psychological effects or results of having to face challenges like these?
10. Describe how you have thought about and felt about your child's overall condition, including his/her health.
11. Please tell me about any symptoms of depression you may have, such as sleeplessness or sleeping too much, sadness, being negative, having low levels of energy, being easily irritated, feeling hopeless, experiencing less pleasure in life than usual, finding it hard to focus, eating more than usual or less than usual, feeling restless, drinking more alcohol or caffeine than usual, feeling anxious, or feeling worried or nervous.
12. Coping skills help to reduce stress and include such things as having a positive attitude, getting regular exercise, having the support of a spouse, having social support and doing something enjoyable like a hobby. Do you find any of these things helpful in relieving stress?
13. Is there anything else that you do to control or decrease the stress in your life? Which of these do you find the most helpful?
15. Can you please tell me about the people and organizations who make up your personal support system, such as respite workers, family members, spiritual resources, friends or teachers?

16. How do you maintain your emotional well-being when disturbing sicknesses, hospitalizations, emergencies or other difficult incidents or events related to your child arise?

17. If you could change one thing about the way that you have learned to cope with your child's disability, what would it be?

18. What recommendations or advice would you give to the parent of a newborn that has just been diagnosed with an ID?

19. Please describe your relationship with your spouse (if married). How about with any other, non-disabled children? If you have other children, how do they get along with your child with special needs?

20. Please describe how your child's disability has affected your family.

21. How do you imagine your life would be different if your child were typically developing?

22. When you think about your child's life, what are some of the joyful or happy memories that come to mind?

23. Please describe some of the important milestones in your child's life.

24. Thank you so much for being willing to participate in this interview and in this study. You have given me a lot of information, and I appreciate it. I have one more question before we finish today: Do you have anything that you want to add so that I have a pretty complete picture of your experience as a parent of a child with PIMD?

Appendix F

Cognitive Representation Instructions

Rationale: To talk about a scene requires the construction of propositions, consisting of truth-valued assertions about information which can serve as a basis for discussion, inferences, and reasoning. A major task for a theory of cognitive representation is to identify the types of concepts and relations that interpret and represent the participants' experiences as parents of children with profound intellectual and multiple disabilities.

Instructions: Sometimes we are able to draw or give a pictorial representation that summarizes or encapsulates our experiences. I am going to give you a blank piece of paper, some colored pencils and markers to use. Would you please take a few minutes to draw, sketch or write words that would describe your experiences as the parent of a child with profound intellectual and multiple disabilities? Let me know when you are finished, and we will talk about what you have created. Our conversation will again be recorded.