THE ROLE OF SOCIAL SUPPORT IN MITIGATING PARENTAL BURNOUT FOR

MOTHERS OF CHILDREN WITH MEDICAL COMPLEXITY

By

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DEDICATION

I dedicate this dissertation to my family. My doctoral journey would not have been possible without the support of my loving husband, Dr. Kosj Yamoah. His patience, encouragement, and confidence in me helped me overcome many hurdles throughout my doctoral journey. My precious daughter, Zoe-Elle, encouraged me and prayed the sweetest prayers over me. I pray this accomplishment shows you that, "You can do all things through Christ who strengthens you." To my parents, Edwin and Diana Perez, thank you for the sacrifices you made to provide me opportunities to learn and grow. To my sisters, Lia Gonzalez and Samantha Perez, I love you and am eternally grateful that we have each other.

To my firstborn son, Zion Yamoah, your four years on this earth left an eternal mark on me and so many others. You are forever loved and always remembered. Because of your journey, our journey, I am forever changed.

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Abstract

Parental burnout is a complex syndrome resulting from chronic parenting stress. The components of parental burnout include overwhelming exhaustion, emotional distancing, and a sense of ineffectiveness in the parenting role. Parents of children with medical complexity (CMC) face a wide range of parenting stressors related to their child's diagnosis. The purpose of this case study was to explore the role of social support in mitigating parental burnout in mothers of CMC. Five mothers participated in semi-structured interviews using Zoom video conferencing. Results of the study revealed three salient themes: types of social support, isolation, and helping others. Types of social support included four subcategories: church support, practical support, mental health support, and respite/childcare support. Results of the study indicated that community-based organizations should maximize partnerships with churches and other non-profit organizations to mitigate parental burnout and feelings of isolation for mothers of CMC. Findings suggested that mothers of CMC may experience positive benefits from helping others. Future studies on the role of helping may provide valuable insight into the motivations, outcomes, and benefits for mothers of CMC. To mitigate parental burnout and feelings of isolation, community-based organizations, practitioners, and mental health advocates can help families of CMC to find social support and opportunities to help others.

*Keyword*s: parental burnout, medical complexity, social support, parenting children with medical complexity, mothers of children with medical complexity

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I. INTRODUCTION

Parental burnout is a specific syndrome resulting from prolonged chronic parenting stress (Mikolajczak et al., 2018). The study of parental burnout emerged from existing literature on occupational burnout (Maslach & Jackson, 1981). Prior research has focused on the conceptualization of parental burnout and the development of valid and reliable instruments for measuring parental burnout (Roskam et al., 2018). Additionally, risk factors and causes of parental burnout have been explored. Ultimately, researchers sought to provide guidance for prevention and interventions for parents experiencing burnout (Mikolajczak et al., 2018).

Researchers have explored parental burnout in parents of children with special healthcare needs (CSHCN), such as cancer, intellectual disabilities, and complex medical conditions (Kahrıman et al., 2019; Lindahl Norberg et al., 2014; Lindström et al., 2010). Expectedly, parents of children with complex conditions experienced more parental burnout than parents of children without complex medical conditions (Gérain & Zech, 2018). Children with medical complexity (CMC) were generally defined as a subgroup of CSHCN with significant health problems that affect multiple organ systems, resulting in functional limitations, high health care needs, and often the need for medical technology (Kuo & Houtrow, 2016). Because parents of CMC were at a greater risk of parental burnout (Gérain & Zech, 2018), exploring the role of social support filled a gap in current research about this population's needs.

This chapter describes a research study that examined the role of social support in mitigating parental burnout for mothers of CMC. Social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109). The case study was based on qualitative interviews conducted with five mothers of CMC. The following chapter presents the study's background, identifies the problem, describes its significance, and gives an overview of its methodology. The chapter concludes by noting the study's limitations and defining specific terms used frequently throughout the study.

Background of the Study

Occupational Burnout

Maslach and Jackson (1981) defined the term burnout to address occupational burnout, especially for those in the helping professions. Individuals engaged in human services were at a greater risk of burnout due to the stressors and demands of helping others cope with their challenges in life. Researchers identified three aspects of occupational burnout: emotional exhaustion, depersonalization, and diminished personal accomplishment. The Maslach Inventory was the primary tool utilized to capture the experience of burnout for individuals at a higher risk of occupational burnout, such as nurses, doctors, and other medical professionals. Occupational burnout led to employee turnover, absenteeism, low morale, and more severe consequences, such as deterioration of patient care and drug and alcohol abuse (Maslach & Jackson, 1981).

Parental Burnout

Parental burnout was considered a distinctive syndrome, empirically different from occupational burnout, parental stress, or depression (Roskam, 2018). The study of parental burnout was relatively novel. A global interest in the study of parental burnout emerged out of

Europe in the last decade. However, traces of interest can be found as early as 1989, following the rise in popularity of the occupational burnout concept. Pelsma et al. (1989) explored the concept of parental burnout in a sample of mothers. Findings of this early study recommended further exploration of the depersonalization construct, as it did not seem to adequately describe mothers' experiences (Pelsma et al., 1989). No further investigation occurred until 2007 (Lindahl Norberg, 2007). The concept of parental burnout consisted of three dimensions: "overwhelming exhaustion related to one's parenting role, an emotional distancing with one's children, and a sense of ineffectiveness in one's parenting role" (Mikolajczak et al., 2018, p. 602).

Parenting is complex due to the range of factors influencing the experience. An example of acute parenting stress is a child choking, while chronic stressors would be a child with a behavioral issue, learning challenge, or medical condition. Chronic parenting stress can significantly impact a parent's wellbeing, their ability to bond with their child, and their marital relationship (Mikolajczak et al., 2018).

Overwhelming Exhaustion

The first dimension of parental burnout was overwhelming exhaustion. Parents described their fatigue as a feeling of being overwhelmed by parenting tasks. They expressed being emotionally drained by the parenting role. Parents described feeling tired upon waking up in the morning at the thought of facing another day of parenting (Mikolajczak et al., 2018).

Emotional Distancing

The second dimension of parental burnout was emotional distancing. Parents who experienced emotional burnout became less engaged in child-rearing. Parents described doing the bare minimum to care for their children, such as "functional/instrumental aspects at the expense of emotional aspects" (Mikolajczak et al., 2018, p. 603). Interestingly, occupational

burnout identified depersonalization as the second dimension of burnout (Maslach & Jackson, 1981). Roskam et al. (2018) identified emotional distancing as a more accurate description after completing an in-depth qualitative study.

Lack of Personal Accomplishment/Ineffectiveness

The third dimension of parental burnout was lack of personal accomplishment or ineffectiveness in the parenting role (Gérain & Zech, 2018; Mikolajczak et al., 2018). Parents felt unable to navigate the challenges of parenting calmly or effectively (Mikolajczak et al., 2018). Consequently, parents experienced a lack of efficacy and a low sense of personal accomplishment in the parenting role (Roskam et al., 2017).

Risk Factors

Mikolajczak et al. (2018) identified three main predictors of parental burnout: "parent's stable traits, parenting, and family-functioning" (p. 602). Parent's stable traits referred to individual qualities related to one's personality. In particular, neuroticism was identified as a significant predictor of parenting stress. Anxious and avoidant attachment styles were associated with less productive parenting styles and increased parental burnout (Mikolajczak et al., 2018).

Parents who experienced lowered leisure time for oneself or as a couple were also at a greater risk for parental burnout. Marital satisfaction was associated with decreased parental burnout (Lindström et al., 2010). Successful co-parenting wherein both partners cooperated on parental decisions resulted in less parental stress and burnout (Mikolajczak et al., 2018).

Parental burnout affected both mothers and fathers (Lindström et al., 2010; Roskam et al., 2018); however, mothers of children with a cognitive disability displayed more symptoms of burnout than mothers of children without cognitive disabilities (Lindström et al., 2010). Gender

increased the risk of burnout, because women were generally more involved in their child's care than men (Lindahl Norberg, 2007).

Instrumentation

The *Maslach Inventory* was developed to assess occupational burnout for individuals at a higher risk of burnout, such as nurses, doctors, and other medical professionals (Maslach & Jackson, 1981). Currently, two measurements exist to evaluate parental burnout (Roskam et al., 2018). The *Parental Burnout Inventory* was adapted from the *Maslach Inventory* in 2017 (Roskam et al., 2017; Roskam et al., 2018). Researchers developed the *Parental Burnout Assessment* to assess parental burnout more accurately following a qualitative study on parental burnout (Roskam et al., 2018). The *Parental Burnout Assessment* was a 23-item scale used to measure parental burnout.

Treatments/Intervention

Mikolajczak et al. (2018) theorized that therapeutic support should be delivered to parents according to their associated risk factors. For example, if a parent described burnout symptoms related to their parenting style, then psychologists could focus on interventions that prioritized positive parenting and self-efficacy beliefs. Interestingly, interventions that emphasized emotional competency have been shown to reduce parental burnout. Researchers recommended further study to determine the extent to which improving emotional competencies, adult attachment, marital satisfaction and co-parenting and parental self-efficacy would reduce parental burnout. Importantly, practitioners were encouraged to ensure active listening in light of the intense feelings of guilt and shame associated with parents' feelings of failure. Empathy and unconditional positive regard were cited as essential aspects of creating a safe environment for parents to express their emotions and challenges (Mikolajczak et al., 2018).

Parental Burnout in Parents of Children with Special Healthcare Needs

Prolonged parental stress led to parental burnout (Mikolajczak et al., 2018). Few studies on this topic have examined burnout in parents of children with chronic medical conditions, such as type 1 diabetes mellitus (T1DM) and inflammatory bowel diseases (Lindström et al., 2010). Lindström et al. (2010) compared burnout in parents of chronically ill children to parents of healthy children. The study results revealed the difference in clinical burnout was significant only for mothers of children with T1DM compared with the control group of mothers of healthy children (Lindström et al., 2010).

Lindahl Norberg (2007) examined burnout in mothers and fathers of children surviving a brain tumor. Findings suggested that parents of children with brain tumors experienced more burnout than parents of children without medical conditions (Lindahl Norberg, 2007). Lindahl Norberg (2014) examined the occurrence of burnout in a Swedish sample of parents of children who underwent pediatric hematopoietic stem cell transplantation. Results indicated that parents should be monitored and provided appropriate support as needed (Lindahl Norberg et al., 2014). Researchers noted the importance of follow-up with fathers in the "mother-dominated pediatric setting" (Lindahl Norberg et al., 2014, p. 302). Gérain and Zech (2018) explored parental burnout in a broad sample of parents of children with special needs (CSN). The study results showed significantly more parental burnout among parents of CSN, especially in the presence of a comorbidity (more than one medical condition) and/or multiple CSN in the family (Gérain & Zech, 2018).

Children with Medical Complexity

Children with medical complexity comprised less than 1% of all children in the United States (Murphy & Clark, 2016). Children with medical complexity were generally defined as a

subgroup of CSHCN with significant health problems that affect multiple organ systems, which result in functional limitations, high health care needs, and often the need for medical technology (Kuo & Houtrow, 2016). As a result of advances in neonatal care and life-saving technology, researchers have witnessed an increased prevalence of CMC (Mattson & Kuo, 2019).

Definitions of Terms

Examples of Chronic Conditions

Children with medical complexity often include children with congenital, genetic, and multisystem conditions (Mattson & Kuo, 2019). Children with medical complexity have multiple chronic conditions that often require the care of various specialists in the community and hospital setting (Kuo et al., 2013). According to Allshouse et al. (2018), "Examples of CMC include those with cystic fibrosis, serious congenital heart defects, or complex metabolic disorders" (p. S196).

Functional Limitation

Functional limitations refer to a child's ability to do the same activities that typically developing children of the same age can do in their daily routines, such as walking, getting dressed, or eating independently (Kuo & Houtrow, 2016). Depending on the severity, a functional limitation may be classified as an impairment, an activity limitation, or a participation restriction. Children with functional limitations often rely upon medical technology to support their health and wellbeing (Kuo & Houtrow, 2016).

Use of Medical Technology

Two terms were often associated with the use of medical technology: *technology-dependent* and *technology-assisted*. Technology-dependent described an individual or child who required medical technology to compensate for the loss of a vital body function. Examples included supplemental oxygen, ventilators, dialysis machines, and gastronomy tubes (Kuo &

Houtrow, 2016). Technology-assisted referred to the use of medical technology to compensate

for lost function but is not essential for survival. Examples of assistive technology included

"augmentative communication or assistive devices such as wheelchairs" (Kuo & Houtrow, 2016,

p. e3). Interestingly, researchers noted that technology-assisted is the preferred person-first

terminology as it is considered to be more inclusive (Kuo & Houtrow, 2016).

Challenges of Parenting Children with Medical Complexity

Parents of CMC faced a wide range of challenges following their child's diagnosis.

Social, emotional, physical, and economic impacts were substantial for families of CMC (Kuo et

al., 2013). Numerous studies have addressed the challenge of care coordination for CMC (Glader

et al., 2016; Kuo et al., 2013; Kuo & Houtrow, 2016). According to Glader et al. (2016), the

medical home model was initiated to provide "accessible, family-centered, continuous,

comprehensive, coordinated, compassionate, and culturally effective care' to patients with the

goal of improved health outcomes" (p. 1117). This framework enhanced patients' outcomes by

reducing hospitalizations, emergency room visits, and overall decreased family stress (Glader et

al., 2016).

Caregiver stress was even more significant for families of children with higher medical

complexity (Mattson & Kuo, 2019). However, limited literature existed to address the social-

emotional needs of CMC and their parents (Kuo et al., 2013). Parents of CMC who lacked

respite, coping skills, or adequate social and community support were at a greater risk of reduced

quality care of the child, which could even lead to child abuse or neglect (Mattson & Kuo, 2019).

Edelstein et al (2017) conducted a scoping review to identify the full range of support

interventions aimed at reducing caregiver stress. Six domains emerged from the 49 studies

included in the review: "care coordination models (n=23); respite care (n=8); telemedicine (n=5)

peer and emotional support (n=6); insurance and employment benefits (n=4); and health and related supports (n=3)" (p. 323). Although a limited number of studies have explored parental burnout in parents of CMC, the stressors of parents of CMC have been well documented (Edelstein et al., 2017; Kuo & Houtrow, 2016; Kuo et al., 2013; Mattson & Kuo, 2019).

<div align="center">

Social Support

</div>

Support interventions to reduce caregiver stress in parents of CMC have been explored. Edelstein et al. (2017) conducted a scoping review to identify and describe the full range of available resources to support parents of CMC. Edelstein et al.'s (2017) review offered specific examples of social support interventions available as part of a network of social support. Social support interventions included support groups, peer mentoring, the use of internet-based support, and professional interventions, such as counseling and self-help coaching (Edelstein et al., 2017). Early researchers studied the concept of social support. Presently, social support did not have an operationalized definition, rather various perspectives. For the purpose of this study, social support was viewed through a social network perspective (Lin et al., 1979).

Definition(s)

Hupcey (1998) conducted a review of social support definitions and found five distinct theoretical categories:

- Category 1: Type of support provided

- Category 2: Recipient's perception of support

- Category 3: Intentions or perceptions of the provider

- Category 4: Reciprocal support

- Category 5: Social networks

Each category of social support was empirically studied. For the purpose of this study, social support was viewed through the social network category. According to this perspective, "social support may be defined as support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109).

Perceived support referred to one's access to available social support, while *received support* referred to the reported receipt of support resources, especially during a specific time frame (Uchino, 2009). Perceived social support is the perceived availability of social support should it be needed, not the actual receipt of support (Uchino, 2009). Perceived social support has been conceptualized and studied in multiple populations of interest (Zimet et al., 1988). Interestingly, prior research has suggested that perceived social support has been more consistently linked to positive health outcomes than received support (Uchino, 2009).

Social Support for Parents of Children with Medical Complexity

The medical community widely embraces a family-centered care model as a fundamental and necessary approach to caring for the medically complex child (Kuo et al., 2013). Parents and siblings of CMC have unique mental health needs that must be addressed as part of CMC's holistic care (Glader et al., 2016). Kuo et al. (2013) suggested an enhancement in care coordination is, unfortunately, "insufficient to address the pervasive emotional and physical needs of families of CMC" (p. 7). Identification of resources is the role of team members connected with community-based opportunities (Glader et al., 2016). Bridging the gap between social support and parent needs is essential. Social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109). Currently, empirical evidence is lacking in the area of well-documented benefits of social support for these parents, especially mothers.

Theoretical Framework

Theoretically, mothers are considered the primary caregivers of children in most societies (Lindahl Norberg, 2007). The wellbeing of mothers directly impacts their role in the family, as well as individually. Especially for mothers of CMC, appropriate social support can lead to better care of children and themselves by providing them with coping skills and practical support (Mattson & Kuo, 2019). For this study's purpose, social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109).

Social constructivism is a theoretical framework for understanding the world by constructing meaning through the complex and rich exploration of a chosen topic or subject (Creswell & Poth, 2018). For this study, mothers of CMC provided meaning regarding the role of social support in mitigating parental burnout. Using a case study design, complex views were derived from mothers of CMC (Creswell & Poth, 2018). The process of studying the role of social support for mothers of CMC yielded new interpretive meaning in the context of participants' social interactions (Creswell & Poth, 2018).

Conceptual Framework

The dimensions of parental burnout provide the necessary foundation for understanding the phenomenon. Mitigating parental burnout is gaining traction as a topic of interest to psychologists and social workers alike. For the purpose of this study, understanding the unique and vast challenges of parents of CMC informs researchers of interventions that can support mothers of CMC, as they are particularly vulnerable to parental burnout (Lindahl Norberg et al., 2014; Lindström et al., 2010). The study's goal was to add depth of understanding to the role of social support in mitigating parental burnout, especially for mothers of CMC. As identified in

prior research, numerous studies have analyzed effective interventions for reducing parental stress, but limited study has explored the impact of social support. For this study's purpose, social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109). Figure 1 shows a visual representation of the three concepts: dimensions of parental burnout, criteria for medical complexity, and social support.

Figure 1

Conceptual Framework Diagram
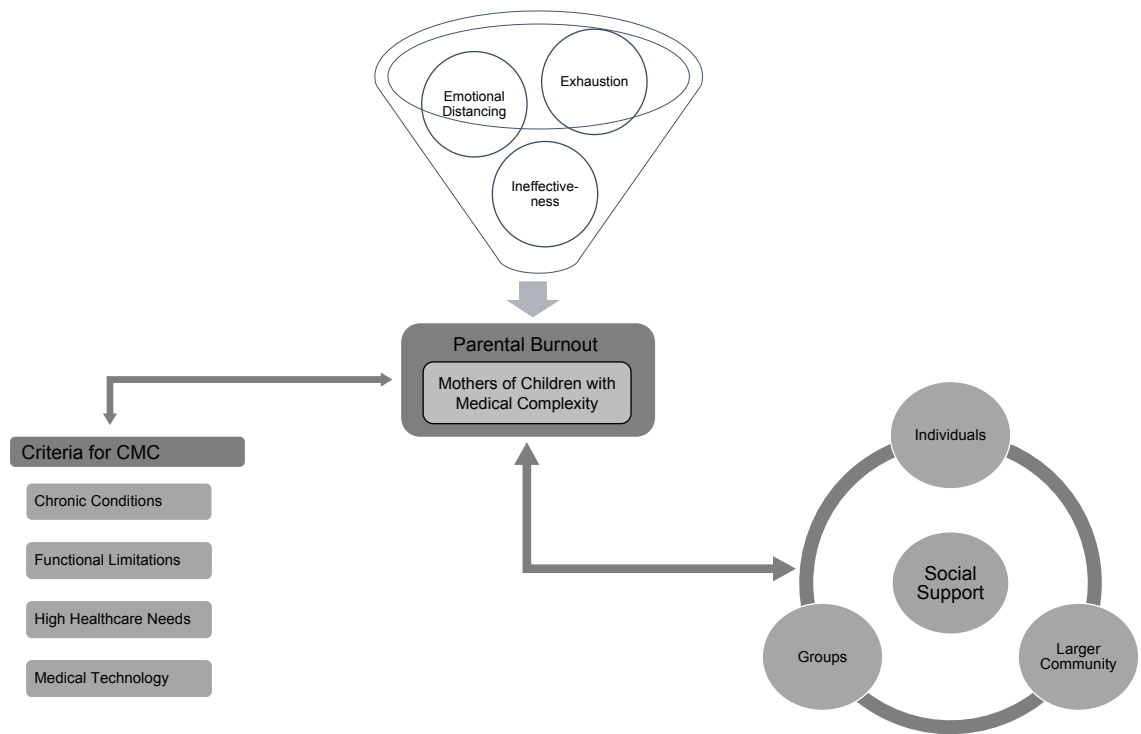
Problem Statement

Parental burnout is characterized by exhaustion, emotional distancing, and a sense of ineffectiveness in the parenting role (Mikolajczak et al., 2018). Parents of CMC face various challenges due to their child's diagnosis (Kuo & Houtrow, 2016). Specifically, mothers of children with medical conditions experience more parental burnout symptoms than mothers of

healthy children (Lindström et al., 2010). Multiple studies have identified interventions for mitigating caregiver stress in parents of CMC (Edelstein et al., 2017). However, social support is of interest to organizations that provide services geared toward the family unit's social-emotional wellbeing. Healthcare workers, non-profit organizations, and mental health advocates would benefit from gaining a deeper understanding of the role of social support in mitigating parental burnout, especially for mothers of CMC.

Purpose Statement

In light of the gap in current research, the purpose of this case study was to explore the role of social support in mitigating parental burnout in mothers of CMC. Social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109). Parental burnout was generally defined as a specific syndrome resulting from prolonged parental stress. Dimensions of parental burnout included exhaustion, emotional distancing, and a sense of ineffectiveness in the role of parenting (Mikolajczak et al., 2018). Children with medical complexity were generally defined as a subgroup of CSHCN. Children with medical complexity have significant health problems that affect multiple organ systems, which result in functional limitations, high health care needs, and often the need for medical technology (Kuo & Houtrow, 2016).

Significance of the Study

Increased social support for caregivers of CSHCN has been associated with reduced risk of stress, loneliness, depression, and anxiety in parents (Mattson & Kuo, 2019). Understanding social support is essential to organizations that provide services geared toward the family unit's social-emotional wellbeing. Healthcare workers, non-profit organizations, and mental health advocates would benefit from gaining a deeper understanding of social support's role in

mitigating parental burnout, especially for mothers of CMC. Empirical evidence for social support is explicitly needed for mothers of CMC. The benefits of social support have not been thoroughly examined in the literature. Therefore, gaining a deeper understanding of the role of social support for mothers of CMC will produce a stronger foundation for program development geared toward mitigating parental burnout.

Overview of Methodology

Research Design

A qualitative case study approach was utilized to explore the role of social support in mitigating parental burnout in mothers of CMC. Participants were recruited using a pre-screening tool to determine eligibility (See Appendix A). A sample of five mothers of CMC participated in an interview regarding the role of social support in mitigating parental burnout (See Appendix B). Within-case analysis was used to identify overarching themes, followed by cross-case analysis to determine similarities and differences between participants' experiences (Creswell & Poth, 2018).

Research Question

How does social support help mitigate parental burnout in mothers of children with medical complexities?

Sample Recruitment

Upon obtaining approval from the Institutional Review Board (IRB) of Southeastern University, the researcher invited a diverse sample of mothers of CMC to participate. Participants were recruited via social media, email, and word of mouth. The researcher had access to the special healthcare needs community through non-profit activity. Snowball sampling

was useful, as participants referred their peers to the study (Creswell & Poth, 2018). Participants met the following criteria:

- must be a biological or adoptive mother of a living child (between ages 3 to 18) with medical complexity
- must identify with the experience of parental burnout
- must be willing to participate in an interview

Participants completed a pre-screening tool to determine their eligibility. Upon evaluating participants' responses, five participants were selected to participate in a semi-structured interview using Zoom video conferencing.

Procedures

The researcher created a digital flyer that was disseminated via social media, email, and word of mouth (See Appendix D). A Google Form was used as a pre-screening tool (See Appendix A). Upon evaluating responses from the pre-screening tool, five participants were invited to participate in a semi-structured interview via Zoom video conferencing. Digital consent forms were utilized (See Appendix C).

Audio and visual recordings from this study were kept private. All transcriptions and analysis omitted identifying information. Names were masked for privacy. Research records were stored on a password-protected computer in a locked office. Only researchers and individuals responsible for research oversight had access to the records. Within-case analysis was used to identify overarching themes, followed by cross-case analysis to determine similarities and differences between participants' experiences (Creswell & Poth, 2018). Video recordings were transcribed and will be destroyed within 5 years of the interview. Data will be destroyed 5 years after the completion of the study.

Limitations

According to the literature, some parents experienced feelings of guilt and shame when discussing their challenges in parenting (Roskam et al., 2018). For this reason, the interview focused primarily on the role of support interventions. Parents were asked to discuss their experience of parenting CMC, parental burnout, and social support.

Definition of Key Terms

The following words and phrases are key terms for the study.

- **social support**: "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109).

- **parental burnout:** a specific syndrome resulting from prolonged parental stress. Dimensions of parental burnout include exhaustion, emotional distancing, and a sense of ineffectiveness in the role of parenting (Mikolajczak et al., 2018).

- **medical complexity:** a form of complexity expressed in cases with a combination of multiorgan systems resulting from chronic health conditions, functional limitations, high resource utilization, and often a reliance on medical technology (Kuo & Houtrow, 2016; Mattson & Kuo, 2019). A variety of terms have been used interchangeably with medical complexity, including *complex chronic, medically complex, medically fragile, and technology-dependent* (Kuo & Houtrow, 2016). "Examples of technologies include supplemental oxygen, ventilators, dialysis machines, and gastrostomy tubes" (Kuo & Houtrow, 2016, p.e2).

- **special healthcare needs**: a population of children who require health and related services "for a chronic physical, developmental, behavioral or emotional condition" (Kuo & Houtrow, 2016, p. e1).

Summary

In conclusion, the following case study yielded rich insight for implementation and direction to support families of CMC. Investigating the role of social support for mitigating parental burnout can significantly impact mothers of CMC. Based on the novelty of parental burnout, this qualitative study contributed to the literature concerning parental burnout in parents of CMC. Particular interest in mothers provided a foundation for understanding their unique support needs. This study's findings will inform social support organizations, hospitals, and mental health professionals on the appropriate allocation of resources to yield the most significant benefit for these parents.

II. REVIEW OF LITERATURE

The purpose of this case study was to explore the role of social support in mitigating parental burnout in mothers of CMC. Social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109). Parental burnout was generally defined as a specific syndrome resulting from prolonged parental stress. Dimensions of parental burnout included exhaustion, emotional distancing, and a sense of ineffectiveness in the role of parenting (Mikolajczak et al., 2018). Children with medical complexities were generally defined as a subgroup of CSHCN. Children with medical complexities have significant health complications that affect multiple organ systems, which result in functional limitations, high health care needs, and often the need for medical technology (Kuo & Houtrow, 2016).

Three key concepts formed the basis of this study. The first section of this literature review describes the parental burnout concept. A review of relevant literature exposed the prevalence, dimensions, risk factors, consequences, and interventions for parental burnout. The second section discusses the population of interest to this study, parents of CMC. A review of the literature regarding the stressors and evidence-based interventions for parents of CMC is explored. Finally, section three contains a review of relevant literature on social support's history, sources, and role in parenting.

The theoretical underpinnings of this study are based on the social constructivism theory. Creswell and Poth (2018) described social constructivism as a theoretical framework for interpreting the world, constructing meaning by exploring a chosen topic or subject. For this study's purpose, mothers of CMC provided meaning to the role of social support in mitigating parental burnout. The importance of social support will be discussed throughout each section of the following literature review.

<div align="center">**Parental Burnout**</div>

Parental burnout is a complex syndrome resulting from chronic parenting stress. Three dimensions of parental burnout are: overwhelming exhaustion, emotional distancing from one's children, and a sense of ineffectiveness in the parenting role (Mikolajczak et al., 2018). In recent years, researchers have conceptualized parental burnout, developed measurements for assessing parental burnout, and explored risk factors for, and consequences of, parental burnout. Parental burnout is considered distinct from depression and occupational burnout (Mikolajczak et al., 2020).

Prevalence

Parental burnout occurs when parenting stress becomes chronic and overwhelming. The problem of parental burnout became more apparent over the last decade when researchers began to explore its effect on the general population. Prior studies on parental burnout only examined parents of children with medical conditions or special healthcare needs (Mikolajczak et al., 2020). According to Mikolajczak et al. (2019), "at least 3.5 million U.S. parents are currently suffering from parental burnout" (p. 1320).

Dimensions of Parental Burnout

Overwhelming Exhaustion

According to Mikolajczak and Roskam (2018), the first dimension of parental burnout is overwhelming exhaustion. Exhaustion is considered to be the primary symptom of parental burnout. Parents who experienced burnout described feeling tired upon waking up at the thought of another day of parenting. Parents felt "they have reached the end of their tether" (Mikolajczak et al., 2018, p. 603) emotionally and physically. Exhausted parents often expressed a feeling that being a parent required too much involvement. Parents who were exhausted lacked the energy needed for daily parenting tasks (Mikolajczak et al., 2018).

Emotional Distancing

The second dimension of parental burnout is emotional distancing from one's child. Parents described being able to provide for their child's primary or functional needs but not emotional needs. Parents experiencing burnout described doing the bare minimum for their child. Parents became less involved in the details of their child's upbringing and described feeling like they were on autopilot (Mikolajczak et al., 2020).

Ineffectiveness in the Parenting Role

The third dimension of parental burnout is a sense of ineffectiveness in the parenting role. Parents perceived themselves as unable to handle the challenges of parenting. Exhausted parents felt that they lacked the patience to deal with problems calmly and efficiently. Parents no longer enjoyed parenting. They described a lack of confidence in themselves related to parenting (Mikolajczak et al., 2018).

Risk Factors

When parents lacked the necessary resources to manage parenting stress, they were at a greater risk of parental burnout. Researchers have theorized that risks and resources must be in balance for parents to cope with parenting challenges (Mikolajczak & Roskam, 2018). Mikolajczak and Roskam (2018) conducted a two-wave longitudinal study, using a sample of 923 parents. The primary goal of the study was to propose a theory of parental burnout which could be useful for predicting risk and providing direction for intervention. The secondary goal was to create a tool that researchers and clinicians could use to predict the risk of burnout and identify risk factors. Results of the study showed that the balance between risks and resource (BR^2) theory could adequately explain and predict parental burnout. The BR^2 theory was applied by assessing whether various risk factors outweighed parents' available resources or protective factors. Mikolajczak and Roskam (2018) suggested that parental burnout occurred when parents experienced a chronic imbalance between demands or risk factors and resources or protective factors.

Mikolajczak et al. (2018) studied the antecedent risk factors by conducting a quantitative study with a sample of 1,723 French-speaking parents. Mikolajczak et al., (2018) studied the "relationship between parental burnout and 38 factors belonging to five categories: sociodemographic, particularities of the child, stable traits of the parent, parenting, and family-functioning" (p. 602). The study results indicated that three sets of factors accounted for the most weight: parents' stable traits, parenting, and family functioning. Although these three items were considered the weightiest, gender and particularities of the child, the other two factors, were of importance to the current study (Mikolajczak et al., 2018).

Parents' stable traits, such as perfectionism and neuroticism (emotional instability), were relatively unchanging; however, evidence has shown that change can occur through therapeutic interventions. Parenting referred to parental self-efficacy and skills for coping with challenging behavior in children. Lastly, family functioning referred to the emotional or practical support from a co-parent or a social support network. When parents had a successful co-parenting relationship, they were less prone to parental stress (Mikolajczak et al., 2018).

Researchers have noted the importance of knowing the risk factors to apply the most appropriate therapeutic intervention. While Mikolajczak et al. (2018) concluded that sociodemographic factors, such as gender and the child's particularities, weighed less as risk factors, they still played a role. As it relates to the current study, an examination of mothers was warranted based on the premise that mothers were often the primary caregivers of children. Gender and having a child with a special healthcare need acted as amplifiers to other risk factors (Mikolajczak et al., 2018).

Gender

Séjourné et al. (2018) assessed maternal burnout rates and identified factors associated with exhaustion or parental burnout in a study of 263 French mothers between the ages of 20 and 49 years old. Participants completed a questionnaire on maternal burnout, perceived social support, parental stress, depression, anxiety, and history of postnatal depression. Researchers concluded that 20% of mothers in the study were affected by maternal burnout (Séjourné et al., 2018). According to Séjourné et al. (2018), the contributors of maternal burnout included "having a child perceived as difficult, history of postnatal depression, anxiety, satisfaction of a balance between professional and personal life and parental stress" (p. 276). Interestingly,

previous postnatal or postpartum depression was a significant predictor of maternal burnout (Séjourné et al., 2018).

Roskam et al. (2020) explored gender differences in nature, antecedents, and consequences of parental burnout. A matched-pairs sample of 900 French and English-speaking parents were surveyed to determine if the same parental burnout criteria applied to both genders. Results of the study found higher levels of parental burnout in mothers, but recognized fathers as particularly vulnerable to serious consequences of parental burnout (Roskam & Mikolajczak, 2020). Mothers were consistently identified as more exhausted, while fathers experienced more detrimental effects when experiencing parental burnout. Researchers theorized that societal norms prepared women better for motherhood, than men for fatherhood. Fathers experienced higher rates of suicidal ideation and escapism compared to mothers (Roskam & Mikolajczak, 2020).

Sorkkila et al. (2019) examined the role of socially prescribed perfectionism in a sample of 1,725 Finnish parents. Results of the questionnaire-based study indicated higher levels of socially prescribed perfectionism resulted in higher levels of parental burnout. Additionally, mothers reported higher levels of socially prescribed perfectionism and self-oriented perfectionism as compared to fathers. Therefore, researchers concluded that mothers were more burned-out as parents. Recommendations for interventions included compassion and self-acceptance skills training for mothers (Sorkkila et al., 2019).

Particularities of the Child

Lindahl Norberg (2007) published the initial article on burnout in parents of children with a brain tumor. The study included 24 mothers and 20 fathers of brain tumor survivors. A control group of parents of children with no history of medical conditions was utilized for reference. The

study results revealed that mothers' burnout scores were significantly higher than those of mothers from the control group (Lindahl Norberg, 2007).

Lindström, et al. (2011) examined the prevalence of burnout symptoms in parents of children with chronic illnesses. Specifically, a total of 252 parents of children with type 1 diabetes mellitus (T1DM) and 38 parents of children with inflammatory bowel disease were compared with a control group of 124 parents of children without medical conditions. The study revealed that 36% of parents of children with chronic conditions and 20% of parents without medical conditions experienced burnout. Researchers also concluded that mothers of children with T1DM had significantly higher clinical burnout than the control group (Lindström et al., 2010).

Gérain and Zech (2018) conducted a broad study on parental burnout in parents of children with special needs (CSN) as compared to parenting children without special needs. Prior studies examined burnout in parenting children with specific medical conditions, such as brain tumors, inflammatory bowel disease, and type 1 diabetes mellitus (Lindahl Norberg, 2007; Lindström et al., 2010). The purpose of Gérain and Zech's (2018) study was to take a global approach to assess the impact of caring for a child with a special need (CSN) on parental burnout. The study results indicated significantly more parental burnout among parents of CSN, especially in the presence of comorbidity (Gérain & Zech, 2018). Parents with more than one child with a special need were also more vulnerable to parental burnout (Gérain & Zech, 2018).

Consequences

Unfortunately, for parents experiencing parental burnout, personal consequences, and consequences to the child can be severe. Parental wellbeing, difficulty bonding with one's child, and marital discord have been identified as parental burnout consequences (Mikolajczak et al.,

2018). Common occupational burnout consequences were also relevant to parental burnout, including alcohol abuse, disordered sleep, and unexplained physical ailments (Mikolajczak et al., 2020).

Mikolajczak et al. (2018) explored the effects of parental burnout on parents and children in a cross-sectional study. Participants included 1,551 French-speaking parents. Questionnaires covered topics, including escape and suicidal ideation, addictions, sleep, conflict between partners or spouses, neglectful and violent behaviors toward children, and social desirability. Results of the study revealed higher rates of child neglect and violence resulting from parental burnout, even when controlling for educational level, income, and addictions. Researchers concluded that adopting a more preventative perspective in future studies would benefit children of burned-out parents (Mikolajczak et al., 2018).

Mikolajczak et al. (2019) conducted a cross-lagged longitudinal study to determine the impact of parental burnout on escape ideation, parental neglect, and parental violence. Participants (496 parents) completed questionnaires three times over one year. Results revealed that parental burnout strongly increased violent and neglectful behaviors toward children and increased escape ideation (Mikolajczak et al., 2019). This research underscored the need for additional research in the area of social support to identify appropriate interventions and prevention efforts.

Roskam et al. (2020) added depth to the knowledge of parental burnout consequences by highlighting gender differences between mothers and fathers. A sample of 900 mothers and fathers were recruited and matched regarding their sociodemographic characteristics. such as marital status, educational level, age, and work arrangement. Results confirmed that parental burnout was found to have more detrimental consequences for fathers than for mothers.

According to Roskam and Mikolajczak (2020), "In particular, escape and suicidal ideations as well as neglectful behaviors toward children were more common in burned-out fathers than in mothers" (p. 485).

Interventions

Currently, interventions for parental burnout have not been specifically studied. Recommendations for studies were highlighted throughout the literature. Mikolajczak (2018) suggested that clinicians would benefit from first assessing the risk factors to determine the appropriate therapeutic approach. Validated and efficient intervention therapies exist to address improving emotional competencies, adult attachment, marital satisfaction, co-parenting, and parenting practices. Researchers have also suggested that future studies should examine the extent to which using targeted approaches would reduce parental burnout (Mikolajczak et al., 2018).

Parenting Children with Medical Complexity

Children with medical complexity are known as *complex chronic*, *medically complex*, or *medically fragile*. Children with medical complexity have significant health problems that affect multiple organ systems, which result in functional limitations, high health care needs, and often the need for medical technology. Researchers have examined the challenges of recognizing medical complexity and have aimed to define terms to optimize healthcare, reduce costs, and support families of CMC (Kuo & Houtrow, 2016).

Prevalence

Children with medical complexity comprise less than 1% of children in the United States. However, this small subset of children has high healthcare costs and resource utilization. According to Glader et al. (2016), "They are characterized by having severe chronic multiple

system conditions, functional limitations, and family needs" (p. 1116). The care of CMC has improved due to advances in neonatal care and other life-saving technologies (Mattson & Kuo, 2019), resulting in a higher prevalence of CMC. According to Kuo and Houtrow (2016), "consistent and reliable recognition of complexity is difficult" (p. e2) due to variations in constructs of complexity at the individual and population level.

Family Stressors/Challenges

Mattson and Kuo (2019) produced a clinical report on the psychosocial factors in CSHCN and their families. Children with special healthcare needs were defined as a population of children who required health and related services "for a chronic physical, developmental, behavioral or emotional condition" (Kuo & Houtrow, 2016, p. e1). Children with medical complexity are a subset of the CSHCN population. The report raised awareness regarding the needs of CSHCN and their families by "increasing protective factors and ameliorating risk factors" (Mattson & Kuo, 2019, p. 1). Recommendations were consistent with Mikolajczak and Roskam's (2018) balance of risk and resource BR^2 theory.

Risk Factors

Caregivers of CSHCN and CMC experienced more significant financial and caregiving demands than families of children without special healthcare needs. Additionally, challenges related to inadequate insurance coverage were also noted. Mattson and Kuo (2019) also recognized that when parents of children with disabilities lack respite, coping skills, or adequate social and community support, it can result in children being at risk for decreased medical care and attention, abuse, or neglect (Mattson & Kuo, 2019). Importantly, researchers identified that caregiver stress could be even more significant in families with children who have higher medical complexity. For families of children who rely on medical technology, the added pressure

of managing "round-the-clock specialized and intensive care (e.g., tracheotomy changes, oxygen and suctioning)" (Edelstein et al., 2017, p. 324) puts caregivers at a high risk of breakdown.

Protective Factors

Protective factors were described at the individual, interpersonal, and community levels. Evidence showed that fostering stable relationships through communication skills training helped children and parents cope with medical complexity. Positive relationships and interactions in the community helped increase coping and build resilience in families. According to Mattson and Kuo (2019), "Higher social support for caregivers of CYSHCN has been associated with decreased risk of stress, loneliness, depression, and anxiety in caregivers" (p. 4).

Interventions to Support Caregiver Stress

Edelstein et al. (2017) conducted a scoping review of interventions to support caregiver stress. This study revealed six domains of interventions aimed at reducing stress in caregivers of CMC. Forty-nine studies were included in the review. Six domains of interventions were found: care coordination models, respite care, telemedicine, peer and emotional support, insurance and employee benefits, and health and related supports. Common themes across all domains included a focus on streamlining services and reducing the burden of care related to time, finances, care needs, service access, and more (Edelstein et al., 2017). Of interest to this study were the findings on peer and emotional support. Studies included strengths and weaknesses of parent-led peer support groups (Kingsnorth et al., 2011), one-to-one peer matching approach (Nicholas & Keilty, 2007), increased use of social media and the internet as a support mechanism (Baum, 2004), clinician-led support interventions (Giallo & Gavidia-Payne, 2008), and self-help coaching (Toly et al., 2014).

Parent-led Peer Support Group

Kingsnorth et al. (2011) explored the role of parents as transition experts. Researchers revealed the gap in available resources for families of children transitioning from pediatric care to adult care. Kingsnorth et al. (2011) explored the benefits, limitations, and outcomes of a parent support group geared toward transition. The results of the study revealed three themes:

- increased awareness related to personal challenges in planning and shifting viewpoints on future orientation,
- increased active planning concerning knowledge building and actions taken, and
- the value of experiential knowledge (Kingsnorth et al., 2011).

One-to-one Peer Matching Approach

Nicholas and Keilty (2007) conducted a pilot intervention study for parents of children with chronic lung disease who were also technology-assisted. Parents were paired with other parents with similar caregiving responsibilities. Peer support was defined as empathetic listening, encouraging one another, and sharing personal experiences (Nicholas & Keilty, 2007). Results of the 4-month study indicated that one-to-one peer mentoring provided participants with an opportunity to feel understood, which resulted in decreased feelings of isolation. Benefits included learning new information, strategies, and resources. The intervention limitations included incompatibility and lack of motivation to open up or share personal information. Overall, this study shed light on the need for a variety of social support options for families of CMC (Nicholas & Keilty, 2007).

Internet Parent Support Groups

Baum (2004) conducted an exploratory study with a sample of 114 participants. Participants, primary caregivers of CSHCN, were invited to complete an internet survey. Results

indicated that 90% of participants suggested other caregivers join internet parent support groups (IPSGs). Baum (2004) noted that primary caregivers described a significant deterrent for obtaining support as a lack of childcare. The utilization of computer-based support groups allowed for parents to receive support without needing to find childcare. According to Baum (2004), participant satisfaction with IPSGs was high. The most significant factors associated with satisfaction were

- gaining useful information or ideas,

- improvements to the caregiver and child relationship, and

- connecting with people to trust (Baum, 2004).

Researchers concluded that clinicians working with parents of CSHCN should consider promoting internet support groups as an additional form of social support.

Clinician-led Emotional Support Interventions

Giallo and Gavidia-Payne (2008) conducted a randomized controlled trial study with 21 siblings of children with a disability or chronic illness and their parents. The 6-week, family-based psychoeducational intervention was aimed at assisting parents and siblings in externalizing their feelings. Participants completed a pre-test before the intervention and post-test following the intervention. The intervention consisted of weekly content, activities, and a 20-to-30-minute session with a clinician. One significant finding of this study was that parental participants reported an increase in routines and time spent together as a family. However, the intervention was insufficient to improve long-term family-functioning (Giallo & Gavidia-Payne, 2008). In congruence with parental burnout research, family-functioning was considered a key determinant in parental burnout risk (Mikolajczak et al., 2018).

Self-help

Toly et al. (2014) conducted a randomized longitudinal controlled pilot study with 22 mothers of technology-assisted children. A pre-test and post-test were administered to assess negative emotions and depressive cognitions. The Resourcefulness Training (RT) intervention included in-person teaching of eight resourcefulness skills using the acronym RESOURCE. Mothers received a card with resourcefulness skills and were instructed to use the strategies every week. Mothers were required to record their use of RT skills by journaling. Mothers also received 5–10-minute follow-up calls. Results indicated that "The most frequently used resourcefulness skills were rely on family and friends, seek professionals and experts, organize daily activities, and use positive self-talk" (Toly et al., 2014, p. 3). Researchers concluded that RT was an acceptable and feasible intervention for the target population. Additionally, RT was believed to positively affect mental health despite a small effect size when assessing mental health outcomes.

Social Support

Edelstein et al.'s (2017) review of support interventions provided specific examples of available social support within the greater community for parents of CMC. However, a much broader field exists on the concept of social support. Social support research dates back to the mid-1970s (Hupcey, 1998). Over the last 50 years, social support has been further defined and conceptualized to produce numerous scales for measuring social support or perceived social support. The following section examines relevant literature about the history, conceptualization, and nuance of defining social support. In previous sections, priority was given to peer-reviewed articles published within the last five years, this section contains important studies from the last

50 years, when social support was first being discussed. This section concludes with social support studies pertaining to parents of CSHCN or CMC.

History

Social support was initially studied in the mid-1970s to early 1980s, emphasizing interactions between people or specific relationships (Hupcey, 1998). However, over the next 15 years, the concept evolved to include perceptions, quality of support, the quantity of support interactions, social systems, and more. This evolution resulted in a more abstract and "fuzzy" (Hupcey, 1998, p. 1231) concept of social support. Hupcey (1998) studied the linkage between social support theory and research. The inquiry's results maintained that social support was a multifaceted concept that was difficult to conceptualize, define, and measure. Though many attempts have been made to define and conceptualize social support, consistency across domains has not been achieved. According to Hupcey (1998), "Although this concept has been extensively studied, there is little agreement among theoreticians and researchers as to its theoretical and operational definition" (p. 1231).

Conceptualization

Cohen and Wills (1985) examined the process through which social support benefited wellbeing. Four support resources were discussed: *esteem support* (emotional support) was described as support that informs a person that they are valued and accepted. *Informational support* (advice, appraisal support, and cognitive guidance) was described as support with defining, understanding, and coping with problematic events. *Social companionship* was described as spending time with others by partaking in leisure or recreational activities. *Instrumental support* was categorized as tangible or material support, such as financial aid or the provision of needed services. Instrumental support provided recipients with increased time for

relaxation or entertainment. The review concluded that support needs vary according to the stressor type (Cohen & Wills, 1985).

Sources of Social Support

Family, Friends and Significant Other

Zimet et al. (1988) developed the multidimensional scale of perceived social support (MSPSS) to measure the perceived availability and quality of social support from three sources: family, friends, and significant others. These subscales were designed to be used separately or combined into a general measure of perceived social support (Porter et al., 2019). Researchers concluded that high levels of perceived social support were associated with low levels of depression and anxiety symptoms (Zimet et al., 1988). Recently, researchers developed and evaluated a 6-item version of the MSPSS using a large sample of military spouses and a sample of undergraduate students (Porter et al., 2019). Results indicated that the reduced version adequately captured perceived social support (Porter et al., 2019).

Community/Social Networks

Other researchers examined the more extensive social support networks available. Oritt et al. (1985) created a tool for measuring social support networks, *Perceived Social Network Inventory*. The support network was defined as the set of people who engage in supportive interactions with the individual during times of stress (Oritt et al., 1985). Participants were asked to list individuals who they would turn to for support. Participants were then asked to categorize each individual as spouse/partner, family member, friend, co-worker, professional help-giver, religious leader, or self-help group member (Oritt et al., 1985).

Lin et al. (1979) explored the effect of social support and stressful life events on psychiatric symptoms. Researchers hypothesized that individuals with greater social support

networks would be less likely to experience psychiatric symptoms. A sample of 170 Chinese

Americans completed interviews and questionnaires to determine stressful life events (SLE) and

social support. Researchers defined social support broadly to include support from family/kin,

friends, acquaintances, co-workers, and the greater community (Lin et al., 1979). Results of the

study confirmed that stressful life events and social support are important factors in explaining

psychiatric symptoms. According to Lin et al. (1979), "Compared to stressors (SLE), the social

support measure was much more significantly (and negatively) related to psychiatric symptoms"

(p. 115). Implications of the findings included improved understanding of the role of social

support in mitigating psychiatric symptoms in a specific population, which could lead to

effective interventions and improvement to general public health. Researchers noted that future

research using a wider population would allow for confirmation of results.

Religious Identity

Research on religion and mental health indicated that membership to a religious group or

the association with a religious institution and belief in a god or higher power provided

individuals with a sense of significance, positive emotions, self-esteem and also had a buffering

effect against depression (Hashemi et al., 2020). Merino (2014) examined "how the religious

dimensions of close, interpersonal relationships are related to the provision of social support" (p.

595). The regression study results indicated that same-faith relationships were significantly more

likely to be sources of help "in times of need" (Merino, 2014, p. 595). The findings underscored

a need for continued research to consider the role of religious identity in shaping social

support research and intervention (Merino, 2014).

Vitorino et al. (2018) examined the effect of spirituality and religiousness on quality of

life, depressive symptoms, anxiety, optimism, and happiness among adults. Results of the cross-

sectional study indicated that individuals with high spirituality and high religiousness were significantly correlated with better mental health outcomes, when compared to those with low spirituality and low religiousness. Individuals with higher levels of religious practices experienced improved mental health outcomes when compared to others with higher levels of spirituality. Researchers suggested that the group component of religiousness "can unleash functional behavior, positive feelings, social support and emotion of gratitude" (Vitorino et al., 2018, p. 5).

Social Support and Parenting Children with Special Healthcare Needs

Florian and Krulik (1991) studied loneliness and social support of mothers of chronically ill children. A mixed methods study explored the relationship between loneliness and social support in a sample of 33 mothers of children with chronic life-threating diseases, 57 mothers of children with chronic non-life-threatening diseases, and 92 mothers of children without medical conditions. Participants completed two questionnaires, the *UCLA Loneliness Scale* and the *Norbeck Social Support Questionnaire*, and an in-home interview. Results of the study confirmed that mothers of children with life-threatening and chronic conditions experienced higher levels of loneliness than mothers of children without medical conditions. Importantly, this study suggested that "the severity of a chronic life-threatening illness raised the mother's loneliness and diminished her perceived social support" (Florian & Krulik, 1991, p. 1295). These findings affirm the importance of social support, especially for mothers of children with more complex needs (Florian & Krulik, 1991).

Weiss (2002) assessed the effect of hardiness and social support on the stress levels in mothers of children with disabilities and mothers of typical children. Participants in the quantitative study included 40 mothers of children with Autism Spectrum Disorder, 40 mothers

of children with intellectual disabilities, and 40 mothers of children who were typically developing (Weiss, 2002). Results indicated significant predictors of positive coping were hardiness and social support. Hardiness was defined as a personality attribute that consisted of three characteristics: commitment, challenge, and control. These characteristics resulted in healthy adaptation to stressful life events. Informal social support was measured using three different scales to measure perceived availability of support, receipt of functional support, and marital satisfaction. Formal social support was measured using a six-item questionnaire to understand mothers' access to medical, educational, and informational support. Parental burnout was also assessed using a modified version of the *Maslach Burnout Inventory* (Weiss, 2002). Results of the study indicated that mothers with more hardy attitudes perceived support as more available to them. Additionally, the importance of the marital relationship was highlighted as an important source of social support for mothers. Findings of this study reinforced the idea that social support from family, friends, and the community mitigated stress-related symptoms associated with parenting a child with a special healthcare need (Weiss, 2002).

Baum (2004) defined social support as perceived aid and assistance exchanged through social relationships or networks. In an exploratory study about internet parent support groups, Baum (2004) assessed social support types for families of CSHCN. Participants included 114 parents of CSHCN. Types of support included family, IPSGs, religion, therapist, other parents of CSHCN, face-to-face support groups, nurses, and clergy. Results indicated the highest-ranking source of emotional support was family, followed by IPSGs. Findings suggested that well managed IPSGs provided a viable means of support to parents. The following limitations of IPSGs were reported: misinformation and exposure to people who may recommend untested therapies and products or promote distorted group beliefs (Baum, 2004).

Conclusion Leading to the Relevance of the Current Study

In conclusion, the three concepts of parental burnout, parenting CMC, and social support are interconnected. Threads of each concept can be found in each realm of existing literature. However, the specific examination of the three concepts has not been studied in the proposed manner. This study's significance will yield value to each domain and ultimately allow for greater advocacy and effective interventions for mothers of CMC. The methods of the study will be further discussed in Chapter 3.

III. METHODOLOGY

The purpose of this case study was to explore the role of social support in mitigating parental burnout in mothers of CMC. Social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109). Parental burnout was generally defined as a specific syndrome resulting from prolonged parental stress. Dimensions of parental burnout included exhaustion, emotional distancing, and a sense of ineffectiveness in the role of parenting (Mikolajczak et al., 2018). Children with medical complexity were generally defined as a subgroup of CSHCN. Children with medical complexity have significant health complications that affect multiple organ systems, which result in functional limitations, high health care needs, and often the need for medical technology (Kuo & Houtrow, 2016).

Description of Research Design

A case study approach was utilized to investigate the role of social support in mitigating parental burnout for parents of CMC. The purpose of case study research is to develop an in-depth understanding of a case or cases within a real-life context (Creswell & Poth, 2018). The current case study examined the unique similarities and differences among cases defined by specific boundaries (Creswell & Poth, 2018). Boundaries or limits to the study included gender of participants (female), ages (between 3-18 years old) of CMC, and parental burnout experience. Creswell and Poth (2018) described time and place as unique features of case study

design. The current case study examined a specific part of participants' lived experiences while parenting a CMC.

Participants were recruited via social media, email, and word of mouth. Five participants completed a pre-screening survey and interview. Interviews were conducted using Zoom video conferencing. Each interview was transcribed and analyzed for initial codes and categories. Subsequently, cross-case analysis was used to determine salient themes across all five participants.

Participants

Participants were recruited via social media, email, and word of mouth. Three mothers were recruited directly by the researcher. Snowball sampling was encouraged. As a result, two additional participants were recruited for the research study. Altogether, five mothers of children (between the ages of 9 and 16) with medical complexities participated in the study (See Table 1). Participant 1 was the mother of a CMC associated with bacterial meningitis, intellectual disability, and autism spectrum disorder. Bacterial meningitis is an infection caused by the spread of several different types of bacteria throughout the body (*Bacterial Meningitis*, 2019). Serious side effects include "brain damage, hearing loss, and learning disabilities" (*Bacterial Meningitis*, 2019, para. 1). Participant 2 was an adoptive mother of a child with cerebral palsy. Cerebral palsy (CP) is a condition which affects a person's ability to control their muscles (*What is Cerebral Palsy,* 2020). Symptoms of CP can vary from person to person. More severe cases of CP are characterized by the use of medical equipment and need for long-term care. Participant 3 was the parent of a child with congenital central hypoventilation syndrome (CCHS). CCHS is a rare chronic condition which affects the central nervous system (*Congenital Central Hypoventilation Syndrome,* 2019). Symptoms of CCHS include inability to control breathing

resulting in the need of long-term use of ventilatory support (*Congenital Central Hypoventilation Syndrome,* 2019). Participant 4 was the mother of a survivor of astrocytoma/glioma, brain tumor. Astrocytoma/glioma is the most common type of brain tumor in children (*Astrocytoma Glioma,* n.d.). Common symptoms of astrocytoma/glioma include seizures, loss of balance or difficulty walking, and vision, hearing, or speech problems (*Astrocytoma Glioma,* n.d.). Participant 5 was the mother of a daughter with trisomy 9 and Dandy-Walker syndrome. Trisomy 9 is a chromosomal abnormality caused by some cells having three copies of chromosome 9. Symptoms of trisomy 9 vary from person to person but may include brain malformations, kidney problems, and congenital heart defects. The Dandy-Walker malformation causes extra pressure on the brain. Some individuals with Dandy-Walker syndrome have physical or intellectual disabilities (*Dandy-Walker complex,* n.d.).

Table 1

Participant Details

Participant Number	Age of Child	Total Number of Children	Diagnosis
1	16	4	bacterial meningitis (5-months-old), intellectual disability, autism
2	15	9	cerebral palsy (CP)
3	11	1	congenital central hypoventilation syndrome (CCHS)
4	12	3	astrocytoma/glioma
5	9	1	trisomy 9 with Dandy-Walker syndrome

Role of the Researcher

The researcher's background in special education initially exposed her to the special healthcare needs community. In addition to education, the researcher also experienced personal loss of a child from a brain tumor. Because of this experience, the researcher co-founded an organization, *Out of Zion*, to support families of CSHCN. After working with numerous families

and witnessing the journeys of parents of CMC, the researcher investigated empirical evidence for the role of social support in mitigating burnout for mothers of CMC. The researcher positioned herself as an insider who could relate to the experience of parenting a CMC (Creswell & Poth, 2018). Additionally, the role of the researcher in this case study was to provide a safe, confidential, and empathetic environment for mothers to openly share their experiences.

In order to account for researcher bias, the researcher utilized bracketing to ensure that the personal experience of the researcher did not cloud the judgement or interpretation of the data. Bracketing is commonly used in phenomenological research studies in which researchers "set aside their experience, as much as possible, to take a fresh perspective toward the phenomenon under examination" (Creswell & Poth, 2018, p. 126). The researcher limited the study to only include mothers of living children to ensure that the child loss experience would not be a part of the research study. The researcher practiced reflexivity by allowing the participants to get to know her work experience and personal history throughout the interview. Sharing pertinent details allowed for mothers to connect with the researcher and promote vulnerability.

Measures for Ethical Protection

Before conducting the study, the researcher obtained institutional review board (IRB) approval from Southeastern University. As outlined in the IRB guidelines, participants were required to digitally provide consent to participate in the research study before giving any personal information (See Appendix C). The digital consent form was included in section one of the pre-screening tool, using Google Forms. The digital consent form provided the details of the study, risks, benefits, and instructions regarding confidentiality and storage of data. Risks of the study were considered minimal. Participants were aware that they could experience

uncomfortable feelings when discussing their experiences with parental burnout. Benefits included participant empowerment and an opportunity to give voice to the population they represented. Participants' names and any identifying information was masked for their protection. Audio and visual recordings and files were stored on a password-protected computer in a locked office. All participants received transcripts for approval via email. In accordance with IRB policies, all files and recordings will be deleted within 5 years of the study's completion.

Research Question

How does social support help mitigate parental burnout in mothers of children with medical complexities?

Data Collection

Instruments Used in Data Collection

A pre-screening tool was utilized to ensure participants met the criteria for the study (See Appendix A). The pre-screening tool included three required questions. The first question verified the age and presence of a child with medical complexity. Question two presented the criteria for medical complexity and asked participants to select all that applied. The final question verified mothers' experiences with parental burnout using a yes/no question. A definition of parental burnout was included. Finally, the participants' contact information was requested.

An interview protocol was utilized to guide all five interviews (See Appendix B). All interviews were conducted using Zoom video conferencing. Each interview was recorded and transcribed using the Otter transcription tool. Each interview began with a description of the research study and definitions of key terms, including parental burnout, medical complexity, and social support. Interviewees were thanked for their participation and reminded that their answers

would remain confidential. Six questions were asked, with follow-up questions as needed for clarity. The first open-ended question was intentionally broad to allow participants to share their story and journey of parenting a CMC. Each interview concluded with a question regarding recommendations for forms of social support that could benefit other mothers of CMC.

Procedures

The researcher utilized a digital flyer to recruit participants via social media, email, and word of mouth (See Appendix D). Participants who completed the digital consent form and pre-screening tool were contacted via text message to schedule an interview if they met the criteria. All five participants received a Zoom meeting invitation in their email after agreeing upon a scheduled time. Each interview was recorded using Zoom cloud recording. All recordings were transcribed using the Otter transcription tool. Transcriptions were edited for accuracy and sent to each participant via email for approval. Follow-up questions were asked as needed during the analysis of the data.

Methods to Address Assumptions of Generalizability

The objective of case study research is to develop an in-depth understanding by examining different cases of one experience (Creswell & Poth, 2018), not to achieve generalizability. This case study allowed for five unique representations of the role of social support in mitigating parental burnout for mothers of CMC. The experiences of five mothers of CMC cannot be applied to the general population. However, the rich insights of participants can lead to future studies for generalizability.

Data Analysis

Research Question

How does social support help mitigate parental burnout in mothers of children with medical complexities?

According to Joyner et al. (2018), case study research requires an inductive analysis process. The researcher sought to provide meaning by uncovering themes based on the data collected. Through an immersive process, three salient themes emerged from the data across all cases: types of social support, isolation, and helping others. The researcher circled the data multiple times to arrive at the current three themes. As described by Creswell and Poth (2018), qualitative data analysis can be viewed in the visual form of a spiral contour. The stages of data analysis include organizing the data, reading and taking notes on emergent ideas, classifying codes into themes, developing interpretations, and representing the data (Creswell & Poth, 2018).

Raw data was analyzed for codes and themes using Excel spreadsheets and word documents. With-in case analysis was used to identify repeated words and phrases for each participant (Creswell & Poth, 2018). Codes ranged from 30-50 categories per participant. A codebook was created using Excel spreadsheets to categorize and organize all data. Upon completion of with-in case analysis, the researcher collapsed or combined categories to identify similarities and differences among participants. Subsequently, cross-case analysis was used to identify relevant themes across all five participants.

According to Joyner et al. (2018), "triangulation is a process of using multiple perspectives and data sources" (p. 95). Triangulation of data sources was used to validate findings across participants. Four types of triangulation can be used to validate findings, including method triangulation, investigator triangulation, theory triangulation and data source

triangulation (Carter et al., 2014). For the purpose of this study, data source triangulation was used.

Summary

In closing, this case study examined the parenting experiences of five mothers of CMC between the ages of 9-16 years old. Participants were interviewed to reveal the role of social support in mitigating parental burnout. The qualitative research approach allowed for an inductive and intuitive process of data analysis. The results of the study will be further discussed in Chapter 4.

IV. RESULTS

The purpose of this case study was to explore the role of social support in mitigating parental burnout in mothers of CMC. Social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109). Parental burnout was generally defined as a specific syndrome resulting from prolonged parental stress. Dimensions of parental burnout included exhaustion, emotional distancing, and a sense of ineffectiveness in the role of parenting (Mikolajczak et al., 2018). Children with medical complexity were generally defined as a subgroup of CSHCN. Children with medical complexity have significant health complications that affect multiple organ systems, which result in functional limitations, high health care needs, and often the need for medical technology (Kuo & Houtrow, 2016).

Methods of Data Collection

After receiving Institutional Review Board (IRB) approval from Southeastern University, the researcher began recruiting participants for the research study. A digital flyer was disseminated via social media, email, and word of mouth (See Appendix D). Interested participants were directed to complete a pre-screening tool using Google Forms to determine eligibility (See Appendix A). All participants were provided with a digital consent form (See Appendix C). The researcher contacted all eligible participants via text message to assess the best time to schedule an interview. Five participants were recruited for the study. All interviews were conducted using Zoom video conferencing. Interviews were recorded and stored on Zoom cloud. Interviews were transcribed using the Otter transcription service. Transcripts were sent to

participants via email for accuracy using Word documents. Upon final approval of transcripts, the researcher began the inductive process of qualitative data analysis.

The researcher used with-in case analysis to determine significant words and phrases during each participant's interview. Direct quotes from each participant were copied into a Google Sheets spreadsheet, according to the categories identified. Approximately 30-50 categories or codes were identified per participant. Cross-case analysis was then used to compare significant words and phrases across all five participants. The researcher assigned a color code to each of the five participants and then combined all codes on one sheet. After sorting the sheet, the researcher determined which codes were shared by all participants. Eighteen relevant themes emerged from the data:

- Accessibility of resources
- Asking for help
- Childcare/Respite
- Church
- Counseling/Therapy
- Faith
- Future/Vision of the child
- Grief/Sadness/Depression
- Guilt
- Helping Others/Advocate
- Identity
- Isolation
- Learning/Learning curve/Training

- Mental health

- Mentoring others

- Online support

- Practical support

- Support from other parents

Based on the frequency of discussion by all or most participants, the themes were combined and reduced to seven themes:

- Childcare/Respite

- Church support

- Mental health

- Practical support

- Isolation

- Learning curve/Training

- Helping others

After continual analysis, the themes were collapsed into three salient themes with subcategories:

- Types of social support
  - Church support
  - Practical support
  - Mental health support
  - Respite/Childcare

- Isolation

- Helping others

Findings by Research Question

The present study examined the role of social support in mitigating parental burnout in mothers of CMC. This central question was answered by mothers of CMC who experienced parental burnout. Data was gathered regarding the role of social support and the parental burnout experience for mothers of CMC. Each participant's experience with social support related to parental burnout, and parenting a CMC is described in the following section. Three themes and subcategories that emerged from the case study analysis were presented.

Research Question

How does social support help mitigate parental burnout in mothers of children with medical complexities?

Participant 1

Participant 1 was the mother of a 16-year-old son with medical complexity, intellectual disability, and autism spectrum disorder. She currently has four children altogether. She described her pregnancy as "completely normal." She explained that her child with medical complexity was her second child, so she expected things to go as uneventfully as her first experience. She described the beginning of her journey when her son was diagnosed with bacterial meningitis at 5 and a half months old. As a result of meningitis, her son suffered two strokes and multiple seizures. The family spent 6 and a half weeks with their child in the hospital before returning home with a VP shunt, feeding tube, and breathing machines. Participant 1 explained her son's current challenges included behavioral challenges, communication challenges, and a lack of depth perception, which affects his walking.

Participant 1 described a significant turning point in her life around her child's 6th birthday when he started walking independently. This time also marked the moment when she

connected with resources for parents of CMC, gained a sense of community through her church, and began giving back to support other families. She explained that her church played a significant role in providing social support. Participant 1 also noted that her relationship with her husband provided her with the most social support, given that he "is in the trenches" with her. Participant 1 explained that her faith also helped her find meaning and purpose in life. She stated, "I don't believe anything happens by accident. I don't believe that what we experienced with our son was just for us. I truly believe that it was for us to be able to reach back and help someone else." Around six years after her son's diagnosis, Participant 1 and her husband started a support group for caregivers of CSHCN through the local children's hospital. The support group is now approaching its 10th year.

Participant 2

Participant 2 was the mother of nine biological and adopted children ranging from 4 to 27 years old. She described her children as having multiple special healthcare needs. Her parenting journey with medical complexity began in 2015 when she and her husband adopted two boys from China, both with CP. She described her older son's need for a wheelchair and walker for mobility assistance because of his CP. The older child with more complex CP was the child she referred to most when answering questions. Her older son with CP was adopted at the age of 10 years old and is currently 15 years old. Participant 2 explained how she and her husband were required to take parenting classes before adopting the boys. She researched what his medical needs would be before the adoption and tried to prepare but noted that "you could never fully prepare."

Participant 2 explained her experience with parental burnout as ongoing or seasonal. She emphasized the role of her church and community group in meeting tangible needs during the

adoption transition. Participant 2 also discussed social media support groups as a significant resource in her life. She also noted that the teachers at her child's school have kept in touch over the years. She stated that many of them "genuinely care." She explained the importance of emotional support and described talking with close friends who provide "a listening ear" or even professionals who helped her see things "in a different light."

Participant 3

Participant 3 was the mother of an 11-year-old son with congenital central hypoventilation syndrome (CCHS). She described a normal and healthy pregnancy with her firstborn and only child. She described the moment when she delivered her son and heard the nurse say, "Come on, breathe, baby. You need to breathe." Her son stopped breathing and was immediately taken to the operating room of the neonatal intensive care unit (NICU). After numerous assessments, he tested positive for the rare condition, congenital central hypoventilation syndrome (CCHS). CCHS is a rare chronic condition which affects the central nervous system and a person's ability to breathe independently. Participant 3 and her husband were given the option to arrange hospice care for comfort measures for their son. She and her husband decided they would move forward with treatment and surgery to help their child live, despite the unknown future. His first surgery was to place a tracheostomy and temporary feeding tube. After 68 days in the NICU, the family was trained to care for their son at home on a ventilator. They were also introduced to other medical equipment, such as suction pumps, apnea monitors, and pulse oximeters. She described his current medical needs are not better or worse than those early days, just different. She noted that now she is not as worried about him stopping breathing but still has ongoing medical needs. For example, he recently underwent heart monitor placement surgery.

Participant 3 explained that in-home nursing and friends' support helped them get through their difficult times. She also received tangible and prayer support from her church. Participant 3 attended classes and in-person support groups through her child's hospital. When her child was approximately 7 years old, she began advocating for children and families with medical complexity. At that point, Participant 3 became a speaker and an advocate for families of CMC at a national and local level. She also offered her contact information to the hospital social workers to freely give to other families of children with the same diagnosis. Participant 3 emphasized the importance of helping other parents learn how to advocate for their needs and find the resources needed to cope.

Participant 4

Participant 4 was the mother of three children. The oldest was a 12-year-old son and cancer survivor with medical complexity. She explained that she had a completely normal pregnancy with her son. When her son was 4 months old, she and her husband noticed that he was not meeting milestones. At 6 months old, he was diagnosed with hydrocephalus and a brain tumor known as astrocytoma/glioma. He underwent 13 rounds of chemotherapy. At one point during treatment, he needed a gastronomy tube due to difficulty swallowing safely. He experienced brain trauma from numerous surgeries and shunt revisions. Participant 4 noted other challenges, such as left-sided weakness and a significant stutter. Currently, he takes medication for epilepsy and has two shunts. He recently reached 1 year of being seizure-free.

Participant 4 described her friends, church, and family's active role in providing practical support during her son's treatment. She stated, during her son's cancer treatment, "people just carried us." Participant 4 sought a mentor to help her navigate the journey, but the mentoring program did not exist at her child's hospital. When the program was launched, she became

enthusiastically involved in the mentoring program to help other families in their cancer journey. She emphasized the value of knowing someone who is "5-10 steps ahead," who could provide hope for the future. While she currently serves as a mentor to others, she said that she would benefit from a mentor who could help her navigate the unknowns she still faces with her child's development and transition into adolescence.

Participant 5

Participant 5 is the mother of a 9-year-old daughter with medical complexity. She explained that she and her husband were "late bloomers," having their daughter when they were older. At the time of their child's birth, she was a 36-year-old social worker, and her husband was a 56-year-old military veteran. During the first trimester of her pregnancy, doctors discovered that their child might have a rare chromosomal abnormality. After an amniocentesis, it was confirmed that their child had trisomy 9. She expressed that her faith was part of her decision to carry the pregnancy to full-term. As a previous social worker, Participant 5 sought out resources and support groups to help her navigate the potential loss of pregnancy. Against all odds, their daughter survived. When their child was 1 year old, further genetic testing revealed that she had trisomy 9 with Dandy-Walker syndrome. The challenges of everyday parenting included difficulty navigating accessible parking at appointments; lifting her daughter, who uses a wheelchair; and changing her diapers in public bathrooms not suited for older children.

Participant 5 described receiving the most support initially from her daughter's specialized clinic. Through the specialized clinic, she became connected with a parent support group that helped her feel less alone. She also found support in private Facebook groups. She described some of those online groups as her "lifeline." Participant 5 also described the role of friends and church members who helped her financially when she endured the loss of her

husband. Participant 5 emphasized the importance of mental health support for parents of CMC and stated that she has a team of mental health professionals and friends readily available to her, when needed.

<div align="center">**Themes**</div>

Three salient themes emerged from the data analysis. Participants discussed their experience with social support and parental burnout as it related to parenting a CMC. Types of social support, isolation, and helping others were discussed by all or most participants. Table 2 outlines the three themes with subcategories.

Table 2

Themes and Subcategories

Theme/Subcategory	Description
1	Types of Social Support
Subcategory 1	Church Support
Subcategory 2	Practical Support
Subcategory 3	Mental Health Support
Subcategory 4	Respite/Childcare Support
2	Isolation
3	Helping Others

Theme 1: Types of Social Support

All participants shared about various forms of support they experienced throughout their parenting journey. Types of support that were most frequently mentioned by all or most participants were grouped into subcategories. Church support, practical support, mental health support, and respite or childcare support were discussed by all or most participants. The following subcategories described four types of social support most relevant to the participants in this research study.

Subcategory 1: Church Support

When asked about forms of social support that helped with parental burnout, Participant 1 expressed church as a primary source stating, "I would have to say that it came from my church. Um, for a long time, we weren't able to go to church. Um, just because of how medically fragile he was. We just didn't feel comfortable." She further explained how challenging attending church was due to the amount of medical equipment her child needed.

Participant 2 expressed church support as "the greatest measure of support" she had during the early stages of her international adoption of two CMC. She stated, "I think our greatest social support was, has been through our church, I feel like just even you know, when you are active in your church, and you build those relationships, even through your community groups, that helps." She explained how she had a supportive small group that acted as a team, during the early stages after the adoption. The church played a significant role in the transition of bringing her children home from China.

Participant 3 expressed a similar experience to Participant 1 about the length of time before she was able to take her child to church. When asked about the types of social support she experienced, she stated, "Church support, not so much early on, because we weren't a member of any church for probably his first two years." She further explained that, although she was not attending church, she knew people in the churches and began connecting with them after her child turned approximately 2 and a half years old. She explained how attending church allowed her to obtain faith and prayer support. Later in the interview, Participant 3 explained the role of church support and having a community of people to talk and pray with. She said, "And then as far as church service, the support I get there, asking for prayer, them just reaching out to see how

I'm doing. That, that's definitely been a huge, a huge stress relief." She explained how beneficial it was to know there are people she can reach out to when she is having a difficult day.

Participant 4 became emotional when discussing the role of her church community during her child's cancer treatment. She stated, "And so we had a great family around us we had our church family, it was very small and very strong…" She shared about how a friend from her church did her laundry on a weekly basis for a year, because during that time they lived in an apartment that did not have laundry amenities. Friends from church provided her with practical support during a very difficult time. Later in the interview she added that many friends in her community have "had to change churches because they couldn't bring their kids [with special healthcare needs] there. They couldn't come as a family. Because nobody was comfortable dealing with their child. It's not fair."

Participant 5 expressed the need to find a new congregation that was better suited for her family's needs. When asked about different forms of support she had, she included, "but that congregation didn't and does not know how to serve my family, as a special needs family. I found another congregation that does. And they have come alongside and helped in tangible ways, cleaning, breaking down medical boxes." Later in the interview she expressed that church members also helped financially and by delivering meals and groceries.

Subcategory 2: Practical Support

Discussions on practical support were often mentioned along with church support, but due to the slight differences, practical support was analyzed as a separate theme. Church support encompassed spiritual and communal support, while practical support referred to specific task-oriented support. Participant 1 did not comment on receiving practical support, however she explained how she offered practical support to others in the form of meals and childcare.

Participant 2 discussed how helpful practical support in the form of meals was when she stated, "those moments I, I still remember … I could just take a break and not worry about feeding everybody…Just that extra bit of help, whether it's providing a meal, or just taking the other kids." Participant 3 expressed how some friends were willing to provide tangible support, such as meals and help with cleaning but not anything more, due to feelings of discomfort. She stated:

> I've had friends that have tried to reach out and, you know, I kind of discovered that I had friends who were willing to come over and sit with me. I had friends that were willing to bring food or go grocery shopping, people who were willing to come over and clean. And then I had the other. I had other people who just said, I am not comfortable with this, you know, I will bring you food, but I am not comfortable being, you know, trying to take care of him or learning how to do and care for him. So, I had to kind of accept that and respect them for that, even though it didn't necessarily meet my needs or what I was expecting.

As previously mentioned under church support, Participant 4 received practical help from her church community, family, and friends. She noted that prior to her son's diagnosis, she was a very self-sufficient person. She described being in such need of help as a humbling experience. She noted that having a friend she could count on to take care of the laundry gave her some stability during an unstable time.

Participant 5 also attributed practical support to members of her church who helped with meals, financial support, and cleaning. She also described the financial strain that she experienced from losing her career and income when she became the full-time caregiver of her

child. She described, "And friends have grocery shopped before when it was just too, you know… there was so many people that helped keep us afloat."

Subcategory 3: Mental Health Support

Participant 1 described the importance of addressing mental health for mothers. She stated, "And that it's extremely important as a mom to not isolate, and not, you know, just go into our own space, and not allow other people in, it's not healthy, and it can cause depression." She highlighted how important it is to have "different pockets of moms" that she can turn to about different issues she is facing. She explained that without social support people can have "some pretty negative thoughts, which can turn into some pretty bad outcomes."

Participant 2 discussed how she coped with mental health struggles saying, "When you're dealing with it [parental burnout], and so being able to communicate, and honestly, authentically, where you're at how you're feeling, and I think helps you to process it, so that you can kind of let it go." She also discussed different support systems she had in place for her other child with a special healthcare need. She noted that she has counselors and psychological support available to her as it related to her other child's needs.

Participant 3 explained how helpful counseling services have been for her. She noted how easily she can schedule an appointment anytime. She stated, "And even though we haven't used the service lately, I know I could easily schedule an appointment and talk to them, you know, with stuff that's going on. So that's been a huge help." She also suggested that mental health assessment and planning should take place at discharge to determine what kind of help would be in place for the family.

Participant 4 referred to being in a dark place: "But if you're by yourself, and that's all you've got, you just kind of sometimes you can cycle and be in a really dark place without

somebody to, to lift you up." She also discussed seeking counseling after experiencing the loss of two friends' children who were patients at the same hospital where her son was treated. She explained, "We did talk to psychology services a few times, especially when we lost our first patient friend. That was devastating." She further explained that she wished she had prioritized seeking help sooner. Participant 4 stated:

I went ahead and finally went to counseling … if I had known what I know now, I would have, I like to think that I would have gone to counseling sooner …The more you can take care of yourself, the healthier person you are to take care of your baby and to take care of the rest of your life. Whereas for me, I had it, I had it backwards.

Participant 5 noted how much anxiety she experienced during the first six weeks postpartum. She stated, "I said [to the doctor], I don't need anything for depression. I need something for my nerves, because keep in mind, my child could die at any moment." She also stated that, as a former social worker, she was well aware that she needed professional help. She described a mental health team that she relies on for support. She stated, "But that includes a psychiatrist, a psychotherapist, and five friends on speed dial…if I run into trouble, I could call them at any time in middle of the night. I also keep professional crisis line numbers available to myself."

Subcategory 4: Respite/Childcare

Participants discussed the need for respite and childcare options. Most mothers elaborated on the limited resources available and lack of insurance related benefits. However, Participant 3 did not reference childcare specifically but did speak about the role of night-nursing as a valuable asset for her family in the early stages of her child's diagnosis.

Participant 1 emphasized the importance of offering childcare along with support groups. She described how she and her husband started a parent support group at the local clinic where her son receives care. She stated, "We wanted to offer childcare, because we know that that's a barrier to attending groups."

Participant 2 discussed the need for more support options that could potentially be covered by insurance. She expressed how often other mothers of children with special needs provide the support needed because they are keenly aware of the challenges. She explained how beneficial it would be if there were more community outreach groups focused on providing childcare or respite care. She described how mothers often stretch themselves to help one another. She stated, "I think a lot of moms that I have talked to feel like that probably over half of the support they get are from other moms of children with special needs."

Participant 4 discussed programs that provide date nights for parents. She explained that these programs are helpful for families; however, due to the times available, their family did not participate. She stated, "But I do know families who participated in it, families who, with kids, like on the spectrum or with you know, traches and g-tubes." She also emphasized that she was previously nervous about offering to help care for a child with behavioral issues but now she promotes learning, training, and asking questions.

Participant 5 expressed how limited options are for medically appropriate childcare. She stated, "So the childcare/respite piece and summer programming when school is out. Summer or any break. No one wants our kids. It has to be medically appropriate." She explained her experience of calling local organizations for medically appropriate summer camps. She stated that many programs do not have wheelchair transportation or elevators. She also emphasized

that, even if all the available supports for parents existed, without childcare, parents cannot attend.

Theme 2: Isolation

Feelings of isolation were discussed by all participants in the research study. When asked to describe their experience with parental burnout, all or most of the participants noted that they "felt alone" or "on their own". Participant 1 expressed the importance of social support in the context of isolation saying:

> Social support is so important because as a mom, I did feel isolated. A lot of times, I did feel like nobody understood what I was going through. And there would be times where people would give me advice, who did not have children with any type of medical condition, behavioral issue, disability, whatever. And they would say certain things to me that were extremely hurtful. They would say things to me that I considered to be thoughtless and cruel. They weren't trying to be, but they just didn't get it, they didn't understand.

Participant 2, the adoptive mother, elaborated on the challenges of connecting with people who may be afraid or reluctant to interact with her child. Further, Participant 2 commented that being a part of a parent support group for another one of her children allowed her to be supported as a parent of a child with a special need. She stated, "And so I feel like we're getting that emotional, psychological support for that. And then, um, you know, just even having the parents in, to be able to kind of share ideas and struggles, helps you feel less alone." This detail from Participant 2 reflects the theme of isolation, because as a parent of multiple CSHCN, her experience with social support had an effect on her life as a whole. In a follow-up email, Participant 2 elaborated on her experience with isolation. She stated:

Isolation has definitely been part of my experience in parenting my child with medical complexity. My husband and I found that most people hesitate to invite us over knowing about our child's mobility challenges. We also feel that parenting children with cerebral palsy sometimes creates a barrier in relationships as people have a hard time relating to our situation or might fear interacting with our children. This loneliness has taken a profound toll on our feelings of happiness, to be honest. I feel it takes more time and effort to develop relationships now that we parent children with medical complexities. Most often, it requires us to initiate interactions by inviting others over to our house first. This can be draining since it requires some preparing (entertaining, food, cleaning the house) while keeping up with other responsibilities. We do believe the extra effort is worth it, but there are times we have to get through a season of burnout before we are ready to engage.

Participant 3 described losing contact with friends and family. Participant 3 discussed how she felt she was "on her own" when she and her child were being discharged from the hospital after 6 weeks of NICU care. Participant 3 expressed how helpful it would be if there were "more counseling times, whether it's child life or mental health discharge planning, just to see what they're going to need in the home." Specifically, she suggested that the hospital team help parents identify caregiver roles prior to discharge. She elaborated on her experience with isolation by stating:

And then just losing contact with family and friends because they were scared, you know, they didn't want to come over because they didn't know what they were going to see. All these people that I thought would be willing to help all of a sudden just disappeared, you know, they weren't willing to do anything but or return a call or reach out.

Participant 4 expressed how parenting a medically fragile child exacerbated feelings of isolation that she had prior to her son's diagnosis. She explained that having a child with a chronic illness required medical isolation. She expressed how difficult it was to tell friends, "if you've been around anybody with a cough, don't come to my house." Participant 4 elaborated on the "sudden severing of relationships, community, and stability" which she felt like she "had to do it just to keep him safe. Just to keep him alive." Participant 4 highlighted the value of having friends and a community to help her overcome negative thoughts. She explained how isolation can affect one's mental and emotional status. Participant 4 stated, "And then when you have that social isolation required, whether it's, you know, because of counts or because your child is medically fragile. It just intensifies it because you don't have anybody else speaking into your life."

Participant 5 discussed the role of internet-based support in helping her stay connected. She elaborated on how helpful online resources can be for parents of CMC. She explained how she belongs to several private Facebook groups. She stated that these groups were a "lifeline to not sink in the dark at home." She explained that when she stopped working, "that gave a new meaning to isolation." She described how she initially sought support through books and blogs, but eventually found internet support groups. Participant 5 explained how the connections she has made with other mothers are "closer than some of the blood relatives I have". She stated that because they understand the challenges and also "live it around the clock." She explained that mothers in these online support groups are able to understand each other and help her to stay connected.

Theme 3: Helping Others

Participant 1 co-founded a support group for caregivers of CSHCN. She stated that the group she needed did not exist; therefore, she created a support group for this purpose. Participant 1 stated, "it really was about trying to find something for myself. And I wasn't able to really find a group where I felt like, you know, we, we fit in." Participant 1 and her husband decided to create the group she wished she had. She explained how critically important it is for families to find a support group. She explained, "And sometimes the support groups are virtual, sometimes they're face-to-face. I mean, we're dealing with COVID now, so everything's virtual." She also explained the role of her faith in helping her find purpose. She described how helping others changed her perspective.

Participant 1 explained that she feels down when she thinks about circumstances that are not going well. However, when she reaches out to others, she feels better. She explained some of the ways she supports others, such as, "babysit for them for a couple hours, so they can take a nap or they can go take a shower or go to the store, bake cookies for them, send a meal." She described how engaging in helping activities caused her to feel better about her circumstances. She stated, "And it gave me a sense of fulfillment that I didn't have."

Participant 2 did not initially discuss helping others as part of her journey as an adoptive mother of CMC. In a follow-up email, she provided additional comments on how she shares her experiences with other parents who are considering adopting a CMC. She stated that she also helps other parents find medical resources, such as therapists and doctors.

Participant 3 discussed realizing how an in-person support group was not only beneficial to her, but how her presence could benefit others. She explained the realization that attending support groups was a great opportunity to talk to other parents that were dealing with similar

situations, but then realized that she could be a help as well. She stated, "because parents may be experiencing something that I've already been through. I can say, 'I've been through a similar thing that you're going through. And here's what helped me.' I could share my story and any resources I had."

Around the time when her child was about 2 years old, the hospital's Governmental Relations Department approached her to ask if she would be willing to share her story in Washington, D.C. Participant 3 was not ready to travel with her son at that time, but, after a few years, she agreed to share her family's journey with a CMC. In the years that followed, she engaged in more parent advocacy work in Tallahassee, Florida and Washington, D.C., becoming a board member of several organizations serving CSHCN.

Participant 4 discussed her strong desire for a mentor during the time of her son's treatment. She described asking her child's doctor if he could connect her with another parent of a child with an astrocytoma/glioma. Her child's doctor could not give her any contact information due to HIPPA laws, but she remained in communication with the hospital over time and became a mentor to others when the program was developed. She stated,

> And as a mentor, now, on the other side…the one 5-10 steps ahead, is just, it's just so humbling to be a part of somebody else's journey. And whether I say, or do something that they remember, or has no effect on their life is not the point. The point is just being there.

Participant 5 discussed helping administrators of Facebook support groups, using her professional background in social work. She explained how moms have shared their mental health needs in a Facebook group. She explained how she helps other mothers online. She noted that some mothers type, "I need to go inpatient, but I have nowhere to leave my child or I am

about to commit suicide." Therefore, she created a resource including national crisis hotline numbers for the group administrator to post. Participant 5 also explained how she shares her story to let parents know they are not alone. She gave an example of some of the advice she gives other parents stating:

No, you're not crazy. Yeah, it happens this way in Florida. And you're not a bad parent for having to stop work or feeling this way, work through it, find a good therapist, talk it out. It's okay. But don't sit there at home and just keep sinking and sinking to the point where you consider taking your life. But even if you have to have an inpatient stay, it's okay. You can recover. You can find a healthy level of maintenance.

Evidence of Quality

As suggested by Creswell and Poth (2018), the data was circled numerous times to uncover patterns and themes. The researcher included participants in the verification process by providing transcripts for their approval and member checking for participant feedback during the analysis of the data. Any questions the researcher had during analysis were verified in follow-up calls or emails with the participants. Using data source triangulation, themes were corroborated by all or most participants. By interviewing more than one data source, results were triangulated, which provided validity and richness to the themes.

Summary

Mothers of CMC provided rich data to answer the research question. The five mothers provided unique perspectives on how social support mitigates parental burnout. Through a cross-case analysis, salient themes and subcategories were identified among the five cases. Three salient themes emerged from the data analysis: types of social support, isolation, and helping others. Four subcategories of social support were identified: church support, practical support,

mental health support, and childcare/respite support. The findings and implications of this study

are discussed in Chapter 5.

V. DISCUSSION

The purpose of this case study was to explore the role of social support in mitigating parental burnout in mothers of CMC. Social support was generally defined as, "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al., 1979, p. 109). Parental burnout was generally defined as a specific syndrome resulting from prolonged parental stress. Dimensions of parental burnout included exhaustion, emotional distancing, and a sense of ineffectiveness in the role of parenting (Mikolajczak et al., 2018). Children with medical complexity were generally defined as a subgroup of CSHCN. Children with medical complexity have significant health complications that affect multiple organ systems, which result in functional limitations, high health care needs, and often the need for medical technology (Kuo & Houtrow, 2016).

Parents of CMC face a wide range of challenges related to their child's medical condition. Parental burnout is a syndrome that impacts approximately 20% of all parents and 36% of parents of children with chronic conditions (Lindström et al., 2010). Mothers were consistently identified as more exhausted when compared to fathers (Roskam & Mikolajczak, 2020). Mothers of children with special needs or chronic illnesses experienced higher levels of parental burnout than mothers of children without medical or special needs (Gérain & Zech, 2018; Lindström et al., 2010). This study contributes to the literature on the role of social support for mothers of CMC and provides greater insight into mothers' parental burnout experience.

Parental burnout can affect any parent regardless of the particularities of the child (Mikolajczak et al., 2018). However, parents of CSHCN are at a greater risk of parental burnout (Lindström et al., 2010). Prior research on parental burnout and parents of CMC has focused on identifying and measuring parental burnout, not on support interventions. Other research on social support has examined specific forms of support for parents of CMC, not specifically to mitigate parental burnout.

Therefore, the research in this case study filled a gap in current research by exploring the role of social support in mitigating parental burnout in mothers of CMC. Participants included five mothers of children with various forms of medical complexity resulting from bacterial meningitis, CP, CCHS, astrocytoma/glioma, and trisomy 9 with Dandy-Walker syndrome (See Table 1). At the time of the study, the children's ages ranged from 9-16 years old. The participants' experiences provided meaning to the role of social support in mitigating parental burnout.

Table 1

Participant Details

Participant Number	Age of Child	Total Number of Children	Diagnosis
1	16	4	bacterial meningitis (5-months-old), intellectual disability, autism
2	15	9	cerebral palsy (CP)
3	11	1	congenital central hypoventilation syndrome (CCHS)
4	12	3	astrocytoma/glioma
5	9	1	trisomy 9 with Dandy-Walker syndrome

Methods of Data Collection

After receiving Institutional Review Board (IRB) approval from Southeastern University, participants were recruited for the research study. A digital flyer was disseminated via social media, email, and word of mouth (See Appendix D). Interested participants completed a pre-screening tool using Google Forms to determine eligibility (See Appendix A). All participants were provided with a digital consent form as part of the pre-screening tool (See Appendix C). All eligible participants were contacted via text message to assess the best time to schedule an interview.

All interviews were conducted using Zoom video conferencing. An interview protocol was used to conduct semi-structured interviews (See Appendix B). Interviews were recorded, stored on Zoom cloud, and transcribed using the Otter transcription service. Transcripts were sent to participants via email for validation. Upon final approval of transcripts, the inductive process of qualitative data analysis began. All files and electronic records will be deleted 5 years after the study's completion.

Summary of Results

Five mothers of CMC were interviewed regarding the role of social support in mitigating parental burnout. In alignment with the social constructivism theory, social interaction was explored to construct knowledge (Creswell & Poth, 2018). Three salient themes emerged from the data analysis: types of social support, isolation, and helping others. Four subcategories of social support were identified: church support, practical support, mental health support, and childcare/respite support.

All participants described different types of social support from social networks and the greater community, which benefitted them throughout their experience of parenting a CMC (Lin

et al., 1979). Participants described church support as both practical and spiritual. Participant 2 emphasized the role of her church community group in meeting tangible needs, such as meal delivery and providing the emotional support of listening and helping her see things "in a different light." Participant 3 discussed receiving prayer support from her church community. Participants shared the types of practical support they received, such as help with cleaning, laundry, groceries and meal delivery, and financial support. Participants explained that practical support relieved emotional and financial pressure during difficult times. Participants discussed the value of seeking mental health support as an important part of mitigating parental burnout. Participants discussed the need for more respite and childcare supports. Participant 1 explained that lack of childcare is a barrier to attending support groups for parents of CMC.

All participants discussed feelings of isolation. When describing their experiences with parental burnout, participants noted feeling alone or "on their own." Participant 1 described the feeling that no one understood what she was going through. Participant 2 described how parenting a CMC can create "a barrier in relationships" since many people do not know how to interact with her child. Participant 3 described losing contact with friends and family members who were scared or uncomfortable around her child.

Despite the challenges each of the participants faced, all participants described how helping others has become a part of their lives as parents of CMC. Participant 1 explained how helping others helped change her perspective. Participant 3 discussed her active role in public speaking and raising awareness for CMC. Participant 3 also discussed how she attends support groups, not only for herself but to provide support to others. Participant 4 explained how she became a parent mentor in the mentoring program at her child's hospital. Participant 4 described the importance of being there to listen and support parents on their journey.

Discussion by Research Question

Research Question

How does social support help mitigate parental burnout in mothers of children with medical complexities?

One research question guided the study on the role of social support in mitigating parental burnout in mothers of CMC. The participants of the study expressed their experience with parental burnout as it related to parenting a CMC. Each participant elaborated on the types of support they received and how they cope with parental burnout. Frequently expressed words and phrases were coded and combined to form themes and subcategories. All participants highlighted the following types of support: church support, practical support, mental health support, and childcare/respite support. All participants shared feelings of isolation in addition to parental burnout symptoms: overwhelming exhaustion, emotional distancing, and a sense of ineffectiveness in the parenting role (Mikolajczak et al., 2018). All participants expressed how helping others find support had been an important part of their journey.

While all participants had variations in their social support experience, each discussed types of social support, isolation, and helping others. Participant 1 emphasized the support she received from her church and her husband. Participant 2 highlighted her church's role in helping her find support after adopting two children with CP. Participant 3 focused on the role of hospital support, friends, and church members who helped meet practical needs. Participant 4 discussed her friends, family, and church's role in providing her with practical support. She also discussed seeking professional support. Participant 5 emphasized the support she received from her church and private online support groups. All participants expressed having positive experiences with

social support. The following discussion reveals the connection of each theme to existing

literature (See Table 2).

Table 2

Themes and Subcategories

Theme/Subcategory	Description
1	Types of Social Support
Subcategory 1	Church Support
Subcategory 2	Practical Support
Subcategory 3	Mental Health Support
Subcategory 4	Respite/Childcare Support
2	Isolation
3	Helping Others

Theme 1: Types of Social Support

All participants readily shared the types of support they experienced throughout their

parenting journey. Participants explained that they had received support; however,

improvements to existing supports should be prioritized. All participants discussed the role of

church support. Four out of five participants discussed receiving practical support, mental health

support, and respite care or childcare support.

Cohen and Wills (1985) discussed four support resources: esteem or emotional support,

informational support, social companionship, and instrumental support. Participants affirmed the

value of these categories in their account of social support. Participant 2 highlighted the

emotional support from close friends who provided "a listening ear." Participant 3 discussed the

informational support she received through her child's hospital in the form of training.

Participant 3 also noted that she offers informational support to newly diagnosed families.

Participant 4 described her role as a parent mentor to other families of children with pediatric

cancer. Participant 4 explained how she provides social companionship to other families, by

simply being there to listen. All participants described the value of instrumental support in the form of practical support, such as cleaning, delivering meals, and financial support. However, church support or religious support was not represented in Cohen and Wills' (1985) model.

Edelstein et al.'s (2017) systematic review of support interventions for parents of CMC covered six categories of support interventions: care coordination models, respite care, telemedicine, peer and emotional support, insurance and employee benefits, and health and related supports. The participants in the current study confirmed the importance of the intervention approaches described by Edelstein et al. (2017), including peer support groups, mentoring, internet-based support groups, and professional support. Participant 1 facilitates a peer support group for parents of CSHCN. Participant 2 and 5 discussed the role of social media as a source of support. Participant 3 discussed the benefit of peer support groups and professional counseling. Participant 4 described her involvement in a peer mentoring program through her child's hospital. Participant 5 emphasized the benefit of connecting with other parents using social media and internet support groups. In addition to peer support groups, mentoring, and internet-based support groups, all participants discussed the role of religious or church support as a vital part of their social support networks.

Participants discussed the role of church support on their journey with parenting a CMC and parental burnout. Positive experiences with churches were described by four out of five participants. Participant 1 described the church as a primary source of social support, although she faced challenges attending church during the early stages of her child's diagnosis. Participant 2 referred to her church as the "greatest measure of support" she had when she adopted her son with CP. Participant 3 explained the benefit of having a church community she can turn to when she is having a difficult day. Participant 4 shared her church community's vital role in providing

tangible support during her son's cancer treatment. Participant 4 also contributed that some

friends of hers have changed churches because of the lack of available opportunities for their

child's special healthcare need. Participant 5 expressed the need to find a new church that would

be able to support her family better.

Merino (2014) explored the religious dimensions of social ties and the provision of social

support. The current study's findings related to church support affirm Merino's (2014) conclusion

that individuals with religious social ties are likely to receive more social support within same-

faith communities. Likewise, all participants explained how people from the churches they attend

offered practical or spiritual support. This finding underscored the role of churches in providing

social support to this small population of families of CMC. Vitorino et al. (2018) examined the

effect of spiritual and religious practices with improved mental health outcomes and concluded

that individuals with high spirituality and religiousness were significantly correlated with better

mental health outcomes. Based on the participants' accounts, being involved in churches

provided necessary supports that improved their lives emotionally, practically, and spiritually.

Participants discussed how their friends, family, and church communities supported them

in practical ways. Practical supports included meal delivery, grocery shopping, financial support,

and cleaning. Participants expressed deep appreciation for these gestures. Participant 4 described

receiving practical support as a humbling experience. When discussing practical support,

Participant 5 described how "so many people helped keep us afloat." Cohen and Wills (1985)

discussed the various types of social support, including instrumental support. Instrumental

support was described as tangible or material support, including financial or in the form of

services provided (Cohen & Wills, 1985). Participants 2, 3, 4, and 5 affirmed the value of

instrumental support when they expressed their gratitude for tangible support in the form of

meals, groceries, and finances. Mattson and Kuo (2019) asserted that providing parents of CMC with coping skills and practical support can lead to better care of children and the parents themselves. Practical support can alleviate everyday stressors and does not require special skills or training by the person offering help. The current study supports Mattson and Kuo's (2019) conclusion that practical support contributes to social support for mothers of CMC. Participants described how practical supports alleviated anxiety and helped them to focus on their child rather than worrying about everyday tasks.

Four out of five mothers discussed seeking professional counseling. Participant 3 discussed knowing how to access counseling services through her child's hospital, when needed. Participant 3 described the counseling services as "a huge help." Participant 4 discussed wishing that she had prioritized her mental health sooner. She described being "in a dark place" before seeking counseling. Participant 4 expressed that now she understands the importance of prioritizing her own mental health as a way to care for her child. She stated, "the more you can take care of yourself, the healthier person you are to take care of your baby." Participant 5 explained the importance of having a mental health team as part of her support system. She proactively assembled a support team for herself and recommended that other mothers of CMC do the same. Glader et al. (2016) described a family-centered care model, which promotes a holistic view of the family, thereby improving health outcomes for the child and reducing stress for the whole family. The participants affirmed this perspective as a priority for mothers of CMC. All participants shared that prioritizing their mental health allowed them to be more effective at taking care of their children.

Participants in the research study discussed the importance of respite care as part of social support. Participant 1 explained that inadequate childcare is a barrier to attending support groups;

when she started a support group through her child's hospital, childcare was included. Participant 1 knew attendees would require childcare to participate. Participant 2 explained how most support often comes from other mothers of CMC. To offset the high cost of childcare, Participant 2 expressed how helpful it would be if there were more respite care options available that insurance could cover. Participant 5 explained how challenging it was to find summer programs for her daughter. She emphasized the importance of medically appropriate and accessible childcare options. Participant 5 expressed, "no one wants our kids." Participants 1, 2, 4, and 5 affirmed that there is a need for more respite care options and medically appropriate childcare for CMC.

Theme 2: Isolation

The goal of the research study was to explore the role of social support in mitigating parental burnout for mothers of CMC. In the process of discussing parental burnout, all participants highlighted the shared feeling of isolation. This finding provided valuable insight into the parental burnout experience for mothers of CMC. Participant 2 described how "loneliness has taken a profound toll on our feelings of happiness" due to a lack of community. Participant 2 explained how difficult it is to initiate relationship building with people who are not comfortable around her child with CP. Participant 3 described losing relationships due to family and friends' feelings of discomfort around her child with CCHS. Participant 4 explained the "severing of relationships" caused by medical isolation. She explained how difficult it was to ask friends and family to stay away if they had a cough, in order to protect her child with pediatric cancer. Participant 5 also expressed how difficult it was when she stopped working. She stated, "that gave a new meaning to isolation." She elaborated on how being a part of internet-based support groups helped her to not feel alone.

Florian and Krulik (1991) explored loneliness and social support for mothers of chronically ill children. Researchers concluded that mothers of children with chronic illnesses experienced higher levels of loneliness than mothers of children without medical conditions. Further, Mattson and Kuo (2019) recognized the value of social support in reducing the risk of stress, loneliness, depression, and anxiety in caregivers of CSHCN. Participants in the current study affirmed the conclusion of Florian and Krulik (1991) regarding loneliness in mothers of CMC, when they discussed the feelings of isolation associated with parenting a CMC.

Theme 3: Helping Others

All participants discussed helping others as part of their journey while parenting a CMC. Participant 1 was the co-founder of a local support group for caregivers of CSHCN. Participant 1 and her husband have facilitated a monthly support group for a decade. She and her husband started the group, because there were no support groups available that met their needs. Participant 1 explained that helping others gave her a sense of fulfillment. Participant 3 described her role as a parent advocate, speaker, and mentor to other parents of CMC. Participant 3 explained that she had offered her contact information to the hospital social workers to allow other parents to contact her for support. Participant 3 elaborated on the importance of sharing her story and resources she had discovered along her journey, with other parents of CMC. Participant 4 volunteered as a mentor to families of children facing pediatric cancer through her child's hospital. Participant 4 explained how much she desired a mentor during her son's medical treatment. When the mentoring program was formed, Participant 4 became enthusiastically involved. Participant 4 described being available to other parents as a humbling experience. Participant 5 described how she utilized her prior experience as a social worker to provide resources, such as mental health hotlines and advice to other parents through private internet-

based support groups. Participant 5 gave examples of the advice and encouragement she provided to other families of CMC. All participants expressed the importance of helping others find information and resources needed for parenting CMC.

Study Limitations

Although the current study has the merit of providing insight into parental burnout and social support for mothers of CMC, it is not without limitations. According to Creswell and Poth (2018), case study research often includes the use of field observation and analysis of archival data. First, no medical records were required as part of the study design. Examining medical records could have enhanced the case study. Participants completed an eligibility survey to indicate whether they had a CMC. All participants indicated that they had a CMC; however, collecting medical documentation could have helped provide more insight into the child's diagnosis. Second, there were no field observations due to the COVID-19 pandemic. Observing mothers in their natural environment with their children could have enhanced the research by providing context to the interactions between mothers and their children. Finally, the research was conducted during the COVID-19 pandemic, which could have potentially exacerbated feelings of isolation. Feelings of isolation could have increased because of the physical and social distancing guidelines throughout the United States and the world, resulting in less social interactions during the time of the research study.

Implications for Future Practice

The findings of this study provide insight for community-based organizations, practitioners, and mental health advocates. Future practice recommendations are geared toward individuals and organizations that work with families of CMC. The findings regarding church support provide insight into how community-based organizations can partner with churches to

provide training and resources to support families of CMC. Although research studies have not

prioritized examining the role of churches in supporting families of CMC, the participants of this

study underscored the prominence of the church setting as a location occupied by families of

CMC. According to Lin et al. (1979), churches are part of a greater network of social support.

Churches that seek to provide practical support to people in need can fulfill this mission by

providing consistent support to families of CMC. Churches often include ministry outreaches

that emphasize practical support, such as delivering meals, helping with groceries, and cleaning.

These practical supports can effectively meet some of the basic needs of families of CMC.

According to Merino (2014), same-faith relationships were significantly more likely to provide

"help in times of need" (p. 595). For families of CMC to join churches, it is imperative for

church staff and volunteers to make coming to church as smooth and welcoming as possible,

given the challenges expressed by participants. Churches can implement plans to ensure physical

accessibility, including appropriate accommodations made available for parents and CMC.

Implementation of these recommendations could make a lasting difference in the lives of

families facing long-term medical care for their children.

Community-based organizations should administer needs-assessment surveys on an

ongoing basis to identify the needs of families of CMC and inform program development. Long-

term wrap-around services using a holistic or family-centered care model can help ensure that the

entire family receives adequate social support (Glader et al., 2016). Recommendations for

community-based organizations include long-term support opportunities for parents of CMC.

Practical or instrumental support can be offered to families on a rotating long-term basis.

Participants in the research study emphasized the need for long-term follow-up as their children's

conditions are chronic and life-long. Participant 3 noted that her son's medical needs are not

better or worse than when her son was younger, just different. Participant 4 also discussed how she still desires a mentor who can help her navigate her son's transition into adolescence.

Community-based organizations should secure partnerships with mental health advocates to provide mental health support services. It may be beneficial for partnerships between counseling centers and community-based organizations to offer sponsored counseling services or peer support groups to those individuals who do not have adequate insurance or resources through their child's hospital. Enhanced respite and childcare support should be prioritized as a highly needed program for development. Possible solutions can be provided in partnership with other organizations and specialized camps.

To address the experience of isolation, community-based organizations can create strategic plans to ensure mothers social-emotional needs are being met. Online resources, webinars, and podcasts can provide educational material to help mothers navigate available resources. Professional coaching may be beneficial, especially for mothers who struggle with asking for and receiving help. Community-based organizations or mental health professionals can encourage parents of CMC to join websites, such as Caringbridge.org, where mothers can easily share email updates with their community and social support network. Video content or reading material can allow mothers to process the benefits of allowing others to help.

Providing mothers of CMC with opportunities to help others may add value to community-based support services. Mentoring programs can allow experienced mothers to impart knowledge to mothers of newly diagnosed children. Mothers who help provide support or raise awareness for families of CMC may experience positive benefits, such as fulfillment and a greater sense of purpose.

Recommendations for Future Research

According to Creswell and Poth (2018), a goal of case study research is to identify a diverse sample of cases to understand a particular issue. Therefore, the present case study included five mothers of children with various forms of medical complexity to understand the role of social support in mitigating parental burnout. Participant 2 represented an even smaller group of mothers of CMC who have adopted children. The variations in her account suggest that different support channels may be appropriate to help mitigate parental burnout for adoptive mothers of CMC. Future qualitative studies focused on examining the parental burnout experience in adoptive parents of CMC are recommended.

Merino (2014) and Vitorino et al. (2018) highlighted the role of religious identity on social support and mental health among adults. Future studies on spirituality and religious identity may yield greater insight into church support as a vital source of support for parents of CMC. Additionally, a more in-depth study on social support and religious organizations or denominations would reveal which types of churches are more experienced or equipped for providing social support services to parents of CMC.

The field of parental burnout research is expanding rapidly. The current study provides insight into possible topics for further investigation. As confirmed by Roskam and Mikolajczak (2020), the consequences of parental burnout for fathers can be even more detrimental than for mothers. Future studies should explore the experience of parental burnout and the role of social support for fathers of CMC. Because isolation was identified as a common theme among all participants in the research study, further research is warranted to discover if isolation is a predictor or relevant criteria for parental burnout in mothers of CMC. Future quantitative or mixed-method studies would be beneficial to explore the relationship between parental burnout

and social support using validated measurements. Quantitative research on social support and parental burnout in parents of CMC would produce greater generalizability.

Findings of the current study suggest that mothers of CMC may experience positive benefits from helping others. Future studies on the role of helping may provide valuable insight into the motivations, outcomes, and benefits for mothers of CMC. Additionally, further studies on the types of helping activities and timing of engaging in volunteering may provide information regarding the experience of parenting a CMC.

Conclusion

Appropriate social support provides mothers of CMC with resources to cope with parental burnout symptoms. Social support from friends, family, and the greater community contributes to decreased feelings of isolation. In particular, church support, practical support, mental health support, and respite/childcare support emerged as prominent themes for mitigating parental burnout in mothers of CMC. This research has contributed to the body of literature concerning the parental burnout experience and the role of social support for mothers of CMC. Community-based organizations can utilize this data to help identify needs and create programs that will effectively support this target population. By creating robust social support opportunities, community-based organizations can partner with other agencies to mitigate parental burnout and feelings of isolation. As presented in the data, parents of CMC may find purpose in helping others. To mitigate parental burnout and feelings of isolation, community-based organizations, practitioners, and mental health advocates can help families of CMC to find social support resources and opportunities to help others.

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Appendix A

Pre-screening Tool (Google form)

1) Are you the mother of a child with a complex medical condition between the ages of 3-18 years old? Yes/No

2) If yes, please select the following (checkboxes):

   - My child has a significant functional limitation, such as limited ability to walk, feed, or breathe independently.

   - My child receives care from multiple specialists.

   - My child relies on medical technology, such as mobility assistance, a communication device, or a feeding tube.

3) Have you ever experienced parental burnout? Parental burnout is defined as a specific syndrome resulting from prolonged parental stress. Dimensions of parental burnout include exhaustion, emotional distancing, and a sense of ineffectiveness in the role of parenting (Mikolajczak et al., 2018).

Appendix B

Interview Protocol

Time of Interview: TBA

Date: TBD

Place: Zoom conference call

Interviewer: Jaymi Yamoah

Interviewee: TBD

Position of interviewee: video conference call

Project description: At the beginning of the interview review the purpose of the study. The purpose of this case study will be to explore the role of social support to mitigate parental burnout in mothers of children with medical complexities (CMC). Social support was generally defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community" (Lin et al. 1979 p. 109).

Parental burnout was generally defined as a specific syndrome resulting from prolonged parental stress. Dimensions of parental burnout include exhaustion, emotional distancing, and a sense of ineffectiveness in the role of parenting (Mikolajczak et al., 2018).

Children with medical complexities (CMC) was generally defined as a subgroup of CSHCN. CMC have significant health problems that affect multiple organ systems, which result in functional limitations, high health care needs, and often the need for medical technology (Kuo & Houtrow, 2016).

Explain that the interview will be approximately 30 minutes.

Questions:

1. Tell me about your journey as a mother of a child with medical complexity.

2. Tell me about your experience with stress and parental burnout due to the diagnosis of your child.

3. Tell me about any sources of social support in your life as they relate to parenting a child with medical complexity.

4. What is your experience with group support or peer mentoring?

5. What role (if any) does social support have in helping you with parenting stressors in your experience?

6. What recommendations do you have for other forms of social support that could help other mothers of children with medical complexities?

End the interview by thanking participants for their participation. Remind participants that their responses and identity will remain confidential (Creswell & Poth, 2018).

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Appendix C

Digital Consent Form

PARTICIPANT INFORMATION SOUTHEASTERN UNIVERSITY

Title: The role of social support in mitigating parental burnout in mothers of children with medical complexity

Investigators: Dr. Laura Brown, Southeastern University & Jaymi Yamoah, Southeastern University

Purpose: The purpose of this case study will be to explore the role of social support in mitigating parental burnout in mothers of children with medical complexities (CMC).

What to Expect: This research study is administered online. Participation in this research will involve completion of a prescreening tool and an interview. The pre-screening tool will take approximately ten minutes. The interview will occur on Zoom and will take approximately 30 minutes.

Risks: There is minimal risk to participating in this study. Participants may feel uncomfortable when talking about the stressors associated with parenting a child with medical complexity.

Benefits: The benefits of this study include participant empowerment. Participants will give voice to the population they represent. Participants will also be provided with the opportunity to advocate for the needs of their group. Participants may also gain an appreciation and understanding of how research is conducted. Participants may experience positive emotions associated with sharing their experiences. The study may help researchers develop interventions and strategies to help mitigate parental burnout.

Compensation: There is no compensation for participating in this study.

Your Rights and Confidentiality: Participation in this research is voluntary. There is no penalty for refusal to participate, and participants are free to withdraw consent and participation in this project at any time.

Confidentiality: The recordings of this study will be kept private. Any written results will not include information that will identify you. Participants' names will be masked for privacy. Research records will be stored on a password protected computer in a locked office and only researchers and individuals responsible for research oversight will have access to the records. Data will be permanently destroyed five years after the study has been completed. Video recordings will be transcribed and permanently destroyed within 5 years of the interview.

Contacts: Please contact any of the researchers at the following email addresses and phone numbers, should you desire to discuss your participation in the study and/or request information about the results of the study:

Dr. Laura Brown

lcbrown@seu.edu

863-667-5041

Jaymi Yamoah

jyamoah@seu.edu

If you have questions about your rights as a research volunteer, you may contact the IRB Office.

IRB@seu.edu

If you choose to participate:

Please click YES if you choose to participate. By clicking YES, you are indicating that you freely and voluntarily agree to participate in this study, and you also acknowledge that you

are at least 18 years of age. It is recommended that you print a copy of this consent page for your

records before you begin the study by clicking below.