

5-2021

**PERCEIVED MATERNAL STRESS, COPING STRATEGIES, AND
SUGGESTED INTERVENTIONS IN CARING FOR CHILDREN WITH
BOTH MEDICAL COMPLEXITIES AND DEVELOPMENTAL DELAYS**

Lisa Poff

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PERCEIVED MATERNAL STRESS, COPING STRATEGIES, AND
SUGGESTED INTERVENTIONS IN CARING FOR CHILDREN WITH BOTH
MEDICAL COMPLEXITIES AND DEVELOPMENTAL DELAYS

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Lisa Lynn Poff
May 2021

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ABSTRACT

This qualitative study highlights caretaker stress and coping in mothers of children with complex medical needs in addition to developmental delays. Areas of stress were complex, affecting emotional health, careers, and even vacations. Burnout theory was utilized to address the increased stress levels in these mothers. However, this theory was supplemented with Stress and Coping theory after qualitative data analysis as there were other factors that allowed these mothers to persevere—in particular, a type of coping identified as “meaning-based coping,” where situations are positively re-appraised and ordinary events are imbued with positive meaning. The mothers expressed their desire for more support, particularly after the child’s birth or diagnosis, and at periods of transitions. An effective multicomponent hospital intervention was utilized in Canada with promising results. Nurses met with families in their home environment following initial hospital visits. Not only would a similar program be beneficial for all families, but it is also desired by maternal caregivers.

DEDICATION

This research project is dedicated to all mothers of children with special needs, particularly the ones I have met over the course of the past fourteen years, either in waiting rooms at Children's Hospital, various therapies, or support groups. You were seen and heard. These stories ultimately shaped the course of my life as I wanted the voices of these mothers to be heard and understood. A special thanks to the mothers who participated in this study and were vulnerable enough to share their experiences. I cannot emphasize caring for yourselves enough. Pace yourselves you hopeful warriors.

She's no rose,
not even close,
not a lily,
nor an orchid.

She's more basic—
less fragrance,
less curve,
less grace.

But look how sturdy,
see how bright,
that stalk,
that height,
the way she reaches
towards the sun,
the way she's
fully opened up.

What a sunflower
lacks in elegance,
she more than
makes up for
in passion
and *hope*.

~Lisa Poff

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CHAPTER ONE

ASSESSMENT

Introduction

This chapter begins with a description of the focus of the research study, why it is relevant, and what is hoped to be identified during the implementation process. Next, is an introduction of the chosen paradigm, a brief literature review, and a theoretical orientation which supports the study. Finally, this chapter addresses the potential contributions to the social work practice.

Research Statement/Focus/Question

According to the National Center for Education Statistics (2020), 2% of students ages 3-21 were considered to have multiple disabilities under the Individuals with Disabilities Education Act (IDEA). Due to changes in society, healthcare, and government policy, most of these children are now taken care of at home (Davis et al., 2009; Guyard et al., 2012). Despite fathers becoming more involved in the child-rearing process, mothers still maintain the greater responsibility for the well-being of the children while fathers often focus on financial support (Hallberg, 2014). Children with multiple special needs require a significant amount of care above and beyond a typical child. Because mothers are often the primary caretakers, the burden of caring for children with disabilities is on the mothers, creating significantly higher levels of stress (Bilgin & Gozum, 2009; Day & Alston, 1988; Dykens et al., 2014; Jaramillo et al., 2016;

Kwiatkowski & Sekulowicz, 2017; Lindstrom et al., 2010; Miller et al., 1992). Due to this additional burden, they often experience increased negative symptoms. When the pressure placed upon these mothers exceeds their personal resources, it can contribute to poor physical and mental health (Caicedo, 2014; Davis et al., 2009; Guyard et al., 2012). In fact, Lovell and Wetherell (2011) found that caregivers of children with special needs experienced decreased immunity. In a qualitative study on the impact of caring for children with cerebral palsy, Davis et al. (2009) found that being a caregiver negatively affects sleep, physical health, social relationships, freedom, vacations, employment, free time, and finances.

Children with special health care needs (CSHCN) are “clinically recognized by at least 1 chronic condition resulting in a high family-identified service need, medical equipment addressing functional difficulties, multiple subspecialist involvement, and elevated health service use (Kuo et al., 2011, p. 1020). This research study focuses on the perceived effects of stress in mothers who act as primary caregivers for children who have both medical complexities and developmental delays, the coping methods used to mitigate that stress, and their ideas regarding potential support and interventions.

Paradigm and Rationale for Chosen Paradigm

A post-positivist paradigm is utilized in this study. This paradigm accepts the existence of an objective reality but assumes that reality can never fully be understood because it is impossible to remove oneself from the human

experience to explore it in an objective manner (Morris, 2006). From the perspective of the post-positivist, the quantitative analysis of positivism is only a segment of the whole picture. The qualitative approach of post-positivism is inductive in nature and the data drives the course of the research (Morris, 2013). Data is collected in the form of language rather than numbers (Morris, 2006). This type of study offers the opportunity to hear directly from the mothers themselves in thorough interviews versus the objective reality and stringent methodology of the positivist paradigm (Morris, 2013).

According to Morris (2013), a post-positivist researcher gathers qualitative data in a natural setting and obtains information from multiple sources including a literature review, observations, and personal experience. The post-positivist researcher hears directly from participants in their own words, thus truly experiencing and comprehending their perspective. By creating a genuine relationship with each interviewee and providing an accepting and empathetic listening atmosphere, the researcher gained insight into the perceived best methods for mitigating the perceived physical and emotional effects of caring for children with both medical complexities and developmental delays.

Literature Review

This literature review addresses potential stressors, such as financial, physical, mental, and familial stress. Next, the known effects of excessive stress are mentioned. Finally, the research on coping and parental training is discussed.

Potential Stressors

Multiple stressors plague families that have children with both medically complex conditions in addition to developmental delays. Financial, mental, physical, and familial stress are commonly experienced amongst mothers of children with complex special needs.

Financial Stress. Parents of children with special health care needs must take additional time off work for multiple doctor and therapist appointments (Kuhlthau et al., 2010) According to Caicedo (2014), direct care of CSHCN was reported by parents at an average of thirty-three hours per week. Additionally, hours of phone calls to ensure optimal medical and therapeutic services are the norm (Sullivan, 1979). Employers and employees can become frustrated with the time away from work. If the caretaker parent is not fired from their position, a parent must often terminate employment in order to meet the needs of the child with disabilities (Day & Alston, 1988; Grossberg, 2008). Caicedo's (2014) study found that one-third of parents were forced to quit their jobs and over 80% of parents reported their CSHCN affected employment decisions. Additionally, there are increased expenses for CSHCN versus their typical counterparts for the subspecialists and multiple therapists (Kuhlthau et al., 2008; Lindley & Mark, 2009; Macias et al., 2007). Having a child with medical complexities in addition to developmental delays can compound the amount of time off work and financial strain due to having an even larger medical team than having a child with either medical issues or developmental delays alone.

Mental and Physical Stress. Due to the fact that hospitals are discharging patients earlier than ever, primary caretakers must act as nurses and therapists for their child, frequently providing medical care on a daily basis (Day & Alston, 1988; Macias et al., 2007). If the child is older and heavier and needs toileting and showering assistance, mothers often experience physical strain from repetitive lifting (Buckhard, 2013). According to Macias et al. (2001), the caretakers must understand excessive medical jargon in order to fully comprehend their child's condition. Doctors frequently have little time to explain medical terminology, so parents must either learn the language or place full trust in the medical team without understanding the implications of the course of action. Additionally, the child may need an Individualized Education Plan (IEP) and parents may have to advocate relentlessly for their child to receive the best education (Macias et al., 2001). Physical and mental stress in mothers can be caused by caring for a child who would have been hospitalized longer in the past, physical strain in lifting a child, the necessity of understanding medical jargon, and advocating at IEP meetings.

In Caicedo's (2014) study, parents reported social isolation, frustration, and anxiety about their child's treatment, condition, and future. A lack of respite compounds this mental burden as there is a perceived shortage in home health nurses in the United States (Kuo et al, 2011). Because of the child's significant needs, babysitters are difficult to secure, even among family members (Sullivan, 1979). Primary caregivers of children with significant needs are also concerned

with their own health and longevity in order to be around to support their children, yet they often neglect their own physical and mental health due to the demands placed upon them (Caicedo, 2014; Kuhlthau et al., 2008). The child has so many needs that finding the time for personal appointments becomes difficult (Caicedo, 2014). In a study comparing salivary cortisol, a hormone associated with increased stress, in mothers of typical children versus mothers of children with cerebral palsy, Bella et al. (2011) discovered that elevated cortisol levels caused impairments in the physical and psychological well-being in the mothers of children with cerebral palsy. Due to physical strain, frustration, social isolation, anxiety, a perceived lack of respite care, and a perceived lack of time for self-care, the mental and physical burden in mothers of children with multiple health care needs is often overwhelming.

Family Stress. Despite having the aforementioned stressors, mothers must also strive to maintain family equilibrium (Macias et al., 2001). Because the mother's attention is unequally divided towards her child with special needs, the marriage often suffers, frequently ending in divorce (Grossberg, 2008). Siblings are affected as well. They may feel jealous of the attention the child with special needs receives and subsequently guilty about having these thoughts (Aydogan & Kizildag, 2017; Grossberg, 2008). Depending on the abilities of the child, normal family routines and activities are also affected, and feelings of social isolation persist (Aydogan & Kizildag, 2017; Macias et al., 2007). For instance, if a family

used to enjoy hiking together and they can no longer participate in that activity due to the child with the disability, the entire family is negatively affected.

Known Effects of Stress

Excessive stress in the mothers of children with both medical complexities and neurodevelopmental disorders manifests in several ways. The effects of long-term stress have been discussed in multiple studies: exhaustion, chronic fatigue, gastrointestinal disorders, headaches, muscle tension, hypertension, reduced immune function, insomnia, depressive and anxiety disorders, memory issues and physical weakness are some of the symptoms exhibited by mothers experiencing long-term stress (Bilgin & Gozum, 2009; Caicedo, 2014; Dykens et al., 2014; Maslach & Leiter, 2016). Long-term stress in caretakers can directly affect the children, thus research needs to focus on parental well-being in addition to the child with the disability (Guyard et al., 2012).

Lack of Research and Parental Training Regarding Coping Skills

Although much research has focused on the outcome of prolonged caretaker stress, little is understood regarding the coping mechanisms in mothers of children with disabilities (Miller et al., 1992). In fact, Bilgin and Gozum (2009) mention the magnitude of research regarding the extensive problems handled by families of children with special needs, but they note a dearth of solutions. Interventions for the disabled child is common, but interventions for stress reduction are missing for the mothers caring for these children (Dykens et al., 2014). Raina et al., (2005) suggested “rather than target the child exclusively,

interventions and preventative strategies should also target caregivers, who will in turn be able to respond to the unique characteristics of their child” (p. 634). Fung et al. (2011), successfully developed a strength-based mutual support group for the mothers of children with cerebral palsy and found that early intervention and preventative measures were effective at reducing stress and increasing hope.

This literature review discussed the elements creating stress in the lives of mothers who care for children with medically complex conditions and neurodevelopmental disorders in the areas of financial, mental, physical, and familial strain. Furthermore, the known effects of prolonged stress were addressed. Finally, the lack of information regarding coping methods within the literature was discussed. This study not only addresses the perceived effects of stress in mothers of children with multiple disabilities, but it attempts to identify the most effective coping methods used by the mothers and the solutions they believe may help support them further.

Theoretical Orientation

After review of the literature, burnout theory is a relevant theoretical orientation that can be used to guide the study. Burnout was first defined by Fruedenberger (1974, p.159) as “becoming exhausted by making excessive demands on energy, strength, or resources.” Fruedenberger meant this definition for those employed in human service occupations and much research has followed, particularly that of Maslach, who created the multidimensional theory of

burnout and the much-used measure of burnout called the Maslach Burnout Inventory (Maslach, 1981). Maslach and Leiter (2016) later modified the original three dimensions of burnout:

The exhaustion dimension was also described as wearing out, loss of energy, depletion, debilitation, and fatigue. The cynicism dimension was originally called depersonalization (given the nature of human services occupations), but was also described as negative or inappropriate attitudes towards clients, irritability, loss of idealism, and withdrawal. The inefficacy dimension was originally called reduced personal accomplishment, and was also described as reduced productivity or capability, low morale, and an inability to cope. (p. 103)

Of these three aspects, exhaustion is reported and studied the most (Maslach, 1981). However, Maslach and Leiter (2016) conclude that exhaustion does not thoroughly describe the burnout experience and the other two dimensions are key.

It did not take researchers long to equate the role of mothers as having similar characteristics of those in human service jobs (Pelsma et al., 1989). Pelsma et al. (1989) were the first researchers to apply the Maslach Burnout Inventory to a sample of mothers and found support for exhaustion and lack of personal accomplishment, but not for the then-described aspect of depersonalization. When Roskam et al. (2017) used Maslach's tridimensional theory and measurement to create the Parental Burnout Inventory, they replaced

the depersonalization dimension with emotional distancing. For instance, parents provided for physical needs such as food for their children, but decreased their emotional responses (Roskam et al., 2017). Due to this change, all three dimensions were met in this study, suggesting that parental burnout is similar to occupational burnout (Roskam et al., 2017).

Le Vigouroux et al. (2017), noted distinct personality traits that were prone to parental burnout. Neuroticism was identified as the most prominent determining factor in burnout. Furthermore, Roskam et al. (2017) noted that a majority of the parents experiencing burnout had perfectionist tendencies with high parenting standards. This study is on parents of typical children. Therefore, if a child with multiple disabilities is born to a mother with perfectionist tendencies, she would seemingly have an even greater chance of experiencing parental burnout. Moreover, Mikolajczak et al. (2018) found significant evidence that parental burnout can have severe consequences for both the parent and the child. The consequences of the parents include suicidal thoughts, addiction, and insomnia; and the consequences for the child are physical abuse and neglect (Micolajczak et al., 2018). Burnout theory forms a framework for this study because the long-term arduous caregiving for a child with multiple disabilities has a high potential for burnout, particularly in mothers.

Potential Contribution to Micro and/or Macro Social Work Practice

Micro Level

Social work practice focuses on the children with the disabilities, not on the parents (Dykens et al., 2014) However, stressed parents have been shown to negatively affect the efficacy of early interventions in children with special needs (Osborne et al., 2008). Roskam et al., (2017) posited:

Because of the potentially dramatic and long-lasting consequences that parental burnout may have for children, parental burnout's prospective effect on child development as well as behavioral issues should be a top priority in the research agenda. (p. 10).

Furthermore, due to early intervention programs, new caregivers of children with multiple disabilities receive support in the beginning, but caregivers with older children do not receive that support and report more intense stress levels (Macias et al., 2001). Therefore, mothers of older children with special needs may need more support than they are currently receiving. Supporting mothers of children with multiple disabilities will simultaneously support the children, and potentially, according to Mikolajczak et al. (2018) reduce child abuse and neglect.

Macro Level

After the rise of deinstitutionalization in the seventies, more children with disabilities are in home and community-based settings (Kuhlthau et al., 2010). According to Kuhlthau et al. (2010), now that more parents are providing the

majority of care for children with special needs, “the well-being of parental caregivers is an increasingly important public health issue” (p. 155).

As parental burnout is more common for mothers of children with special needs, this research study may help illuminate the various stressors and coping methods used and potentially generate the need for additional research and parental interventions.

Summary

This chapter discussed the focus of the research in addition to the stress and coping mechanisms in mothers of children with medical complexities and developmental delays. A post-positivist approach was chosen to understand the rich complexities of these mother’s lives in their own words, using Burnout Theory as the theoretical framework. A literature review revealed the common stressors of these mothers, the effects of that stress, and the lack of research on coping mechanisms and interventions. This study will potentially contribute to the social work field at both micro and macro levels.

CHAPTER TWO

ENGAGEMENT

Introduction

The second chapter discusses the study site selection and engagement methods for the gatekeepers of these sites. Additionally, the researcher's self-preparation for the study is addressed. Finally, potential diversity, ethical, and political issues follow, and the role of technology is mentioned.

Study Site

Two online support groups for families with children who have multiple disabilities is the study site. These online study sites are parent support groups for both educational and emotional support. Both sites are mutual aid/self-help support groups meant for the parents of children with special needs. In one of the groups, the children frequently have a combination of both medical complexities and developmental delays. One of the online support groups is Southern California based and has local participants; however, the other online support group with the more complex cases and rare disorders may potentially include participants from all over the world who are likely fluent in English. In both groups, maternal caretakers are the main participants.

Engagement Strategies for Gatekeepers at Research Site

Because the researcher is a personal member of several support groups for parents of children with multiple disabilities, the initial contact took place with the gatekeepers via online messaging. In this communication, the research was presented as a study on mothers of children who have both medical complexities and developmental delays. The researcher explained that perceived caregiver stress, coping methods, and suggestions for support and interventions would be explored through individual interviews with the mothers. Hearing directly from the mothers themselves ultimately benefits the social work field since there is much focus on caregiver burden, but very little on interventions and support. Adding these mothers' concerns and suggestions to the available research can inform future interventions. The gatekeepers were assured of the informed consent, privacy protection, and confidentiality regarding group members who chose to be involved in the study, and this information was relayed to potential study participants.

Once the researcher gained approval from the gatekeepers of the online support groups to announce the project on their social media sites, the researcher posted a brief explanation of the project, the potential benefits, and the need for study participants on California State University San Bernardino letterhead explaining it was approved by the Institutional Review Board. It was made clear the meetings would be via video or telephone for safety and

convenience. Informed consent, privacy, confidentiality, and the potential contribution to the field of social work were addressed.

In order to motivate mothers to participate in the study, the researcher first engaged the participants by explaining that she is also a mother of a child with multiple disabilities, thus gaining the trust of mothers who may be wary of a stranger probing into their private lives. The researcher's self-disclosure likely increased researcher credibility in the minds of the mothers, and one mother specifically commented it was the reason she joined the study. Next, the researcher explained that she wanted to more fully understand the plight of these mothers and be able to pinpoint the biggest stressors and current coping methods. By the time the researcher was finished initially engaging the sites, the mothers understood that the researcher wished to ultimately support them, thereby supporting their children and families by identifying their greatest struggles, coping methods, and potential interventions. The mothers understood that the research increases the available knowledge regarding families such as their own.

Self-Preparation

As a mother of a child with special health care needs herself, the researcher has experienced many of the stressors described in the literature review. Disclosing this fact assisted in the engagement process and participants were immediately comfortable sharing medical terminology and knowledge about particular organizations, knowing that the researcher would be familiar with these

terms and agencies. The researcher suspects this familiarity increased trust and allowed for greater honesty in the interview process. However, the self-disclosure was limited to engage participants as this project is not about the researcher's personal narrative, but regarding the stories and experiences of participants.

In preparing for this project, the researcher completed an extensive literature review and gained a more thorough understanding of the areas needing further exploration. The researcher has already refined the study according to what was discovered in the literature review process. Much of the research on children with medical complexities is regarding children with cerebral palsy. This study does not focus on the particular diagnosis of the child, but on having medical complexities, defined by having a chronic condition, multiple subspecialists, medical equipment, and increased health care use in addition to having developmental delays (Kuo et al., 2011). The literature revealed high levels of stress and burnout amongst mothers of children with these types of diagnoses.

Diversity Issues

Due to the fact that children with various disabilities are born to mothers of all cultures and ethnicities, this research project is diverse in nature. However, since the project is specific to mothers, the gender is female. Due to the online nature of obtaining participants through English language sites, the vast majority are fluent in English, and no translators were necessary, although English is a

second language for a few participants. The researcher practiced cultural humility. Furthermore, the knowledge that white privilege, according to Morris (2013) is “continually operating to some degree and creating situations of power imbalance” was recognized and addressed in discussions with participants (p. 88). In addressing this issue, the researcher asked non-White participants regarding their experiences versus what they think their White counterparts experienced and vice versa.

Since the only requirement for participating in this study was to be the mother of a child with both medical complexities in addition to developmental delays, there was great diversity in the childrens’ disabilities and their severity.

Ethical Issues

When approaching this research project, Rokeach’s (1973, as cited by Morris, 2013) instrumental values consisting of Moral, Competency, and Terminal (personal and societal) values will be considered. Additionally, because this research project is university sponsored, it underwent the Human Subjects Review process managed by the Institutional Review Board, a process described by Morris (2013), as “where a university committee assesses the research project’s potential for harm using federal guidelines” (p. 74).

Due to the fact that this is a post-positivist study, there is greater opportunity to consider and respond to ethical issues posed by participants during the initial engagement process (Morris, 2013). Informed consent was thoroughly considered, and participants were made aware of the interview’s

subject and length prior to the start of the process. Furthermore, respondents were informed they can choose to skip a question or stop the interview at any point.

With the use of videoconferencing, additional precautions were made to ensure any promised confidentiality. Before any recordings began, participants were asked to turn off their videos so that only audio recordings were made. The names were changed in the Zoom recording and then subsequently changed again post recording. Respondents were asked to not mention their children by name or give other identifiable information during the interview. Because the researcher may need to connect the data to its source, the participants were assured that the list of names linked with the data would be kept in a secure location (Morris, 2006).

Political Issues

Post-positivist researchers need to be aware of their potential to affect the research project. Morris (2006) writes, "Post-positivists attempt to curb the influence of their values on the research project and maintain the positivist stance that the researcher, if careful, will not affect the research setting" (p. 258). The researcher of this project has a child with medical complexities in addition to developmental delays and must be vigilant to maintain neutrality and exhibit awareness and control over personal influence. Moreover, parents of children with multiple disabilities may be particularly concerned about confidentiality as they may appear to be bad or unfit parents if they disclose parental burnout.

Some mothers may be concerned if they are honest about their high stress levels, their services might be affected. Therefore, the researcher will clarify that she does not work for any agency and services will be unaffected. Participants were assured that the purpose of the study is to ultimately discover the best ways to support them by thoroughly understanding their stressors and how they might be relieved.

The Role of Technology

Technology used in this research project will be voice recordings of interviewees through the video conferencing application Zoom, with the video feature disabled. Social media sites and emails were utilized for communication.

Summary

This study was conducted via Zoom video conferencing with the video feature disabled after contacting the gatekeepers of various support groups that educate and support parents of children with multiple disabilities. The gatekeepers of these sites were engaged through initial email contact explaining the nature and purpose of the study. Self-preparation included life experience and an extensive literature review. Issues regarding diversity, ethics, and politics were also addressed. This chapter ends with a brief statement regarding the use of technology.

CHAPTER THREE

IMPLEMENTATION

Introduction

This chapter addresses the implementation stage beginning with the characteristics and selection of the study participants. Data gathering methods, collection, recording, and analysis follow. Finally, the findings of the research study and the dissemination plan are discussed.

Study Participants

For this research study, the participants are mothers of children with both developmental delays and medical complexities. The medical diagnoses are not important as long as the child meets both requirements. Because the mothers were selected through various English language online support groups, the mothers are fluent in English. As Southern California has a high population of Hispanic and Caucasian persons, these demographics were reflected in the results. The online support sites have hundreds of participants. The mothers ranged in age from late twenties to late forties.

Selection of Participants

Purposive Sampling was utilized for this study as this type of sampling identifies specific types of participants who have similar experiences (Morris, 2013). In this case, it was mothers who act as primary caretakers of children

with multiple disabilities. After two online support group gatekeepers approved the research project, the researcher was allowed to post the project online. Respondents were included in the study if they still wanted to proceed after hearing more about it. Many people expressed interest in the original post, but then never followed up after repeated contact.

Snowball sampling was also utilized (Morris, 2013). Mothers who participated in the study were encouraged to share the names of other mothers they thought may like to be included, or they could contact these acquaintances and share information about the study. Mothers of children with complex conditions are often members of numerous support groups and informative groups in addition to having personally met other families through the various diagnoses of their children. The researcher benefitted from these connections and gained potential interviewees from an even wider sample of participants.

Although the researcher was able to gather subjects who were diverse in their age, ethnicity, and geographical areas, the researcher used purposive sampling augmented by snowball sampling techniques, relying on participant response and availability. Still, diversity was achieved in study subjects with participants as far away as Canada, Israel, and Japan. Mothers who identified as Caucasian, Hispanic, Asian, and Jewish participated in this study.

The researcher would make it clear that the study is entirely voluntary and there are no personal gains for the mothers besides having the potential to contribute to the field of social work through their experiences.

Data Gathering

Since this study utilized a post-positivist approach, the data was gathered through engaging participants in personal interviews. The post-positivist approach assumes that former research lays the foundation for data collection; thus, the researcher completed extensive research on the topic of caregiver stress and burnout. From this previous knowledge, questions were developed by the researcher to best understand the issues surrounding the perceived physical and emotional toll of long-term caretaking in mothers. Crabtree and Miller (1999, as cited in Morris, 2013), share a trio of categories of inquiry including descriptive, structural, and contract questions. The researcher asked questions regarding perceived caretaker stress, coping methods, and ideas regarding possible interventions if the stress felt unmanageable at times.

Descriptive questions can be broad questions such as “What is your typical day as a caregiver like?” or they can be more focused; for example, “How do you spend your weekends as a caregiver versus weekdays?” Structured questions are inquiries which elaborate on a chosen topic. Within the category of “structured questions,” there exists three subtypes: inclusion, verification, and substitution frame inquiries (Morris, 2013). An example of an inclusion question pertaining to this research topic may be, “How has being a long-term caretaker increased your stress level?” Verification questions are questions which clarify the researcher’s comprehension of the subject (Morris, 2013). In this case, a verification question might be, “Do you even consider yourself as having

additional stress due to having a child with considerable needs?” Substitution frame questions, a category within “structured questions,” removes particular information from the question and asks that the participant replace the information with his or her comprehension of the matter (Morris, 2013). A sample substitution frame question could be, “When I think of the future of being a caretaker, I feel...”

The final category of interview questions as described by Crabtree and Miller (1999, as cited in Morris, 2013), is “contrast questions,” questions which, “develop criteria for inclusion and exclusion for a category of knowledge” (Morris, 2013, p. 184). For example, for the maternal caregiver stress topic, a question might be, “What about being a caretaker makes you feel stressed,” and “What about serving as the role of a caretaker does not make you feel stressed?” These types of questions help decide what topics should be included in the study.

Phases of Data Collection

In preparation for the interviews, the researcher reviewed the literature on the topic and formulated questions. Moreover, the researcher kept a journal to become aware of personal biases and values regarding the perceived physical and emotional effects of maternal long-term caretaking as the researcher is the mother of a child with multiple disabilities and wants to ensure that the data findings are credible.

After the researcher prepared the participant by obtaining the informed consent, ensuring confidentiality, and that no harm will come to the participant during the research process, the researcher explained the importance of the study while engaging the clients and putting them at ease. The researcher used video conferencing but disabled the video feature for participants so that only the audio was recorded without images of the participants.

The researcher broke up the interviews into a typical conversation mode, including engagement, development of focus, maintaining focus, and termination (Morris, 2013). Cultural competence and intuition were important since some interviewees may prefer a long period of engagement while others may wish to proceed directly into answering the questions (Morris, 2013). Morris (2013) describes four types of questions that should be included in the interview process: essential, extra, throw away, and probing. The essential questions are those which are specific to the research topic. They can be bundled together or asked at various points during the interview. Extra questions are the essential questions re-framed, to assure the researcher is getting similar responses. Throw away questions are generally used to establish rapport and probing questions expand upon the topic. With each interview, the researcher will become better at the role of interviewer (Berg, 2009, as cited by Morris, 2013). At the end of the interview, the researcher summarized what was understood, addressed any concerns of the interviewee, and exited the interview with throwaway comments and exchanges to alleviate any anxiety created by the

intensity of the interview. Finally, the researcher provided contact information in case the participant had further questions (Morris, 2013).

Data Recording

Interviews were recorded on a computer via Zoom video conferencing, audio only. Only one participant was uncomfortable with this method and instead requested the questions and wished to respond in writing. Two research journals were kept, one with a narrative account of events of the study from start to finish, and a reflective journal, which is a record of decisions made during sampling, data collection, and analysis over the course of the study (Morris, 2013).

Data Analysis

Since this study uses a post-positivist paradigm, qualitative analysis will be used to interpret the data gathered. Qualitative analysis is a method which uses language rather than numbers for evaluation. According to Morris (2013), data collection and data analysis are entwined in the post-positivist research process. As soon as the data is gathered, the information is analyzed. What is discovered during the analysis dictates how the researcher will gather additional data (Morris, 2013).

This study will utilize the “top down” approach as the researcher wishes to answer a particular question regarding the coping methods used to mitigate the perceived effects of stress in mothers of children with medical complexities and developmental delays.

The constant comparison method was utilized to analyze the data. Initially, the researcher examined the data and placed the data into as many categories as possible (Glaser, 2008). Bits of data were organized according to how they were alike or related (Dye et al., 2000). According to Glaser (2008), there is one rule for this method, “while coding an incident for a category, compare it with previous incidents in the same and different groups coded in the same category” (p. 439). After this initial categorizing, the next step is to not only compare data bits to data bits, but to compare category properties that initiated comparison in the first place (Glaser, 2008). Categories are continually refined until a theory develops (Glaser, 2008). Dye et al. (2000) explained the process using the metaphor of a kaleidoscope. At the start of coding, data bits are constantly reduced as the kaleidoscope is turned, and sub-categories are created until finally a large piece of “glass” reveals the overarching theme.

Communicating Findings

This section will elaborate on the overall conclusions, the theoretical implications, and the contributions of the research (Morris, 2013). The research project will be compiled in a written report presented to the School of Social Work at California State University, San Bernardino, and available on the Scholarworks website upon completion. This website has open access to the general public for reading and reviewing. The mothers who participated in this study have been advised that they can access the entire study on Scholarworks and given steps how to accomplish this task.

The researcher intends to use this research to support the need for select caretaker interventions through hospitals and California Regional Centers, a state-wide organization intended to provide lifelong planning and services for persons with significant developmental disabilities. According to Buck and Alexander (2006), it is crucial to understand the perspective of consumers to advance best practices.

Currently, the major service provided to caretakers is respite care, where a worker relieves the caretaker of their duties for brief periods of time. The results of this study identified additional maternal caretaker needs and may inform future interventions beyond basic respite care.

Termination and Follow Up

During the termination phase, each interviewee was contacted directly, thanked for their time and participation in this study. As this project utilizes the post-positivist paradigm, there is a commitment to report the findings to the study participants due to the relationship formed during the interviews (Morris, 2013). The researcher will keep in mind that the audience members may be laypersons unfamiliar with the research process. The discoveries of the study were discussed in addition to how maternal stress and burnout may be addressed in the future. The researcher inquired if the study participants had any questions. After discussion and answering questions relevant to the study, the participants were thanked for their time and involvement.

Summary

Research study participants were mothers of children with both developmental disorders and medical complexities found through online support groups for parents of children with special needs. Data was collected through video conferencing with the video portion disabled. A qualitative “top-down” approach using the constant comparative method was used to analyze the data. Upon completion of the study, the participants were contacted, the findings discussed, and the paper submitted to the social work department at California State University, San Bernardino.

CHAPTER FOUR

EVALUATION

Introduction

The facts and findings of the research project are described in this chapter. Demographic information is presented on the mothers who participated in this study. Strengths and limitations of the study in addition to notable themes are discussed and evaluated. Various stressors correlating with Burnout Theory in addition to coping methods utilizing Stress and Coping Theory are discussed. The desires of the mothers are explored, and a potential intervention is presented.

Data Analysis

Mothers of Children with Complex Health Conditions

Twelve mothers participated in this study. All mothers except one considered themselves the primary caretakers of their child with complex needs. Nine of the twelve participants are married while the remaining three are divorced. Seven mothers reported their ethnicity as Caucasian, three identified as Hispanic, one as Asian, and the remaining participant as Jewish. Half of the participants work full time, three are at-home moms, two are students, and the remaining mother works part-time. Regarding education, seven of twelve earned a bachelor's degree, two earned graduate degrees, one is currently in a graduate program, one is a bachelor's student, and one took a high school equivalency

exam. The majority of the participants are from the United States, particularly Southern California, but one is residing in Israel, another in Canada, and one is from Japan. Two of the women are fluent in English as a second language. A fairly equal distribution of socio-economic status was described by the participants. Four identified as upper-middle class, five as middle class, and three as lower middle class. Nine of the twelve participants did not know their child would have a disability until the moment of birth, two were aware of complications in utero, and one did not know anything was amiss until the baby was nearly eighteen months old yet did not receive a diagnosis until the child was age three. Nine of the affected children have siblings while three are only children. The children with special needs range from age five to age sixteen. Eight are ages thirteen to sixteen and four ages five to ten. Please see Table 1 for detailed information on the mothers and their children with the medical issues.

Table 1. Characters of Mothers

Marital status	Education	Career	Sex of child	Age of child	Birth order	Clinically Diagnosed	Socioeconomic status	Ethnicity	Country
Married	Bachelor's degree	Full-time	M	15	2 of 2	At birth	Middle	White	USA (CA)
Married	Bachelor's degree	Stay-at-home	M	16	1 of 2	At age 3	Upper	White	USA (CA)
Married	Earning graduate	Student	M	7	2 of 3	At birth	Lower	White	USA (CA)
Married	Graduate degree	Full-time	F	15	1 of 3	In utero	Upper	White	USA (CA)
Married	Earning bachelor's	Student	F	9	1 of 2	At birth	Middle	White	USA (CA)
Married	Bachelor's degree	Full-time	F	15	1 of 2	At birth	Upper	White	USA (TX)
Divorced	Bachelor's degree	Full-time	M	15	2 of 2	At birth	Middle	Hispanic	USA (CA)
Married	Bachelor's degree	Stay-at-home	F	15	1 of 1	At birth	Middle	Asian	Japan
Divorced	G.E.D.	Stay-at-home	M	13	2 of 5	At birth	Lower	Hispanic	USA (CA)
Married	Graduate degree	Stay-at-home	M	5	2 of 2	At birth	Middle	White	Canada
Married	Bachelor's degree	Full-time	M	5	1 of 1	In utero	Upper	Hispanic	USA
Divorced	Bachelor's degree	Part-time	M	15	1 of 1	At birth	Lower	Jewish	Israel

All mothers but one agreed to be interviewed and recorded via the Zoom application with their cameras off. The remaining mother preferred to receive the questions in advance via email and respond in writing. The mothers were not asked for specific diagnoses of their children but self-reported that one of their children had complex medical needs in addition to developmental delays. As the Zoom videoconferencing app shows a participant's name, each participant was asked to choose a pseudonym and change her name in Zoom prior to the recording. Thus, there were no video recordings of participants and their names were changed. Subsequently, the researcher changed their names yet again for even greater confidentiality. The interviews were not saved in any "cloud," but instead were saved to the researcher's password protected individual computer.

When responding to the questions, the mothers spoke about present, past, and future stress inducing situations. They often jumped around in time periods depending on the question asked, and even within certain questions.

After the mothers understood and signed informed consent documents, (See APPENDIX A), data was collected from the mothers based on interviews with questions given in advance (See APPENDIX B). The questionnaires had a variety of open-ended questions. Mothers were informed that although the questionnaires would closely resemble the interview, some questions specific to the conversation may be asked that were not included in the questionnaire. Mothers were informed they could choose to skip any questions and/or stop the interview at any moment. No mothers chose to skip any questions or halt the interview process. The researcher not only took brief notes during the interview itself, but also kept a research notebook and wrote notes directly after the interview while the information was still fresh. The researcher transcribed each interview onto individual Word documents. The only place where the mother's actual names were revealed were in a handwritten notebook secured in a private home. All materials will be destroyed after study completion.

After perusing the interviews multiple times, the researcher utilized the Constant Comparison Method (Dye et al., 2000) to code the qualitative data. This method entailed carefully studying the transcriptions and categorizing the data based on salient quotes from the mothers. A list of all categories emerged, and these categories were further refined as clusters of data were reduced even further in multiple rounds of whittling the data (Dye et al., 2000). Following this open coding, the researcher began axial coding, linking the open codes into

specific themes, creating a comprehensive narrative that explained the linkage between the data.

Data Interpretation

Burnout

As projected, the overarching themes related back to Maslach's Burnout Theory encompassing the three dimensions of burnout: exhaustion and fatigue, depersonalization or a negative or irritable attitude towards clients, and reduced personal accomplishment, or an inability to cope (Maslach and Leiter, 2016). Roskam et al. (2017) later modified Maslach's theory to create the Parental Burnout Inventory, describing the depersonalization portion as emotional distancing, where a parent provides for their child's physical needs, but separates from the child emotionally.

Emotional Distancing. As the first researchers to apply the Maslach Burnout Inventory to a sample of mothers, Pelsma et al. (1989) noted that the dimensions of exhaustion and lack of personal accomplishment was notable in motherhood, but the depersonalization aspect, later described as emotional distancing by Roskam et al., (2017) was lacking in support. While the results of this study echoed this aspect of the burnout theory as the least applicable, a third of the mothers described what could be classified as depersonalization, either exhibiting emotional withdrawal from the child or extreme irritability towards the child. Two mothers expressed frustration and irritability. In her own words, Emma (July 2020) explained, "I want to help and teach her, but it makes me

irritated, and she does not understand easily, so I have pretty much given up on that.” Kelly (July 2020) shared, “It gets very frustrating because those are the things that kind of unless you’re living it, you don’t understand how they wear on you, how they kind of chip away at you because it’s so repetitive.” Two other mothers expressed emotional distancing. Liz (July 2020) shared,

I went to work. I didn’t get to really see him as he was sleeping. So I just didn’t even kiss him....I wanted to bond with him, but I couldn’t because he was literally with so many apparatuses on....Seven years of his life, we really didn’t bond too much because he was basically with foreign people who were trying to help him get caught up.

In response to how having a child with complex needs changed her vacations, Gwen (July 2020) explained, “We haven’t really had to deal with it because if we would go on vacation, he would stay with my parents.” Although these instances might be explained in alternative ways, they potentially represent the depersonalization component of Maslach’s burnout theory further applied to parenting burnout by Roskam et al. (2017).

Exhaustion. All but two of the mothers expressed exhaustion and fatigue. According to Maslach (1998), of the three dimensions of burnout theory, exhaustion is reported and studied the most. Some of the mothers may have been describing moments from the past, but the general agreement was exhaustion over medical, school, and service needs. Even areas that should be

fun for families, recreation and vacations, were hindered by exhaustion and fatigue.

Cindy (July, 2020) shared how her family tried to get away, “He still had his apnea monitor. And we are about two hours from civilization. And at ten o’ clock at night his monitor started beeping....My husband had to drive two hours to get a new cord.” For some families, the exhaustion of planning for a vacation was too much and it was “easier to be at home” (Theresa, August 2020).

The multiple medical appointments and therapies also contribute to fatigue. Cindy (July 2020) shared, “I have to go pick him up, take him out of school, drive 40 minutes to the appointment, stay however long that takes, and then bring him back to school.” Sharon (July 2020) speaks to the hours each week spent on therapies, “That was just nine hours in the clinical setting. That’s not travelling there, getting ready. I kind of forgot who I was I was so busy with his therapies. Theresa (August 2020) explains the physical exhaustion and mental fatigue well:

I had schedules throughout the day for every fifteen minutes, trying to do all the things that the PT wanted me to do and all the things that the speech therapist wanted me to do and all the things that the audcom therapist wanted me to do and all the things that she needed to do so she could eat right because she’s still tube fed and all that, you know, and you’re just like, holy cow, this is impossible for any human being to do.

Some participants expressed fatigue with the lack of care coordination. Cindy (July 2019) explained, “They don’t collaborate with each other. And I’m having to piece the puzzle pieces together, which makes it challenging and extremely exhausting.”

Not only did these mothers have to dash around to multiple appointments during the day, but they also acted as “night nurses” (Haley, June 2020). Theresa (August 2020) shared, “we were so sleep deprived that we would regularly fall down the stairs.” The fatigue is so great that Emma (July 2020) lamented, “I feel my body won’t hold as a caregiver sooner or later.”

Although some of the stories of exhaustion were from the past, the general theme is that although the fatigue may not be as intense as when the child with medical complexities was younger, the fatigue persists and changes according to the most recent stressors. Kelly (July 2020) stated, “I’m at home exhausted with this child,” and Gwen (July 2020), guilt-ridden, shared, “I think about it all the time. What more could I be doing to help him? But I’m exhausted.” The majority of the mothers specifically used the word, “exhausted,” but even if that term was not used, all of the mothers described it in some capacity and met that criteria.

Reduced Productivity. The final dimension of burnout is described by Maslach and Leiter (2016) “as reduced productivity or capability, low morale, and an inability to cope” (p. 103). All twelve of the mothers exhibited this aspect of burnout. This dimension was shared with all of the women except one in relation

to their careers. The mother who is an anomaly shared that having a child with disabilities helps her in her career as it is difficult to get a teaching job where she resides, but since general education and special education are often integrated, she is viewed as someone with knowledge. The rest of the women had to make changes such as quitting jobs, reducing workloads, getting jobs with greater flexibility and pay they did not necessarily want, and refusing higher positions in order to take care of their medically complex child. Sharon (July 2020) explained, "I was doing freelance public relations. I always wanted to go back, but it was also a really fast pace of life....So I had to walk away from that." Theresa (August 2020) shared, "When I look back on it, you know, the job I have leading today...if I wanted it and I didn't have a special needs child, I might have had it ten years prior." She purposely remained in the same position sharing, "So I didn't have that extra taxing of learning a new job." Gwen (July 2020) had a similar story,

He's going to be six and I still have the career I've had for the last several years. I just feel that opportunities for advancement are limited because I know that a medical emergency could and has happened on a moment's notice.

Sarah (July 2020) explained, "I essentially left a job that I had been at full time to care for him the first three years because of all the medical appointments and surgeries." This same mother ended up returning to full time work as it made more sense for her husband to be the child's caretaker as his job has

flexibility. That change left this mother feeling inadequate, as if she is not fulfilling her dream role as a mother. In her perception, having to work full time is not utilizing her desire and capabilities to be the primary caregiver. These women were unable to advance in their desired positions in order to meet the needs of their medically complex children.

Additionally, the mothers expressed a reduction in their capabilities to care for their other children. Seven of nine mothers who had other typical children expressed a difference in the attention the typical sibling receives in relation to the child with special needs. Renee (July 2020) shared that the child with special needs receives 75% of the attention and Liz (July 2020) shared that she “absolutely put 200% more time into the child with disabilities.” Sarah (July 2020) shared, “I try to be equal with it, but it’s not equal.”

The mothers also expressed the facet within this dimension of burnout labeled as an inability to cope. Like the word exhaustion, the word “overwhelming” was utilized multiple times by different mothers. Mothers described Post-Traumatic Stress Syndrome symptoms and what they described as breakdowns. Sarah (July 2019) shared,

I had pretty much a nervous breakdown....It looked like a deep depression where I spent a lot of time in bed....I just couldn't feel like I knew what was going on with life and who I was and what I was doing and how to handle things.

Three of the mothers shared that they are on pharmaceutical drugs to help with mental health issues, although this was not a question that was asked. Beverly (July 2020) shared, “I just bottled it up. I think for a while, and then if I needed a release, it was more like a steam release. It was like a fall apart. Since then, I’ve gotten more medication.” These overwhelming feelings were not limited to the time shortly after the child’s birth. Even though her child is a teenager, Emma (July 2020) shared, “I have so many things I want to do but I can’t do. I’m just too overwhelmed by taking care of my daughter.” The three aspects of burnout theory described by Maslach and Leiter (2016) were exhibited in the mothers, but like Pelsma et al. (1989) found, the mothers leaned more heavily towards the dimensions of exhaustion and reduced productivity.

Anxiety

There is another aspect, related to both fatigue and overwhelming feelings, but a distinct and ongoing presence in these mother’s lives—anxiety. Although worrying about the future of your child is common to all mothers, these mothers of children with multiple medical conditions experienced worry and concern beyond what a typical mother might experience. Their anxiety is palpable and was often noted during and after the interviews in the researcher’s private notebook. The many unknowns about if and how they will be able to care for themselves and who will be responsible after they are gone permeate the thoughts of these mothers, either overtly or covertly. As well as the word “overwhelming,” the words “worry” and “anxiety” were often mentioned terms.

Sharon (July 2020) explained, “I’m worried about the future.” Theresa (August 2020) shared, “There’s the stress of the future.” Cindy (July 2020) said, “I have anxiety about the future.” Renee (July 2020) related, “I would like her to be as independent as she can. Everybody would want that. Sorry. It is overwhelming. All the what ifs.” Sarah (July 2020) divulged, “I am always worried about him and I’m always thinking about his mental health, his physical health, what is going on. I feel overwhelmed by those thoughts to be honest.” Gwen (July 2020) shared,

I have developed a high level of anxiety that I don’t believe I had before, and I think a lot of it surrounds, again, you know, not knowing when he’s going to have a shunt malfunction or a seizure or need long term medical care in the hospital.

Undoubtedly, this anxiety contributes to the burnout that these mothers can experience. While it does seem that many of the mothers were referencing a past point when they were speaking about their extreme moments of overwhelming feelings, it seems that these feelings ebb and flow depending on how things are going right now. And since these women had a choice regarding whether or not to participate in this project, it makes sense that they would not currently be feeling overwhelmed, or it would be unlikely they would have volunteered for such a study.

While there is shock and trauma surrounding the initial diagnosis, the stress of having a child with medical complexities does not disappear, but ebbs and flows, usually increasing around worsening medical symptoms. Theresa

(August 2020) explained, “The highest stress times are obviously the big medical things.” Kelly (July 2020) said, “It just depends on the season I’m in right now. I would say things are more balanced because of the ages, because there aren’t any surgeries looming, and I’m not super-overwhelmed with doctor appointments.” Haley (June 2020) “reduces or increases work hours depending on the year they’re having.” These mothers constantly face uncertainty, more so than mothers of typical children. In fact, two mothers who had promised to be a part of this study were forced to cancel due to their child requiring major medical interventions. One emailed me that her child began having “out-of-control” seizures after having a seizure free year. Furthermore, since this surgery, two of the participants have posted on the social media sites used for the original study regarding their children’s unexpected surgeries. These are two that the researcher is aware of and may not be indicative of the actual percentage of participant’s children who have required unexpected medical intervention post study. This constant uncertainty increases anxiety in these mothers and adds to the overall conditions that create burnout.

Stress and Coping

While Burnout Theory can explain what these mothers experience during the more intense phases of their journey, usually connected to medical events, another theory can explain how they are able to manage the intense stress of having a child with multiple disabilities. Stress and Coping Theory, introduced by Lazarus and Folkman, is a framework for stress and coping which defines stress

as an imbalance between perceived demands and resources and suggests that coping falls into two categories, problem-focused coping which utilizes problem-solving to reduce stress in activities such as information gathering, and emotion-focused coping, which decreases negative emotions through avoidance, distancing, or seeking social support (Folkman, 2010; Lazarus, 1993). When asked regarding their coping methods, the mothers in this study relied mainly upon emotion-focused coping. The principal coping methods were connecting with family or friends, exercise, spirituality, and/or drinking alcohol. Kelly (July 2020) explained it well:

You just have to find healthy outlets. I think I have sought unhealthy ones. If I'm very truthful, like drinking too much or something, especially at the end of a long day or on my free weekends where you just want to numb and feel free of the responsibility and stress, but that's such a temporary escape. So for me, what works best and gives me the most peace is my faith in God.

Although consuming alcohol may be considered a poor coping mechanism by some, Lazarus (1993) posited that there are no universally "good" or "bad" coping methods and that it all depends on the type of stressor, whether it is for the short or long term, and how it affects a person's mood, sleep, and/or social functioning. Furthermore, Lazarus explains that although Westerners tend to value problem-focused coping and consider it superior, he explains that the evidence shows that emotion-focused coping can be superior in certain

circumstances, especially when nothing can be done to alter the outcome.

Therefore, the emotion-focused coping these mothers have utilized is well-suited for their needs as their children have chronic medical conditions.

Still, some of the mothers utilized problem-focused coping as well, particularly when connecting with other parents who have children with similar medical conditions, such as on the social media sites where this study was posted. Seeking this type of instrumental social support can give parents more information for better decision making. Gwen (July 2020) shared, “We’ve had to do a lot of the digging on our own, talking to other parents. We are a part of so many support groups on social media. That’s where we get our answers.”

While Lazarus and Folkman’s original theory had only those two kinds of coping, Folkman later introduced a third type of coping, “meaning-focused coping,” which helps create positive emotions simultaneously with negative emotions (2010). This kind of coping was added after Folkman (2010) did research that supported this addition to stress and coping theory. Folkman (1997) observed that caretaker partners of men with AIDS experienced both high levels of distress and positive psychological states. Folkman explained that

The four types of coping that were associated with positive psychological states have a common theme: searching for and finding positive meaning. Positive reappraisal, problem-focused coping, spiritual beliefs and practices, and infusing ordinary events with positive meaning all involve

the activation of beliefs, values, or goals that help define the positive significance of events (p. 1215).

Ten of twelve of the mothers described this meaning-making coping when they spoke about the positive aspects of caregiving. Cindy (July 2020) shared, “It’s the best thing that ever happened to me, to be honest....He really taught me the meaning of kindness.” Renee (July 2020) explained how having a child with special needs helped increase her compassion, “Because you’re going through your own things with your child, and you see someone else going through something....You just kind of realize, you’re more compassionate towards people.” Theresa (August 2020) shared, “The person I am, and how I see people is very different because of her. I think of all the things I could do with my life. That’s a very valuable, important investment to make in a person.” Folkman (2010) asserted that “these positive emotions serve important functions in the stress process by restoring resources for coping, which helps transform threat appraisals into challenge appraisals, motivating and sustaining coping efforts over the long run” (p. 902). She further explained the types of coping do not work in a vacuum and often work in tandem. For instance, regulating emotions through emotion-focused coping can help with the decision-making which is part of problem-focused coping. These decisions are supported by the intrinsic values of meaning-focused coping. These mothers use multiple methods of coping to be able to manage their long-term stress that can often be associated with burnout symptoms.

Need for Support and Suggested Interventions

All of the mothers had complaints regarding the service system. Liz (July 2020) shared, “When you’re looking at asking for help in the bucket of social services, if you’re not in your game, you’re not educated, you’re not well-versed, they will not give you what the program provides.” Kelly (July 2020) explained, “When he was born, it was a surprise to us and a social worker came in, but she was this young, inexperienced girl that went to Google some information and printed it out.” Darla (July 2020) concurred, “I did not get good social support from the hospital.” Gwen (July 2020) shared, “the hospital was a disaster,” and further explained, “It’s a flawed system and I think there is a lot of work to be done.” Sarah (July 2020) shared her lack of support succinctly, “I remember being in the hospital for a day and then them handing him to us and going “okay,” and you’re like, ‘What? Aren’t you going to tell me how to do this?’” These moms longed for more support. All of the mothers expressed a need for connection to services, greater financial support, and community resources. While social work focuses on empowerment, social workers also have to find the balance when a client may need more assistance due to being overwhelmed. Cindy (July 2020) explained that someone should

make sure you know exactly what you’re entitled to and why you’re entitled to it. So somebody that would actually help with that. And just to take that load off, because sometimes you’re just so tired that you’re like,

'I just need someone to do it for me because I'm mentally and emotionally exhausted.'

Social Workers must recognize when mothers are close to or experiencing burnout and offer that support. Liz (July 2020) explains it well:

I think it would be best for people who were in the same situation that they have it already laid out because you're already reeling from having a child that's completely abnormal. You have to deal with it, let alone all the different medical issues that they come with, and you have to be on top of. And now you've got all of these well-intended government programs that sometimes don't work because the communication gap is immense....What we need to do that would be really good is establish one agency that comprehensively covers the financial like a one-stop-shop, the financial, the emotional support for parents, the family therapist that is walking through this journey...somebody calling you and saying, 'Hey would you like to talk about the week with your son? How did the surgeries go? What are next steps?'

Sarah (July 2020) shared a similar sentiment, "I would have loved if we had an assigned person that we stayed in touch with and that helped us through the years figure out what to do next." Gwen echoed, "I think if there was somebody that laid all these things out, I think there needs to be a position and a resource and a department dedicated to that." All of these mothers shared a

frustration with the lack of coordination among service providers and the desire for greater support.

Implications of Findings for Social Work Practice

These mothers did not feel supported, particularly early on in the diagnosis. When presented with the suggestion of an eight-week psychoeducational program for new parents of children with medical complexities, eleven out of twelve of the mothers expressed interest, particularly at the time of the child's diagnosis and at times of transition, such as when a child is starting school or becoming an adult. However, such a course might be overwhelming to a brand-new parent of a child with medical complexities, particularly if the parents had to attend in person and in a group setting. Barnett et al. (2003), suggested that parents should be past the initial shock before participating in such a group. Nonetheless, the mothers in this study wanted support immediately upon diagnosis and felt it was lacking. Potentially, live video conferencing with an option to record for viewing at a later time could be utilized to remove some of the barriers to access such a program.

Pelchat (2010) wrote, "A variety of studies have shown that intervention with these parents is often inadequate, delayed, and non-systemic. And that clinicians are not properly prepared to respond to the needs of these families" (p. 212). In order to mitigate the negative effects on the family after having a child with medical complexities, Pelchat et al. (1999) developed an intervention called 'Programme d'Intervention Familiale' (PRIFAM) based partly upon Lazarus and

Folkman's Stress and Coping Theory. Families met with specially trained nurses for six to eight meetings, starting with two at the hospital following the child's birth, and four to six more meetings were completed in the homes of the families during the next six months (Pelchat et al., 1999). This is the type of personalized, individual care that many of the mothers in this study desire. This program was assessed at the completion of the program six months post birth, then again at twelve and eighteen months (Pelchat, 2010). This longitudinal evaluation showed that the PRIFAM was an effective intervention. It reduced parental stress, emotional distress, anxiety, depression, and increased spousal support; furthermore, it increased parents' sense of competency in caring for their child (Pelchat, 2010). According to Pelchat (2010), involving the father from the beginning helps maintain family harmony and can potentially reduce divorce rates. Parents were able to make contact with resources early, giving them better control of the situation; and since the program was developed with hospital staff, it developed feelings of partnership (Pelchat, 2010). In a meta-analysis of interventions for parents of children with disabilities, Singer et al. (2007) praised Pelchat's PRIFAM as a superior intervention, noting the success of the multi-component intervention over a long period of time that included siblings and extended family members.

Part of the issue with interventions for new parents is the ability to get to the hospital. The parents in Pelchat's PRIFAM were met in their own homes, a distinct advantage for these parents as they are extraordinarily busy taking care

of an infant with special needs in addition to any other children. If this type of intervention is not possible due to a lack of resources, hospitals now have the advantage of performing follow-up meetings via video conferencing, establishing another means for continuing follow-up with these families.

This study is noteworthy due to the wide diversity of experience including mothers of various educational and marital statuses, differing ethnic groups, and even different countries outside of the United States.

A limitation of this study is the small sample size of only twelve mothers. Additionally, this is a voluntary sample, and therefore may not be generalizable to the wider population. Finally, none of the participants were currently experiencing an extraordinarily difficult time and were occasionally recounting past times or anticipating future events.

The results of this study on mothers of medically complex children highlight the need for intervention, particularly after the child's birth or diagnosis. Social workers should not only be aware of these needs, but support implementing programs such as the PRIFAM and even virtual programs to help support families who are in crisis following the birth of a child with medical complexities.

Summary

This chapter begins with an analysis of the qualitative data and presents the demographics on the mothers of children with medically complex conditions who participated in this study. The method used to code the

qualitative data is discussed. The data is interpreted after notable themes are identified during the coding process. Burnout theory explains some of the symptoms the mothers have experienced, but Stress and Coping theory offers an explanation for their ability to continue to cope as long-term caregivers, with a combination of mainly emotion-focused coping coupled with some problem-focused coping. Meaning-focused coping is a type of coping found to be critical for caregivers and helps mitigate the effects of long-term stress, giving meaning to suffering and creating positive states simultaneously with negative emotional states. The need for interventions is discussed and a potential intervention is introduced.

CHAPTER FIVE

TERMINATION AND FOLLOW UP

Introduction

This chapter outlines the steps taken for the termination process. The results of this study will be communicated with the mothers who participated in this research study. A section regarding continuing relationships in online communities is discussed. Finally, there is an explanation of the dissemination process.

Termination of Study

During the termination phase, each interviewee was contacted directly and thanked for their time and participation in this study. As this study is utilizing the post-positivist paradigm, there is a commitment to report the findings to the study participants due to the relationship formed during the interviews (Morris, 2013). The researcher kept in mind that the participants may be laypersons unfamiliar with the research process and encouraged questions. The discoveries of the study have been discussed in addition to how maternal stress and burnout may be addressed in the future. The researcher inquired if the study participants had any questions or concerns. After discussion and answering questions relevant to the study, the participants were thanked for their time and involvement. All documents on paper and all files on the researcher's personal computer have been destroyed.

Communication of Findings and Dissemination Plan

The research project will be compiled in a written report presented to the social work school at California State University, San Bernardino, and available on the Scholarworks website upon completion. This website has open access to the general public for reading and reviewing. The mothers who participated in this study have been advised that they can access the entire study on Scholarworks and given steps how to accomplish this task. Moreover, research participants will be emailed the file used for “poster day,” an annual event where crucial information about the study is shared in a concise poster format.

The researcher intends to use this research to support the need for select caretaker interventions through hospitals and California Regional Centers, a state-wide organization intended to provide lifelong services for persons with significant developmental disabilities. Currently, the major service provided to caretakers is respite care, where a worker relieves the caretaker of their duties for brief periods of time. The results of this study identified additional maternal caretaker needs and may inform future interventions beyond basic respite care.

Ongoing Relationship with Study Participants

The researcher may have future interactions with the mothers who participated in this study due to their online shared communities for parents of children with special needs.

Summary

This chapter highlights the process of termination. Research study participants were mothers of children with both medical complexities and developmental delays found through online support groups for parents of children with special needs. Termination has been completed as the documents and files were destroyed and participants were informed regarding the results of this study. Additionally, they were shown how to access the Scholarworks site and emailed a study summary with the “poster day” presentation materials.

APPENDIX A
INFORMED CONSENT

The study in which you are asked to participate is designed to explore the perceived stress, coping methods, and suggested interventions of mothers who have children with both medical complexities and neurodevelopmental disorders. Although the mothers can be from around the world, the majority will be from Southern California. This study is being conducted by Lisa Poff, a graduate student under the supervision of Dr. Carolyn McAllister, Director of the School of Social Work at California State University, San Bernardino (CSUSB). This study has been approved by the Institutional Review Board at CSUSB.

PURPOSE: The purpose of this study is to explore the perceived stress, coping methods, and suggested interventions of mothers who have children with both medical complexities and neurodevelopmental disorders.

DESCRIPTION: Participants will be asked questions regarding their stress as a caretaker, their coping methods, and their suggestions for support.

PARTICIPATION: Your participation in the study is totally voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

CONFIDENTIALITY: Your responses will remain confidential and data will be reported in group form only.

DURATION: It will take approximately 30 minutes but no more than an hour for this interview.

RISKS: Although not anticipated, there may be some discomfort in answering some of the questions. You are not required to answer and can skip the question or end your participation.

BENEFITS: There will not be any direct benefits to the participants.

CONTACT: If you have any questions about this study, please feel free to contact Dr. McAllister at mcallis@csusb.edu.

RESULTS: Results of the study can be obtained from the Pfau Library ScholarWorks database

(<http://scholarworks.lib.csusb.edu/>) at California State University, San Bernardino after July 2021

***** I agree to have this interview be audio recorded: _____ YES _____ NO

I understand that I must be 18 years of age or older to participate in your study, have read and understand the consent document and agree to participate in your study.

Place an X mark here _____ Date _____

APPENDIX B
QUESTIONNAIRE

Please state your assigned number, ethnicity, the sex of your special needs child, how many other children you have, if you are married or single, and if you consider yourself the primary caregiver.

How did having a child with both medical complexities and a neurodevelopmental disorder change your life? ie career, dreams, self-care, alone-time, doctor appointments and therapies, daily needs of the child, etc.

How does having a child with both medical complexities and a neurodevelopmental disorder alter your life as a family? ie...recreation, vacations, etc.

Describe your typical day as a caregiver.

How do you spend your weekends as a caregiver versus weekdays?

Has being a long-term caretaker increased your stress levels? If so, how?

Describe any positive aspects of caregiving.

How do you cope as a caregiver?

Who or what is your greatest support?

How would you describe your support from grandparents and extended family?

How do you think your ethnicity has affected what supports you receive as far as social services, familial support, etc.

How do you receive support? ie. respite care through regional center, skilled nursing, etc.

What type of additional supports would you like to have if it was provided through social services?

Would you be interested in a free eight-week psychoeducational support group that provided appropriate childcare and covered topics such as self-care, mindfulness, and resources?

Do you feel your ethnicity has affected any aspect of special needs parenting?

When I think of my future as a caregiver, I feel.....

Developed by Lisa Poff

APPENDIX C
INSTITUTIONAL REVIEW BOARD APPROVAL

June 5, 2020

CSUSB INSTITUTIONAL REVIEW BOARD

Administrative/Exempt Review Determination

Status: Determined Exempt

IRB-FY2020-262

Lisa Poff Carolyn McAllister
CSBS - Social Work
California State University, San Bernardino
[5500 University Parkway](#)
San Bernardino, California 92407

Dear Lisa Poff Carolyn McAllister

Your application to use human subjects, titled “Maternal Stress, coping strategies, and suggested interventions in caring for children with both medical complexities and neurodevelopmental disorders” has been reviewed and approved by the Chair of the Institutional Review Board (IRB) of CSU, San Bernardino has determined your application meets the federal requirements for exempt status under 45 CFR 46.104. The CSUSB IRB has not evaluated your proposal for scientific merit, except to weigh the risk and benefits of the study to ensure the protection of human participants. The exempt determination does not replace any departmental or additional approvals which may be required. **PLEASE READ SUGGESTED COMMENT IN YOUR CONFIDENTIALITY SECTION OF YOUR APPLICATION.**

You are required to notify the IRB of the following as mandated by the Office of Human Research Protections (OHRP) federal regulations 45 CFR 46 and CSUSB IRB policy. The forms (modification, renewal, unanticipated/adverse event, study closure) are located in the Cayuse IRB System with instructions provided on the IRB Applications, Forms, and Submission webpage. Failure to notify the IRB of the following requirements may result in disciplinary action.

- Ensure your CITI Human Subjects Training is kept up-to-date and current throughout the study.
- Submit a protocol modification (change) if any changes (no matter how minor) are proposed in your study for review and approval by the IRB before being implemented in your study.
- Notify the IRB within 5 days of any unanticipated or adverse events are experienced by subjects during your research.

- Submit a study closure through the Cayuse IRB submission system once your study has ended.

If you have any questions regarding the IRB decision, please contact Michael Gillespie, the Research Compliance Officer. Mr. Michael Gillespie can be reached by phone at (909) 537-7588, by fax at (909) 537-7028, or by email at mjillesp@csusb.edu. Please include your application approval number IRB-FY2020-262 in all correspondence. Any complaints you receive from participants and/or others related to your research may be directed to Mr. Gillespie.

Best of luck with your research.

Sincerely,

Donna Garcia

Donna Garcia, Ph.D., IRB Chair
CSUSB Institutional Review Board

DG/MG

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