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Gratitude Among Mothers Raising a Child With Special Health Care Needs

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Abstract

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Keli Jean Kleindorfer

MS, California State University, Northridge, 2010

BS, Arizona State University, 2005

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Health Psychology

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Abstract

For a mother raising a child with special health care needs (CSHCN), maintaining positive feelings of gratitude can become challenging because of the stress associated with caregiving, as well as the consequences of unmanaged stress, which include decreases in both physical and psychological health and well-being. Chronic, unmanaged stress has been associated with various health issues that can be severe and potentially life-threatening. The purpose of this phenomenological study was to examine how mothers raising a CSHCN experience gratitude. A secondary purpose was to identify possible barriers to experiencing gratitude, which, when implemented as a coping style, may decrease the negative effects of daily stress and improve mental health. The broaden-and-build theory of positive emotions along with the transactional model of stress and coping provided an optimal conceptual framework for this study. The research questions were centered around the challenges and stressors unique to each mother, coping strategies, and gratitude. The ways in which the combination of factors contributed to quality of life among the mothers were examined specifically. Data from face-to-face interviews with 15 mothers were transcribed, coded, and thoroughly analyzed for themes. The primary themes that emerged were support from family and friends, feelings of gratitude, coping mechanisms, life satisfaction, gratitude for a flexible job, stress related to full dependency, high stress levels over the past 30 days, increased stress when describing the child, and a need to work on eating habits. Findings and recommendations from this study may contribute to positive social change and support the benefits of gratitude, especially in highly stressful situations.

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Dedication

I dedicate this dissertation and my PhD to my mom and dad, who loved me unconditionally and always taught me to dream big. To my mom, my best friend, you are the most amazing and kind person I have ever known. I strive every day to be like you. Your passing is the hardest thing I have ever gone through, and it is gratitude for the love, laughter, and incredible memoires that provides me with strength and comfort. Although you passed during my first quarter of my PhD program, I am grateful for your guidance throughout the entire process. To my dad, my "Pardner," you are the strongest person I have ever known, and during the times when I thought I was going to break, I remembered your strength and I know that you guided me in the right direction. I miss you both more than words can ever express, and I am so genuinely grateful for the amazing time we had together and all the extraordinary memories.

In addition to the foundation I got from my mom and dad, I would also like to dedicate this dissertation and my PhD to my Grammy Maybell and my Godparents, Jon and Jolene. You all provided me with love, support, and encouragement. The impact you each have had on my life is invaluable. You all played a special part in helping me to accomplish this milestone, and I am grateful for each of you.

To my fur baby, Palatini, who cuddled up next to me during the long nights of research, you have helped me in countless ways, and I love you. To my family, Sheryl and Dee-Dee, who I am lucky enough to call friends, and to my friends, Lauren, Tania, Anishka, and Dan, who I am blessed to call family, thank you for your unwavering support and encouragement. Thank you! I love you, and I am truly grateful for you!

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Table of Contents

List of Tables

Chapter 1: Introduction to the Study

Mothers raising a child with special health care needs (CSHCN) may experience gratitude differently because of the challenges posed by increased stressors in addition to consequences of unmanaged stress, such as decreases in both physical and psychological health and well-being (Lilly, Robinson, Holtzman, & Bottorff, 2012). When compared to men, women have different reactions to stress in areas such as behavioral outcomes, immune function, and activation of both the sympathetic nervous system and the hypothalamic-pituitary-adrenal (HPA) axis (Bekhbat & Neigh, 2018). Chronic, unmanaged stress may contribute to a variety of health issues, including heart disease (Murphy, Cohn, & Loria, 2016), obesity (Hewagalamulage, Lee, Clarke, & Henry, 2016), depression (Juruena, 2014), and diabetes (Kelly & Ismail, 2015). In addition to improving mental health, preventing mental illness, and reducing the risk of both anxiety and depression (Emmons & Stern, 2013), gratitude has been directly related to better sleep, increased physical activity, and improved self-care (Lavelock et al., 2016).

The purpose of this phenomenological study was to explore how mothers raising a CSHCN experience gratitude. These mothers are at an increased risk of diminished physical and psychological well-being (Pinquart, 2017), especially because they frequently put the needs of their children before their own (Kuhlthau et al., 2014). Results from this study may be used to produce sustainable social change by affirming gratitude as an effective coping strategy (Nezlek, Newman, & Thrash, 2017). Chapter 1 includes major sections on the following topics: (a) background of related literature, (b) problem statement, (c) purpose of the study, (d) research questions, (e) conceptual framework, (f) nature of the study, (g) definition of terms, (h) assumptions, (i) scope, (j) delimitations, (k) limitations, and (l) significance of the study.

Background

For the purpose of this study, *gratitude* is operationally defined as appreciation, thankfulness, and affirmation of what is meaningful and valuable to oneself (Emmons & Stern, 2013; Sansone & Sansone, 2010). For example, Anderson and White (2017) found in their study that caregivers of individuals with serious illness defined gratitude as an expression of emotion upon receipt of unexpected gifts or blessings. The mothers in this study were considered caregivers. The term *caregiver* is operationally defined as an individual serving as a personal advocate, performing medical and therapeutic tasks for a family member (American Psychological Association [APA], 2017) in addition to managing family needs, planning, scheduling, following up, and searching for applicable resources (Devault, 1999; Home, 2002). For the purpose of this study, the term *CSHCN* refers to a child who has or is at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also requires health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998).

An individual can feel gratitude for both tangible and intangible objects (Halberstadt et al., 2016; Harvard Medical School, 2011). For instance, Halberstadt et al. (2016) found that children expressed gratitude for a variety of items, such as toys, candy, a trip, their home, money for music lessons, love, time spent with family, and the sounds of birds singing. Caregivers who use gratitude as a coping mechanism may have an increased ability to adjust to life events and may also better manage the health conditions of the person receiving care (Cassidy & McLaughlin, 2015).

It is possible, and beneficial, to find benefits of gratitude in a variety of difficult situations, ranging from natural disasters to traumas to personal losses (Stoeckel, Weissbrod, & Ahrens, 2015). This ability depends more on the individual than the situation (Nolen-Hoeksema & Davis, 2002). Ruini and Vescovelli (2013) focused on the benefits of gratitude in women with breast cancer and found improvements in depression, anxiety, and irritability levels. In another study, individuals who experienced positive emotions following the terrorist attacks on September 11, 2001, were more resilient and less likely to suffer from depression (Fredrickson, Tugade, Waugh, & Larkin, 2003). In addition to being simple and easy to incorporate (Davis et al., 2016), gratitude practices yield positive physical and mental health outcomes (Lavelock et al., 2016).

Women as Primary Caregivers

Women often take on the role of primary caregiver in families regardless of ability, disability, or age of the family member requiring care (Hooymans & Gonyea, 1995; Osafo, Knizek, Mugisha, & Kinyanda, 2017; Sharma, Chakrabarti, & Grover, 2016). Mothers providing care for a chronically ill child often struggle to balance domestic responsibilities with those associated with the unique needs of the child (Macedo, da Silva, Paiva, & Ramos, 2015). Such demands lead to increased stress and may result in both chronic and acute physical disorders, depression, isolation, financial turmoil, and self-accusation.

Caring for CSHCN requires increased levels of time and attention, which can be burdensome and stressful (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010). When compared to mothers with typically developing children, mothers of CSHCN have poorer mental health and poorer health in general (Dillon-Wallace, McDonagh, & Fordham, 2014). These mothers also perceive their lives as more difficult. Caregivers' symptoms may vary along with factors such as the kind of aid required, the amount of time devoted to caregiving, whether the person receiving care has behavioral issues, and whether the caregiver has help with responsibilities (Grosse, Flores, Ouyang, Robbins, & Tilford, 2009; Imran et al., 2010).

Raina et al. (2005) found that a combination of caregiving demands and child behavior significantly influenced the physical and psychological health of caregivers, who were primarily mothers. Based on the many stressors associated with raising a child with a disability, it has been recommended that increased psychosocial considerations be given to families in this situation (Sadati et al., 2015). Reports of increased strain and decreased quality of life among mothers raising a CSHCN in Taiwan further support this suggestion (Tsai & Wang, 2009).

Studies have suggested that women are among those with increased stress-related health risks (Cohen & Janicki-Deverts, 2012; Ostwald, Bernal, Cron, & Godwin, 2009). Dillon-Wallace et al. (2014) studied the well-being of mothers in Australia caring for a CSHCN. However, similar studies are significantly lacking. Specifically, data related to the lived experiences of mothers providing care to a CSHCN in America are sparse.

Children With Special Health Care Needs

More than 11 million children in the United States under the age of 18 years are considered to have special health care needs (U.S. Department of Health and Human Services [HHS], 2013). According to McPherson et al. (1998), a CSHCN has a greater risk for developmental, emotional, physical, or behavioral conditions and often requires additional health-related services more frequently than children in general. A multidisciplinary team is often formed to meet the increased health needs of these children (Carroll & Sixsmith, 2016). In addition to the parents, the child with special health care needs, and other family members, team members typically include speech and language pathologists, physiotherapists, occupational and physical therapists, psychologists, nurses, social workers, and family support workers (Bethell et al., 2015).

Although individuals caring for a CSHCN are at greater risk of psychological distress, caregiving can also be extremely rewarding (Bauer, Sterzinger, Koepke, & Spiessl, 2013; Lovell & Wetherell, 2016; Smith & Grzywacz, 2014). During a discussion with Hart (2013), Emmons confirmed that research supports that gratitude can enhance nearly all domains of functioning. However, data are lacking on the ability to maintain gratitude throughout stressful situations (Rosmarin, Pirutinsky, Greer, & Korbman, 2016). Despite the unique challenges and stressors they face, there continues to be a gap in the literature on how mothers caring for a CSHCN experience gratitude. While the current literature emphasizes the perceptions of caregivers for older adults and the chronically ill, a study of this nature is beneficial because the findings may provide details related to preventive care that multiple populations can implement.

Problem Statement

For a mother raising a CSHCN, maintaining positive feelings of gratitude can become challenging because of the stress associated with caregiving, as well as its consequences, which may include decreases in both physical and psychological health and well-being, which are more prevalent in mothers than fathers (Lilly et al., 2012). Previous studies have focused on caregiver burnout among families caring for an older family member (del-Pino-Casado, Pérez-Cruz, & Frías-Osuna, 2014; Hurley, Patterson, & Cooley, 2014; Willemese et al., 2016), but CSHCN and their families have received significantly less attention (Rucci et al., 2015; Totman, Pistrang, Smith, Hennessey, & Martin, 2015). Specifically, there are few studies devoted to exploring whether mothers of a CSHCN experience gratitude and how such feelings, or lack thereof, influence the life of each mother.

The physical, mental, and emotional health of parents caring for CSHCN are often negatively affected by caregiving stress (Witt, Gottlieb, Hampton, & Litzelman, 2009). Parents may experience frustration, anger, anxiety, helplessness, and decreased energy. They may also feel socially isolated and may constantly worry about their child's future. Smith and Grzywacz (2014) suggested that parents of CSHCN may experience negative long-term health consequences because of such stressors. Although fathers are typically involved with issues associated with a CSHCN, mothers most frequently experience extreme stress and pressure related to caregiving (Sadati et al., 2015).

Data are lacking on the role of gratitude among mothers caring for a CSHCN. Even though parents of a CSHCN typically require more replenishment to sustain their own health, they often put the needs of their child first and fail to care for themselves (Boston University, n.d.; Huang et al., 2013; Kuhlthau et al., 2014). Information specific to the lived experiences of individual mothers may produce positive social change by illuminating gratitude as a beneficial coping mechanism among mothers caring for a CSHCN.

Purpose of the Study

The purpose of this phenomenological study was to examine how mothers raising a CSHCN experience gratitude, as they are more likely than fathers to experience health-related consequences of caregiving such as decreases in both physical and psychological health and diminished well-being (Pinquart, 2017). A secondary purpose was to identify potential barriers to experiencing gratitude, which, when implemented as a coping style, may decrease the negative effects of daily stress and improve mental health (Krejtz, Nezlek, Michnicka, Holas, & Rusanowska, 2014). Women who do not effectively manage their stress may experience family difficulties, decreased social interaction, poor sleeping patterns, emotional distress, decreased exercise, and increased alcohol consumption (McEwen, 2008; McKinzie, Altamura, Burgoon, & Bishop, 2006).

In households where the mother and father both worked full time, 54% of parents reported that the mother dealt more with the management of the activities and schedules of the children, and 47% reported the mothers did more when the children were sick (Pew Research Center, 2015). Additionally, in families where the mother works either part time or not at all and the father works full time, the mothers assume more responsibilities related to household chores and parenting tasks than mothers working full time (Sharma et al., 2016). Because increased health needs and diminished well-being are more prevalent in mothers of CSHCN than in mothers of typically developing children, this study explored the lived experiences of mothers caring for a CSHCN.

Research Questions

Based on a conceptual framework drawing from Fredrickson’s (2004) broaden-and-build theory of positive emotions and the transactional model of stress and coping (Lazarus & Folkman, 1984), I developed the following research questions:

Primary RQ1: For which aspects are mothers raising a child with special health care needs most grateful?

Secondary RQ2: What are the major challenges/stressors faced by mothers raising a child with special health care needs?

Secondary RQ3: What major coping styles are employed by mothers raising a child with special health care needs?

Secondary RQ4: In which ways do gratitude, challenges, and coping styles contribute to quality of life among mothers raising a child with special health care needs?

Conceptual Framework

The conceptual framework for this study was guided by two theories: Fredrickson’s (2004) broaden-and-build theory of positive emotions and the transactional model of stress and coping (Lazarus & Folkman, 1984; Pogrebtsova, Craig, Chris, O’Shea, & González-Morales, 2017). The broaden-and-build theory focuses on how positive emotions broaden the thought-action repertoire of an individual through the discovery of original ideas, actions, and social bonds (Fredrickson, 2004; Van Cappellen, Toth-Gauthier, Saroglou, & Fredrickson, 2016). This expansion builds psychological, social, intellectual, and physical resources (Kiken, Lundberg, & Fredrickson, 2017). Such resources can be used later as effective coping mechanisms (Van Cappellen, Rice, Catalino, & Fredrickson, 2017).

Broaden-and-Build Theory of Positive Emotions

Fredrickson (1998, 2001) provided the example that when an individual experiences the positive emotion of happiness, this emotion is broadened by creating an urge to play, which then builds stronger personal resources (Kerr, O'Donovan, & Pepping, 2015). This process expands and broadens an individual's habitual ways of thinking (Fredrickson, 1998, 2000; Garland, Farb, Goldin, & Fredrickson, 2015). This broadening of previously habitual thinking leads to the development of new skills, creates enduring personal resources, and prepares the individual for future challenges (Fredrickson, 2001; Lin, 2015b).

Subsequent application of Fredrickson's theory provides support for positive emotions as an effective method to manage and cope with stress and increase both behavioral and cognitive resilience (Gloria & Steinhardt, 2016; Meneghel, Salanova, & Martínez, 2016). The implementation of the broaden-and-build theory to leisure coping supports the idea that resilient individuals are more likely to implement constructive coping to cultivate positive emotions, which decreases the effects of stress while also promoting well-being (Denovan & Macaskill, 2016). The broaden-and-build theory has also been incorporated into studies focusing on women with HIV (Wilson et al., 2017), veterans with posttraumatic stress disorder (PTSD; Kearney et al., 2014), pain intensity among individuals with chronic pain (Thong, Tan, & Jensen, 2017), and children with a life-threatening illness (Chaves, Hervas, García, & Vazquez, 2016).

Transactional Model of Stress and Coping

The transactional model of stress and coping suggests that health, health behavior, and psychological well-being are each correlated with stress and coping (Glanz & Schwarts, 2008; Lazarus, 1991). The reactions of an individual are mediated by a cognitive appraisal process where each stressor is characterized by person-environment transactions (Ying, Yap, Gandhi, & Liew, 2017). A key component of this theory is the understanding that different individuals can appraise identical situations differently (Wethington, Glanz, & Schwartz, 2015). Specifically, each person's appraisals are directly related to the core concepts of the transactional model of stress and coping: "primary appraisal, secondary appraisal, coping efforts, meaning-based coping, and outcomes of coping" (Glanz & Schwartz, 2008, p. 230).

The transactional model of stress and coping takes into consideration that individuals differ significantly in what they believe to be stressful (Marks, Murray, Evans, & Estacio, 2011). Additionally, each person reacts differently to the same potentially stressful circumstances (Samios & Baran, 2017). This theory has been applied to a variety of populations, including individuals with cancer, diabetes, HIV, and drug, alcohol, and tobacco use (Graham, 2015; Hulbert-Williams, Morrison, Wilkinson, & Neal, 2013; Paek, Ip, Levine, & Avis, 2016; Schantz & Bruk-Lee, 2016).

Conceptual Synthesis

The synthesis of Fredrickson’s (2004) broaden-and-build theory of positive emotions and the transactional model of stress and coping (Lazarus & Folkman, 1984) provided the foundation for developing a better understanding of gratitude among mothers of CSHCN, who experience increased challenges and stressors (Krakovich, McGrew, Yu, & Ruble, 2016). Conceptually, links between stressors and the interpretations of such stressors have been addressed in the broaden-and-build theory (Fredrickson, 2004; Lin, Kao, Chen, & Lu, 2016), and the transactional model of stress and coping has outlined links between positive emotions and personal growth (Crego, Martínez-Iñigo, & Tschan, 2013; Lazarus & Folkman, 1984). Specifically, these two theories strengthened the framework of the study by detailing the associations between emotions, coping, and health (Gloria & Steinhardt, 2016). Chapter 2 contains more thorough explanations of both theories.

The focus of the transactional model of stress and coping (Lazarus & Folkman, 1984) is on the appraisals given to constant stressors experienced in daily life, with an emphasis on the coping mechanism chosen for each stressor (Riley & Park, 2014). The emphasis of the broaden-and-build theory of positive emotions (Fredrickson, 2004) is that when the appraisals assigned to stressors are positive, the emotions have enduring results (Fredrickson & Siegel, 2017). Additionally, when an individual faced with a problem feels good, optimism broadens and rational problem solving increases (Chang, 2017).

Resources developed through the mechanisms posited within the broaden-and-build theory (Fredrickson, 2004) can be used as effective coping mechanisms for future stressors (Ramsay et al., 2015). Studies have shown that individuals with greater levels of resilience are less likely to experience stress-related health effects (Gloria & Steinhardt, 2016; Peer & Hillman, 2014). These two theories complement each other in relation to the ways in which an individual can draw upon personal, intellectual, physical, social, and psychological resources (Fredrickson, 2004; Kim & Franklin, 2015) in stressful situations, when the individual must evaluate both internal and external coping options (Hulbert-Williams et al., 2013; Lazarus & Folkman, 1984). The combination of these two theories not only served as an optimal foundation of the current study but also substantiated the primary purpose of this study, which was to explore how mothers raising a CSHCN experience gratitude and how their experience of gratitude may function as a buffer against stress and improve their capacity to cope with the myriad of challenges related to caring for a CSHCN.

Nature of the Study

This study used a qualitative phenomenological design, as the purpose was to collect subjective information related to individualized experiences as well as examine the meaning assigned to a situation (Adams & van Mannen, 2017; Creswell, 2014; Ellis, 2016; Quay, 2016). Researchers have used phenomenological approaches to explore gratitude in a variety of contexts (Büssing et al., 2014; Manning, 2014; O'Brien, Donaghue, Walker, & Wood, 2014; Russell, 2016). Specifically, qualitative research using a phenomenological design is used to explore a central phenomenon through the lived experiences of individuals and reveals both diverse and shared components of the experience (Hood, 2016). The goal of phenomenology is to describe a phenomenon more than it is to explain it (Knapp, 2015).

In a phenomenological approach, it is posited that humans are most sure about their subjective analysis of the world around them, and this makes subjective reality more meaningful than objective reality (Connelly, 2015; Greenfield & Jensen, 2012; Smith, 2017; Wilson, 2015). This method is consistent with exploring the experiences of gratitude among mothers raising a CSHCN. Keeping the focus on how mothers successfully cope with daily stressors should be consistent with Fredrickson's (2004) broaden-and-build theory and the transactional model of stress and coping (Lazarus & Folkman, 1984). Insight into the phenomenon of raising a CSHCN was achieved through this phenomenological design.

I collected data from 15 mothers raising a CSHCN. Participants were recruited using purposeful sampling techniques, which allowed me to select information-rich cases to obtain a deeper understanding of the target phenomenon (Benoot, Hannes, & Bilsen, 2016; Patton, 2002). I used a small, discrete audio recorder and transcribed the semistructured, face-to-face interviews. The majority of the questions were open-ended so that the perspectives and opinions of the participants were more thoroughly elicited (Creswell, 2014; Kallio, Pietilä, Johnson, & Docent, 2016).

Definition of Terms

The following are terms and definitions unique to the study:

Caregiver: A caregiver is an individual who serves as a personal advocate, performing medical and therapeutic tasks for a family member (APA, 2017), while also managing family needs, planning, scheduling, following up, and searching for applicable resources (Daniels et al., 2017; Devault, 1999; Home, 2002).

Child with special health care needs (CSHCN): A CSHCN is a child who has or is at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also requires health and related services of a type or amount beyond that required by children generally (McPherson et al.,1998).

Coping: Coping consists of “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands” that an individual appraises as taxing or exceeding the individual’s resources (Lazarus & Folkman, 1984, p. 141).

Gratitude: Gratitude is appreciation, thankfulness, and affirmation of what is meaningful and valuable to oneself (Emmons & Stern, 2013; Sansone & Sansone, 2010).

Quality of life (QoL): QoL is the overall satisfaction felt by an individual regarding life and personal well-being (Schumacher, Olschewski, & Schulgen, 1991).

Self-care: Self-care is an ongoing commitment to engagement in health-promoting behaviors to enhance an individual’s health, nutrition, exercise, stress management, social support, and self-actualization (Pender, Murdaugh, & Parsons, 2010).

Stress: Stress is the “nonspecific response of the body to any demand” (Selye, 2013, p. 15) that can potentially threaten well-being (Lazarus, 1966).

Stressors: Stressors are demands that surpass an individual’s resources (Lazarus, 1966) and cause stress (Ukpo, 2015). Stressors include, but are not limited to, the following: cognitive, biological, environmental, personal behavior, life situation, social, interpersonal, and time management.

Stress-related health risks: Stress-related health risks are health changes influenced by negative emotions that are evoked by stressors, which dysregulate an individual's immunological, physiological, and/or psychological responses (Glaser & Kiecolt-Glaser, 2005).

Well-being: Well-being is pleasure and satisfaction with one's life, which promotes the perception of having a meaningful life (Kashdan, Biswas-Diener, & King, 2008; Kim, Lehning, & Sacco, 2015; Ryan & Deci, 2001). Spiritual, interpersonal, social, emotional, physical, intellectual, and environmental factors influence well-being (Ukpo, 2015).

Assumptions

A key assumption for this study was that the two chosen theories, along with the research that has revealed relationships between gratitude and overall health in the generalized adult population (Elosúa, 2015; Killen & Macaskill, 2015; Lavelock et al., 2016), could all be generalized to individual participants in the study. A second assumption was that each mother would provide honest, detailed responses to the questions asked (Doody & Noonan, 2013). A third assumption was that the inclusion criteria of the sample would be appropriate to ensure that each participant had experienced the same or similar phenomena of interest to the study (Cope, 2014). Also assumed was that each participant would demonstrate a sincere interest in participating in the research without any ulterior motives (Irani & Richmond, 2015).

Another assumption was that narrative-based inquiry was the best approach for obtaining the intended information. The participant can illustrate reality and uncover multiple facets of the events studied through narratives (Brophy, 2016). In addition to portraying meaning, narratives highlight significant features and provide holistic analysis. Narratives also elicit emotional reactions through details regarding specific characters, the setting, and identifying information (Levine & Pizarro, 2004; Martin, 2016; Small & Loewenstein, 2003; Small, Loewenstein, & Slovic, 2007).

The final assumption was that individuals can experience the same phenomenon in a variety of ways and from different perspectives (Bevan, 2014). This assumption, also known as *modes of appearing*, postulates that an experience receives an identity based on the way in which an individual perceives it. The specific language used by the participants to convey emotions and facts is included in the findings to further highlight the individual experiences of the same phenomenon (Matura, 2015).

Scope of Study

Previous research on caregiving stress has primarily focused on burnout among those caring for an older family member (del-Pino-Casado et al., 2014; Hurley et al., 2014; Willemese et al., 2016); mothers caring for a CSHCN have received significantly less attention. Even more, literature is lacking related to stressors, coping styles, and gratitude among such mothers. In the current study, I explored the proposition that mothers raising a CSHCN who implemented gratitude as a coping mechanism would have lower stress levels and increased quality of life when compared to mothers with a CSHCN who did not use gratitude as a coping mechanism.

This study included 15 participants. Although there is no agreed-upon standard for the number of participants in phenomenology, some have estimated the average to be 13 (Francis et al., 2010; Turner-Bowker et al., 2018), whereas others have suggested three to 10 (Creswell, 2014). I included 15 participants to ensure data saturation through the collection of rich and detailed information from the participants (O'Reilly & Parker, 2012). Each participant met the following criteria: (a) speaks English proficiently, (b) mother raising at least one child of any age with special health care needs, and (c) resides in Phoenix, AZ. The rationale for including only mothers of CSHCN was that women continue to take on the role of primary caregiver in families regardless of ability, disability, or age of the family member requiring care (Hooymans & Gonyea, 1995; Osafo et al., 2017; Sharma et al., 2016).

I selected participants via purposive sampling. This is a nonrandom means of ensuring that a specific group of individuals with unique perspectives on the targeted phenomenon become part of the final sample (Robinson, 2014). Specifically, I implemented maximum variation sampling (MVS), as I selected participants with varied perspectives on the phenomenon (Etikan, Musa, & Alkassim, 2016).

Delimitations

Delimitations are the characteristics that define the boundaries and limit the scope of a study (Simon, 2011). One such delimiting factor in this study was the limited geographical area from which I selected participants, specifically central Arizona. Additionally, this study only included mothers raising a CSHCN. Although fathers are typically involved with issues associated with these children, mothers most commonly experience extreme stress and pressure related to caregiving (Sadati et al., 2015). Furthermore, when compared to mothers with typically developing children, mothers of CSHCN have poorer mental health and poorer health in general (Dillon-Wallace et al., 2014).

Despite the consideration given to both quantitative and mixed methods approaches, I believe that a qualitative approach was the most appropriate method, as it allowed for detailed and in-depth views of the issues experienced (Patton, 2002). Qualitative research also allowed for open-ended questions that provided specific insights into the feelings, experiences, and perceptions of each participant. This facilitated the understanding of the lived experience of each mother.

I considered social role theory (Eagley & Steffen, 1984), which suggests that gender influences behavior and that it is common for an individual to act according to the social norms attributed to the individual’s gender (Fyall & Gazley, 2015). However, I did not include this theory in the current study because it does not include stressors unique to caring for a CSHCN. Well-being theory (Seligman & Csikszentmihalyi, 2000) was also considered but not included. Although this theory incorporates the importance of positive emotions (Coffey, Wray-Lake, Mashek, & Branand, 2016), it lacks details related to coping styles.

The participant’s rich descriptions of their experiences increased the transferability of this study (Fusch, Fusch, & Ness, 2017). Results may be generalizable to a diverse population of individuals experiencing high levels of stress. The findings of this study may also transfer over to individuals before they reach the point of stress-related illness and may provide a way for larger groups to increase and maintain happiness and quality of life.

Limitations

Limitations of the current study included self-report response bias, data analyses, and generalizability. Responses provided by the participants may have been biased (Rosenman, Tennekoon, & Hill, 2011). Although such biases are often unintentional, bias may result from perceptions of social desirability, in that participants may fear being portrayed negatively, despite the anonymity of a study (Navarro-González, Lorenzo-Seva, & Vigil-Colet, 2016). Response bias can also result from diverse articulation and perception skills, the researcher’s presence, and misunderstanding of questions (Creswell, 2014; Morales-Vives, Lorenzo-Seva, & Vigil-Colet, 2017).

Another limitation of this study was data analyses. There were substantial amounts of transcribed and translated data in this qualitative study that I organized, coded, and meticulously analyzed (Setia, 2017). Although data from quantitative research can be translated to numbers, this is not the case for qualitative data (Anderson, 2010). Despite the coding and organization of themes, the analyses and interpretation of qualitative data do not typically fit into a standard set of categories.

A final limitation of the study was generalizability, which refers to the expansion of results to a population other than the one studied (Maxwell & Chmiel, 2014; Morse, 2015). This study was limited to mothers residing in Phoenix, Arizona. The responses obtained may not be typical of similar populations in other geographic locations. The ways in which these limitations were addressed are detailed in Chapter 3.

Significance of Study

Results from this qualitative phenomenological study provided insight into experiences of gratitude among mothers raising a CSHCN, who are more likely than fathers to experience decreased physical and mental health as well as diminished well-being (Björquist, Nordmark, & Hallström, 2016; Musick, Meier, & Flood, 2016; Sirois & Wood, 2017). Exploring feelings of gratitude among the mothers provided a deeper understanding of the numerous stressors they experienced, as well as how gratitude may serve as a successful coping strategy (Alkozei, Smith, & Killgore, 2017; Edelstein, Schippke, Scheffe, & Kingsnorth, 2016; Wood & Linley, 2007). In addition to adding to the existing literature on gratitude, findings from this study provide insight into the needs of mothers raising a CSHCN and ways to better support them.

Mothers raising a CSHCN have been underresearched because the primary aim of gratitude studies has focused on individuals with chronic, life-threatening, and nonterminal diseases (Büssing et al., 2014). Among the most commonly studied populations are individuals with recurrent depression, heart disease, and breast cancer (Macaskill, 2012; Ruini & Vescovelli, 2013; Sacco, Park, Suresh, & Bliss, 2014). Although research has concentrated on gratitude in the face of disease and disaster, little is known about how individuals experience gratitude in long-term stressful situations, such as caring for a CSHCN.

Lin (2015a) found individuals with greater levels of gratitude to have increased adaptive coping abilities. Results from this study provided insights into healthy coping strategies that all mothers caring for a CSHCN can implement. Gratitude interventions have resulted in decreased stress and increased happiness among randomly selected adult women and health care professionals (Cheng, Tsui, & Lam, 2015; O'Leary & Dockray, 2015). This study promotes positive social change by providing evidence that mothers who are more grateful report lower stress levels along with increased quality of life. Additionally, the benefits are likely to be passed on to the child, as maternal mental health influences the life of the child (Kingston & Tough, 2014).

Positive Social Change

Data are lacking on the role of gratitude among mothers caring for a CSHCN. Although parents of a CSHCN typically require more replenishment to sustain their health, they often put the needs of their child first and fail to care for themselves (Boston University, n.d.; Huang et al., 2013; Kuhlthau et al., 2014). Results from this study provided more context for information specific to the lived experiences of each mother by illuminating gratitude as a beneficial coping mechanism (Nezlek et al., 2017). Information about how to practice gratitude and its associated benefits can be disseminated through a variety of platforms, including newsletters, brochures, classes, blogs, and applications. This information can provide suggestions for overcoming barriers to experiencing gratitude, along with details specific to establishing, maintaining, and increasing gratitude, which may improve the psychological, social, and physical health of those implementing gratitude practices (Yoshimura & Berzins, 2017). Individuals practicing gratitude are more likely to help others, engage in physical activity, be more optimistic, and report fewer physical symptoms (Emmons & McCullough, 2003; Huffman et al., 2016).

Examining the lived experiences of mothers caring for a CSHCN provided insight into their daily stressors as well as ways in which gratitude facilitated effective coping with such stressors. Individuals' reality is directly influenced by the world in which they live (Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). Specifically, exploration of the lived experiences of participants in this study enhanced the understanding of how mothers of CSHCN experience gratitude and how they use gratitude to cope with stressors related to their unique challenges and obstacles.

Summary and Conclusion

This first chapter introduced the concept of gratitude and addressed how it may be challenging for mothers of a CSHCN to maintain gratitude because of the stress associated with caregiving and its consequences, which may include decreases in both physical and psychological health and well-being, which are more prevalent in mothers than fathers (Lilly et al., 2012). Also included were details related to the benefits of gratitude (Emmons & Stern, 2013; Lavelock et al., 2016) and the consequences of unmanaged stress (Kelly & Ismail, 2015; Murphy et al., 2016). Theories related to positive emotions (Fredrickson, 1998; Kerr et al., 2015) and stress appraisals (Lazarus & Folkman, 1984; Samios & Baran, 2017) were also introduced to explain and create the theoretical synthesis for this study.

This phenomenological study investigated the lived experiences (Moustakas, 1994, 1987) of mothers raising a child with special health care needs to obtain a better understanding of the role that gratitude plays as a coping mechanism (Bryan, Young, Lucas, & Quist, 2018). The problem explored in this study was how stressors associated with caring for a CSHCN can negatively affect the health of mothers (Benson, 2017; Lauderdale-Littin & Blacher, 2017). One purpose of this study was to elucidate ways in which gratitude can serve as an effective coping mechanism and increase both the health and well-being (Cheadle & Schetter, 2017; Elosúa, 2015) of mothers raising a CSHCN. A secondary purpose of this study was to identify possible barriers that such mothers have to experiencing gratitude. The purpose of this study was further substantiated by the gap in the literature related to how mothers caring for a CSHCN experience gratitude and the unique stressors they face (Dardas, 2014; Halberstadt et al., 2016).

Chapter 2 presents a literature review concerning the key concepts of this study. It also includes detailed descriptions and applications of both the broaden-and-build theory of positive emotions and the transactional model of stress and coping. I also elaborate on multiple aspects of gratitude, stress, coping, caregiving, and burnout. The chapter concludes with a review of qualitative methodology.

Chapter 2: Literature Review

Introduction

Mothers raising a CSHCN struggle to maintain positive feelings of gratitude because of the unique stressors they face and the serious health consequences of unmanaged stress (Lilly et al., 2012). Among the stressors unique to caring for a CSHCN are costs of care, problem behaviors, increased educational barriers, and restricted access to both community-based activities and child care services (Shepherd, Landon, Taylor, & Goedeke, 2018). Consequences of unmanaged stress include decreases in both physical and psychological health and well-being, which are more prevalent in mothers than fathers (Li, Pinto-Martin, Thompson, Chittams, & Kral, 2017; Lilly et al., 2012).

Studies have shown that men and women respond differently to stressors, and these variations occur in a variety of areas, such as activation of the sympathetic nervous system and the HPA axis (Bekhbat & Neigh, 2018; Deak et al., 2015). When compared to fathers of autistic children, mothers reported significant decreases in quality of life, which were related to problems with the child’s behavior, communication, and interests (Øien & Eisemann, 2016). Mothers of children with intellectual disabilities have also reported increased levels of anxiety and depression along with more feelings of incompetence than those expressed by fathers (Kalgotra & Warwal, 2016).

Unmanaged stress has been associated with a variety of neuropsychiatric disorders (Albrecht et al., 2017), cardiovascular disease (Esler, 2017), depression, isolation, and physical disorders (Macedo et al., 2015). Implementing positive coping strategies can be advantageous for psychological adaptation and stress reduction

(Kourakos, 2017). Individuals who practiced gratitude on a regular basis reported physical, psychological, and social improvements (Emmons, 2009) with additional benefits including stronger immune functioning, decreased blood pressure, and higher frequency of exercise (Lavelock et al., 2016).

For the purpose of this study, *gratitude* is operationally defined as appreciation, thankfulness, and affirmation of what is meaningful and valuable to oneself (Emmons & Stern, 2013; Sansone & Sansone, 2010). The term *caregiver* is operationally defined as an individual who serves as a personal advocate, performing medical and therapeutic tasks for a family member (APA, 2017), while also managing family needs, planning, scheduling, following up, and searching for applicable resources (Devault, 1999; Home, 2002). Finally, a *CSHCN* in this study refers to a child who has or is at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also requires health and related services of a type or amount beyond that required by children generally (McPherson et al.,1998).

Nearly 18% of children in the United States under the age of 18 years are considered CSHCN (Strickland et al., 2015). Mothers providing care for a chronically ill child often struggle to balance domestic responsibilities with those associated with the unique needs of the child (Macedo et al., 2015). Such demands lead to increased stress and may result in both chronic and acute physical disorders, depression, isolation, financial turmoil, and self-accusation. There is a significant gap in the literature related to how mothers experience gratitude while facing substantial challenges associated with caring for a CSHCN (Chaij, Han, & Graziano, 2014; Dardas, 2014).

This chapter presents information from a review of relevant literature that explores the experiences of mothers raising a CSHCN. The necessity of this study was substantiated by a gap in the literature on the implementation of gratitude as an effective coping strategy (Charzyńska, 2015) among mothers raising a CSHCN. The literature includes studies of mothers raising a CSHCN, addressing struggles they face, stressors, health, quality of life, coping strategies, and details on gratitude (Atamanova et al., 2018; Kirk & Sharma, 2017).

Literature Review Strategy

The literature review was conducted using online databases from the Walden University Library (2018c). Within the EBSCO database, specific subdatabases used for advanced searches included (a) Academic Search Complete, (b) EBSCO, (c) PsycARTICLES, (d) PsychBOOKS, (e) PsychINFO, (f) PubMed, and (g) SAGE Journals. Pertinent keywords and combinations included *gratitude, stress, child with special health care needs, mothers, coping, quality of life, caregiver burnout, stress and health,* and *gratitude and coping*.

After reviewing the literature on these topics, I found that only a few studies explored the lived experiences of mothers raising a CSHCN. Additionally, these studies focused on a single, specific diagnosis and took place in countries other than the United States. Although the majority of research used for this literature review included data published within the past 10 years, older literature was also reviewed (Walden University, 2018a). The inclusion of both old and new literature allowed for data supporting the original theories and ways in which the theories are currently applied.

Conceptual Framework

The conceptual framework for this study was guided by two theories: Fredrickson's (2004) broaden-and-build theory of positive emotions and the transactional model of stress and coping (Lazarus & Folkman, 1984; Pogrebtsova et al., 2017). The broaden-and-build theory focuses on how positive emotions broaden the thought-action repertoire of an individual through the discovery of original ideas, actions and social bonds (Fredrickson, 2004; Van Cappellen et al., 2016). This expansion builds psychological, social, intellectual, and physical resources (Kiken et al., 2017). Such resources can be used later as an effective coping mechanism (Van Cappellen et al., 2017).

Broaden-and-Build Theory of Positive Emotions

Fredrickson (1998, 2001) illustrated the broaden-and-build theory through the example of an individual experiencing the positive emotion of happiness, which is then broadened by an urge to play, which ultimately builds stronger personal resources (Kerr et al., 2015). Through this process, an individual's habitual ways of thinking are expanded and broadened (Fredrickson, 1998, 2000; Garland et al., 2015). When previously habitual thinking is broadened, new skills are developed, enduring personal resources are created, and the individual becomes more prepared for future challenges (Fredrickson, 2001; Lin, 2015b).

"Positive meaning finding" refers to the positive reframing of an individual's broadened mindset (Garland, Gaylord, & Fredrickson, 2011). This reframing is a form of meaning-focused coping and occurs when the meaning of an experience is given a more positive reinterpretation (Samios, Abel, & Rodzik, 2013; Tugade & Fredrickson, 2004). Subsequent neuroimaging studies have supported the benefits of positive reappraisal through the identification of increased activity in areas of the brain associated with reward value (Doré et al., 2017).

The broaden-and-build theory (Fredrickson, 1998, 2000) has been applied to a variety of populations, across diverse situations (Schutte, 2014), and it has supported the supposition that positive emotions can effectively help individuals to manage and cope with stress while also increasing both cognitive and behavioral resilience (Gloria & Steinhardt, 2016; Meneghel et al., 2016; Schutte, 2014). This theory has also provided support to the notion that resilient individuals are more likely to use constructive coping strategies to cultivate positive emotions, which ultimately decreases the effects of stress and promotes well-being (Denovan & Macaskill, 2016). Additional applications of the broaden-and-build theory (Fredrickson, 1998) have been incorporated into studies focusing on veterans with PTSD (Kearney et al., 2014; King & Favorite, 2016), women diagnosed with HIV (Wilson et al., 2017), pain intensity among individuals with chronic pain (Thong et al., 2017), children with a life-threatening disease (Chaves et al., 2016), and individuals with physical disabilities and chronic pain (Alschuler, Kratz, & Ehde, 2016). Additionally, the broaden-and-build theory has been implemented to protect individuals from the development of mental health conditions (Layous, Chancellor, & Lyubomirsky, 2014). Such conditions may be prevented through the process in which an individual broadens thought-action repertoires, which then improves personal resources and ultimately increases resiliency (Wilson & Saklofske, 2018).

Transactional Model of Stress and Coping

In the transactional model of stress and coping (Lazarus & Folkman, 1984), it is postulated that stress and coping correlate with health, health behavior, and psychological well-being (Glanz & Schwartz, 2008). The reactions of an individual are mediated by a cognitive appraisal process in which each stressor is characterized by person-environment transactions (Ying et al., 2017). A primary component of this theory is the understanding that identical situations can be appraised differently by different individuals (Wethington et al., 2015). Specifically, each person's appraisals are directly related to the core concepts of the transactional model of stress and coping: "primary appraisal, secondary appraisal, coping efforts, meaning-based coping, and outcomes of coping" (Glanz & Schwartz, 2008, p. 230; Lazarus & Folkman, 1984).

The transactional model of stress and coping (Lazarus & Folkman, 1984) takes into consideration that individuals differ dramatically in what they believe to be stressful (Marks et al., 2011). A key component of this theory is the idea that different individuals can appraise identical situations differently (Samios & Baran, 2017; Wethington, Glanz, & Schwartz, 2015). Researchers have incorporated this theory into a variety of studies focusing on individuals with HIV, diabetes, cancer, and drug, tobacco, and alcohol use (Graham, 2015; Hulbert-Williams et al., 2013; Paek et al., 2016; Schantz & Bruk-Lee, 2016).

Appraisals of both demands and perceived abilities to cope with demands can be conscious or unconscious (Hulbert-Williams et al., 2013; Lazarus & Folkman, 1987). Stress arises when there is an imbalance between demands and available resources to cope with them (Lu, Liu, Wang, & Lou, 2017). The appraisal of a stressful event is more significant than the actual event (Lazarus & Folkman, 1984; Tierney, Seers, Reeve, & Tutton, 2017). Two coping styles described by Lazarus and Folkman (1984) are problem-focused, in which an attempt is made to either remove or reduce the cause of the stressor, and emotion-focused, which involves an effort to reduce negative emotional responses to the stressor (Compas et al., 2014).

Conceptual Synthesis

The broaden-and-build theory (Fredrickson, 1998, 2004) was used to explore the phenomenon of gratitude among mothers raising a CSHCN who face unique challenges, as this theory emphasizes the ways in which stressful experiences provide a means for broadening the appraisal of the event, which facilitates personal growth and transformation (Garland et al., 2015). Researchers have posited that individuals gain prolonged coping strengths when their mindsets broaden after they experience positive emotions during stressful events (Dolphin, Steinhardt, & Cance, 2015; Folkman, 1997, 2008). Positive emotions such as gratitude and joy can promote personal growth and create an “upward spiral” toward positive outcomes across multiple life events (Armenta, Fritz, & Lyubomirsky, 2017).

Fredrickson (1998, 2000, 2004) suggested that, in addition to being self-perpetuating, the resources broadened and built during stressful times yield positive emotions. Through the application of the broaden-and-build theory (Fredrickson, 2004), Kerr et al. (2015) found that gratitude interventions elicited the acquisition of positive resources including optimism, connection with others, and life satisfaction. The broaden-and-build theory (Fredrickson, 2004) was further supported by Gloria and Steinhardt (2016), who found that resilience was both directly and indirectly enhanced by positive emotions among postdoctoral students. Positive emotions were reported to potentially reduce the development of depression and anxiety.

The transactional model of stress and coping (Lazarus & Folkman, 1984) offered a second beneficial framework for understanding how mothers raising a CSHCN experienced gratitude. When an individual experiences a stressful situation, a transaction occurs between the individual and the environment (Chow & Ho, 2015). The way in which the individual appraises the situation or environment is significantly influenced by the coping resources of the individual (Chow & Ho, 2015; Folkman, Lazarus, Pimley, & Novacek, 1987).

Due to the unique stressors faced by mothers raising a CSHCN (Dillon-Wallace et al., 2016; Dyches, Christensen, Harper, Mandleco, & Roper, 2016), the transactional model of stress and coping (Lazarus & Folkman, 1984) supplements this study through its description of the ways in which an individual’s coping strategies significantly influence outcomes, including healthy and unhealthy behaviors (Matsuo & Sato, 2017). Additionally, this model complemented the current study by emphasizing the ways in which the level of confidence that individuals have when presented with a stressor determines how they appraise the stressor (Li, Chen, & Lai, 2017). Applications of this theory to individuals with multiple sclerosis revealed decreases in depression, fatigue, and anxiety along with increases in both quality of life (Jose et al., 2016) and healthy coping strategies (Sanaeinasab et al., 2017).

Empirical Overview

How Parents Cope With a Special Needs Child

Although controllable situations allow an individual to eliminate or reduce the source of stress through primary or problem-focused coping techniques, parents of CSHCN encounter long-term, uncontrollable stressors (Riley & Park, 2014; Tunali & Power, 2002). Such low-control situations require parents to implement strategies in which they alter themselves in response to the situation (Dardas & Ahmad, 2015; Folkman, Lazarus, Gruen, & DeLongis, 1986). Contrary to behavioral techniques, these secondary or problem-appraisal strategies (Terry & Hynes, 1998) are cognitive because they require a change in perspective and how an individual makes sense of a situation (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Zeytinoglu, Davey, Cerrand, Fisher, & Akyil, 2016). These strategies include acceptance (Heiman, 2002; Luong, Yoder, & Canham, 2009), social support (Calderon & Greenberg, 1999), cognitive distraction, gaining perspective, seeking emotional support (Higgins, Bailey, & Pearce, 2005), humor, optimism (Jones & Passey, 2005), and positive reinterpretation (Ekas, Timmons, Pruitt, Ghilain, & Alessandri, 2015; Lazarus & Folkman, 1984; Obeid & Daou, 2015; Tunali & Power, 2002).

Coping among parents is not specific to any single diagnosis within CSHCN (Churchill et al., 2010; Stein & Jessop, 1989). Some parents search for meaning as a way to cope with the stress and challenges related to raising a CSHCN (Myers, Mackintosh, & Goin-Kochel, 2009; Pryce, Tweed, Hilton, & Priest, 2015). This meaning-making coping strategy was prevalent among a group of parents with autistic children who participated in an email support group (Huws, Jones, & Ingledew, 2001) as well as parents engaging in an internet support group (Baum, 2004). A study in India found that parents often received positive mentorship from special educators and the majority of parents sought religious support, in which inner healing was obtained through prayers, ceremonies, offerings, and consumption of blessed foods (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2016).

Researchers continue to examine why some families are more resilient than others in adapting to and coping with raising a CSHCN (Ferguson, 2002; Reddon, McDonald, & Kysela, 1992). Research is also focused on factors that influence positive outcomes such as family harmony, adaptability, improved communication, and spiritual growth (Ferguson, 2002; Judge, 1998). It has been posited that parents with higher educational levels experience decreased psychological stress and increased coping strategies (Venkatesh Kumar, 2008). Benefits have been documented among parents who receive specific, personalized communication related to a diagnosis, which can then be used to seek additional information (Pain, 1998). Decreased stress has also been documented among parents who maintain contact with other parents raising a child diagnosed with a similar disability, as social, emotional, and practical support are exchanged (Kerr & McIntosh, 2000).

Gratitude: Coping, Health, Disease, and Gender

Gratitude

For the purpose of this study, *gratitude* is operationally defined as appreciation, thankfulness, and affirmation of what is meaningful and valuable to oneself (Emmons &

Stern, 2013; Sansone & Sansone, 2010). Gratitude can be applied to the past by recalling positive memories, the present by appreciating the good in situations, and the future by maintaining an optimistic perspective (Harvard Medical School, 2011). Gratitude has been shown to decrease material desires, increase life satisfaction, and play an integral role in the maintenance and structure of social relationships (Bryan et al., 2018; Emmons & McCullough, 2003; Lambert, Finchman, Stillman, & Dean, 2009).

Expressing gratitude through writing has been reported to be therapeutic and yield benefits such as improved mental and physical health (Lyubomirsky, Sousa, & Dickerhoof, 2006; Suhr, Risch, & Wilz, 2017). In the study conducted by Emmons and McCullough (2003), undergraduate participants were asked to consider the past week and list on paper five things for which they were grateful, five hassles, or five circumstances that affected them, based on their randomly assigned group. Individuals in the gratitude condition reported higher levels of positive mood than the other two groups and reported having offered more emotional support or help to another person (Dickens, 2017; Emmons & McCullough, 2003). Similar studies revealed immediate spikes in positive mood when participants wrote about positive life events across consecutive days (Burton & King, 2004; Gilbert, Foulk, & Bono, 2017; Layous et al., 2017).

Gratitude and Coping

Feelings of gratitude include a confirmation of goodness in life as well as an acknowledgment that the sources of such good things lie outside the self, to at least some extent (Emmons & Stern, 2013). *Coping* includes the strategies utilized by individuals in times of stress as a means to control emotions, behaviors, and cognitions (Lin, 2016;

Thomas, Allen, Phillips, & Karantzas, 2011). According to the coping hypothesis of gratitude, people who are more grateful are more likely to implement numerous active coping strategies (Lin, 2016; Wood, Froh, & Geraghty, 2010). Additionally, the hypothesis suggests that grateful people are more likely to concentrate on the positive features of life which, in turn, promotes an increased eagerness to apply more active coping strategies (Lin, 2016; Watkins, Woodward, Stone, & Kolts, 2003; Wood et al., 2010).

Clinical research studies have suggested that individuals who practice gratitude as a coping strategy can experience significant, long-lasting positive effects (Krause, Emmons, Ironson, & Hill, 2017). Benefits may be seen across multiple areas such as work, interpersonal relationships, and physical health (Armenta et al., 2017). Gratitude practices may be especially beneficial as a coping mechanism among individuals with heightened depressive symptoms (Harbaugh & Vasey, 2014).

Individuals who frequently practice and experience gratitude have demonstrated more effective coping skills with daily stressors than those who do not implement gratitude (Watkins & McCurrach, 2016). These people also exhibit more resilience in times of traumatic stressors. Lin (2016) posited that individuals who use gratitude to cope with stress may experience enhanced well-being that continues long term. Grateful individuals tend to incorporate more emotion-focused coping strategies, such as acceptance, humor, and religion (Lau & Cheng, 2017). Additionally, grateful individuals are more likely to use psychological resources such as social support.

Gratitude and Health

Recent studies have shown a relationship between gratitude and biomarkers of both health and disease (Huffman et al., 2016; Mills et al., 2015). Findings from Hill, Allemand, and Roberts (2013) posited that grateful people are physically healthier because of their greater psychological health, inclination to engage in healthy activities, and propensity to seek help when needed. Grateful individuals often report increased physical health because these individuals are more likely to implement improved self-care practices, such as eating a healthy diet and attending doctor appointments (Frye, 2013).

Gratitude can improve immune function, lower blood pressure (Krause et al., 2017), and drastically decrease the lifetime risks of anxiety, depression, and substance abuse disorders (Emmons, 2009; Hart, 2013). Gratitude is associated with improvements in cardiovascular functioning, decreases in pain, and greater engagement in exercise (Krentzman, 2015). Additionally, gratitude improves sleep quality (Jackowska, Brown, Ronaldson, & Steptoe, 2015), enhances mental health (Wong et al., 2016), increases subjective well-being (Nezlek et al., 2017) decreases levels of inflammation, and promotes healing (Vitek, 2016).

Gratitude and Disease

Individuals often practice gratitude as a means of improving health following an illness or disease (Algoe & Stanton, 2012; Kremer & Ironson, 2014). Studies have proven that gratitude was positively correlated to improved mental and physical health, especially among individuals suffering from a disease or illness (Lambert D’raven, Moliver, & Thompson, 2015; Ng & Wong, 2013). There is a significant association between gratitude and higher immune system function, stronger tolerance to infection, decreased systemic inflammation, and increased survival rates for individuals with major illnesses (Fredrickson, 1998; Fredrickson, 2001).

Individuals diagnosed with Stage B asymptomatic heart failure, who also practiced gratitude, were found to have better sleep patterns, increased self-efficacy, decreased fatigue, and a lower cellular inflammatory index (Mills et al., 2015). Gratitude has decreased depressive moods in individuals diagnosed with breast cancer, heart failure (Mills et al., 2015; Ruini & Vescovelli, 2013), arthritis, and inflammatory bowel disease (Sirois & Wood, 2017). In addition to predicting quality of life among individuals with arthritis (Eaton, Bradley, & Morrissey, 2014), gratitude has also predicted both life satisfaction and psychological quality of life in both healthy and unhealthy samples (Rash, Matsuba, & Prkachin, 2011).

Gratitude and Gender

It has been purported that women are typically more grateful than men and are therefore more likely to reap the benefits of gratitude (Krause et al., 2017; Yue, Hiranandani, Jiang, Hou, & Chen, 2017). Further investigation found that in general, women were more likely than men to experience and express gratitude (Kashdan, Mishra, Breen, & Froh, 2009; Krause et al. 2017). Variations in social roles may contribute to the differences in gratitude among men and women (Yue et al., 2017). While men may fear that expressions of gratitude pose a threat to their masculinity, women are expected to participate more in caregiving roles, in which other-focused emotions are prevalent (Kasdan et al., 2009; Yue et al., 2017).

A child is not born grateful; rather, the child learns the virtue through the practices and encounters of the culture in which the child grows (Wang, Wang, & Tudge, 2015). A study including four middle schools in the Southeastern United States found that females reported higher gratitude than males (Reckart, Huebner, Hills, & Valois, 2017). Research examining gratitude and depression among young adults yielded no significant gender differences in depression, self-esteem, or psychological well-being (Lin, 2015a). However, females scored significantly higher than males in gratitude, which supported the findings from previous studies (Chan, 2012; Froh, Yurkewicz, & Kashdan, 2009; Lin, 2015a; Tian, Du, & Huebner, 2015).

Stress and Coping

Good Stress Versus Bad Stress

Stress in small amounts, and for short durations, can be beneficial in developing skills to manage challenging situations (Centers for Disease Control and Prevention [CDC], 2016). Short-lived, moderate stress has been shown to boost memory and improve performance, alertness, and resilience (Aschbacher et al., 2013; Jaret, 2015). Specifically, short-lived stress may improve overall health by enhancing both physical and cognitive performance while also strengthening immune and wound healing responses (Dhabhar, 2014; Speck, 2016).

Chronic and unmanaged stress correlated with the development, preservation, and exacerbation of serious physical and mental health ailments as well as premature mortality and accelerated biological aging (Holt-Lunstad, Smith, & Layton, 2010; Slavich, 2016). Chronic stress causes the hypothalamic-pituitary-adrenal (HPA) axis to produce increased levels of cortisol and other stress hormones (Acabchuk, Kamath, Salamone, & Johnson, 2017). There is a significant relationship between elevated cortisol levels and mortality (Acabchuk et al., 2017; Noordam et al., 2012). Researchers have associated stress with arthritis, anxiety disorders, depression, stroke, chronic pain, cardiovascular disease, high blood pressure, certain cancers, and autoimmune diseases (American Institute of Stress [AIS], n.d.; Slavich, 2016).

Perceptions of Stress

The perceptions associated with stress play an important role in outcomes (Lee, Joo, & Choi, 2013; McGonigal, 2015). Individuals with a positive outlook are happier, more satisfied with life, have fewer health problems, and more energy (Crum, Salovey, & Achor, 2013). This population also demonstrates greater confidence in their ability to cope with and find meaning in stressful situations (Crum et al., 2013; Crum, Akinola, Martin, & Fath, 2017).

Negative mindsets result in poorer affective and cognitive outcomes (Crum et al., 2017). Those with a negative stress mindset are more likely to use avoidance techniques such as distractions, withdrawal, and substance abuse (Crum et al., 2013; McGonigal, 2015). Individuals who perceive stress to be harmful to their health are more likely to have poor physical and mental health and are also at an increased risk of premature death (Keller et al., 2012).

Positive and Negative Coping

Coping refers to the cognitive, emotional, and behavioral strategies implemented as a means to reduce stress (Lazarus & Folkman, 1984; Thomas et al., 2011). Coping, which can be adaptive or reactive, is a conscious action in which an individual applies specific skills to regulate stress. While some coping strategies effectively minimize stress, others can exacerbate stress (Amirkhan & Marckwordt, 2017).

Coping strategies can be positive or negative (Sam, Muttusamy, Yee, Ayapanaido, & Parasuraman, 2016). Examples of positive strategies include praying, meditating, seeking social support, maintaining a positive attitude, problem solving, and engaging in physical activity (Cuzzocrea, Murdaca, Costa, Filippello, & Laran, 2016; Sam et al., 2016; van der Zwan, de Vente, Huizink, Bögels, & de Bruin, 2015). Negative coping strategies include substance abuse, avoiding others, anger, violent behaviors, engagement in risky or dangerous behaviors, self-criticism, and self-blame (Arbel, Perrone, & Margolin, 2016; Sam et al., 2016; U.S. Department of Veterans Affairs, 2015). Coping styles vary among individuals and result in different effects on the outcomes of stressors, which primarily include functional status, emotional well-being, and health behaviors (Glanz & Schwartz, 2008).

Caregivers: Stress and Burnout

Stress Versus Burnout

Stress is the “nonspecific response of the body to any demand” (Selye, 2013, p. 15) that can potentially threaten well-being (Lazarus, 1966). Stress elicits a coping strategy when the individual deems resources inadequate to meet the demands of the situation (Buffone et al., 2017). *Burnout* refers to the internal response an individual has to environmental stressors (Adriaenssens, De Gucht, & Maes, 2015). Chronic and unmanaged stress lead to burnout, which is a negative psychological experience that may include emotional exhaustion, withdrawal, anxiety, and depression (Kandelman, Mazars, & Levy, 2017; Vicentic et al., 2016).

Caregiver Stress

When compared to non-caregivers, caregivers suffer from greater levels of stress and are more likely to suffer from depression, anxiety, substance abuse or dependence, and chronic disease (Family Caregiver Alliance [FCA], 2016; Semenova & Stadtlander, 2016). More than half of the 44 million caregivers in America experience deterioration in health in addition to sleep disturbances (Bonura, 2016). Additionally, caregivers are more vulnerable to emotional, financial, and physical burdens (Semenova & Stadtlander, 2016).

The associated stressors of caregiving have led to poorer cardiovascular health, both the development and progression of illnesses, decreased immune function, and increased mortality rates (Hilbrand, Coall, Gerstorf, & Hertwig, 2017; Lakkur, Howard, Judd, Haley, & Roth, 2016; Park & Bevans, 2016). Caregivers with unmanaged stress may experience negative effects in blood pressure levels, heart rate reactivity, and health-related activities (Dilworth-Anderson, Goodwin, & Williams, 2004). Many caregivers also suffer from skeletal injury, muscle strain, and other physical pain or discomfort, particularly when the demands of caregiving include physical exertion (Amankwaa, 2017).

Caregiver Burnout

Caregiver burnout refers to the impacts experienced by caregivers as a result of the challenges, negative experiences, and disruptions of life throughout the caregiving process (Panayiotopoulos, Pavlakis, & Apostolou, 2013). The impacts include emotional, physical, and mental exhaustion which may negatively affect the care provided (Krishnan, York, Backus, & Heyn, 2017). Specifically, caregivers experiencing burnout are more likely to suffer from cognitive decline, mood disorders, increased social isolation, disrupted sleep, and loneliness (Vitaliano, Murphy, Young, Echeverria, & Borson, 2011; Wennberg, Dye, Streetman-Loy, & Pham, 2015). The stress associated with caregiver burnout has been linked to an increased risk of cardiovascular disease, kidney disease, hypertension, medication use, obesity, and mortality (Fonareva & Oken, 2014; Wennberg et al., 2015).

Familial caregivers are at increased risk of caregiver burnout because of the personal, close relationship shared with the patient (Vicentic et al., 2016). Providing care to a child with a physical or developmental disability includes unique burdens that impact the physical, emotional, and mental health of the caregiver (Caicedo, 2014). The degree of challenging behaviors exhibited by the individual receiving care influences the severity of such impacts (Fairthorne, de Klerk, & Leonard, 2016). Caregivers with lower perceived social support are at greater risk of burnout (Kokurcan, Yilman Özpolat, & Gögüs, 2014).

Benefits and Consequences of Caregiving

Studies have found that benefits and positive feelings have resulted from caregiving experiences (Sanders, 2005). Caregivers who viewed the experience as meaningful gained benefits such as emotional gratification, a sense of purpose, and lower mortality rate (Bonura, 2016). However, reactions can differ depending on the circumstances. Caregivers providing care for a family member with dementia have been found to be more vulnerable to disease and struggled to provide optimal care to the patient (Fonareva & Oken, 2014). Conversely, female caregivers of pediatric cancer survivors reported benefits such as personal growth and social support (Willard, Hostetter, Hutchinson, Bonner, & Hardy, 2016).

Parents Providing Care for a CSHCN

The physical, mental, and emotional health of parents caring for CSHCN are often negatively affected (Witt et al., 2009). Parents experience frustration, anger, anxiety, helplessness, and decreased energy. They also feel socially isolated and constantly worry about the child’s future. Smith and Grzywacz (2014) suggested that parents of CSHCN may experience negative, long-term health consequences because of the stressors. Although fathers are typically involved with the issues associated with their children, the mothers more commonly experience extreme stress and pressure (Sadati et al., 2015).

Women as Primary Caregivers

Women often take on the role of primary caregiver in families despite ability, disability, or age of the family member (Hooymans & Gonyea, 1995). Mothers providing care for a chronically ill child often struggle to balance domestic responsibilities with those associated with the unique needs of the child (Macedo et al., 2015). Such demands lead to increased stress and may result in both chronic and acute physical disorders, depression, isolation, financial turmoil, and self-accusation.

In a household where the mother and father both worked full time, 54% of parents reported that the mother dealt more with management of the activities and schedules of the children, with 6% who reported that the fathers did more, and 39% who shared the responsibility equally (Pew Research Center, 2015). It was also reported that 47% of the mothers did more when the children were sick, compared to fathers at 6%, and 47% who shared the responsibility equally. Additionally, in families where the mother worked either part time or not at all and the father worked full time, the mothers assumed more responsibilities related to household chores and parenting tasks than the mothers who worked full time. Symptoms reported by caregivers were related to a variety of factors such as the kind of assistance required, the amount of time devoted to caregiving, whether the person receiving care had behavioral issues, and whether the caregiver had help with the responsibilities (Grosse et al., 2009; Imran et al., 2010).

Gratitude as a Coping Strategy in Stressful Situations

While studies have found that gratitude predicted subjective well-being (Chan, 2013; Sapmaz, Yildirim, Topçuoğlu, Nalbant, & Sizir, 2016), it has also been posited that responding gratefully to a life experience was an adaptive psychological strategy (Emmons & McCullough, 2003). Seeking the good in stressful situations results in improved physical health, stronger relationships, and protection against depression

(McGonigal, 2015). Additionally, focusing on the benefits of stress can enhance spiritual growth, provide a sense of personal strength, and increase one's appreciation for life.

Gratitude has been reported to protect an individual from the negative effects of trauma (Vieselmeyer, Holguin, & Mezulis, 2017). Gratitude has been reported to facilitate the growth of psychological resources, which are believed to reduce stress when faced with a stressful event (Fredrickson, 2004; Kashdan et al., 2009; Lau & Cheng, 2017). Specifically, individuals with higher levels of gratitude demonstrate increases in adaptive coping abilities and social support (Lin, 2015b).

A study of a gratitude intervention following a school shooting revealed that gratitude decreased posttraumatic stress and increased posttraumatic growth (Vieselmeyer et al., 2017). Leung and Tong (2017) found that gratitude was an effective coping strategy among drug misusers. Breast cancer survivors who participated in a gratitude intervention reported significant decreases in death-related fear of cancer reoccurrence (Otto, Szczesny, Soriano, Laurenceau, & Siegel, 2016). Caregivers implement coping strategies as a way to handle stressors associated with fluctuating life events and also to manage the illness or disability of the person for whom they provide care (Cassidy & McLaughlin, 2015).

Empirical Synthesis

Stress can be beneficial or detrimental (Slavich, 2016; Speck, 2016) and is influenced by the perceptions an individual has about stress (McGonigal, 2015). Although an extensive amount of research on the stressors related to caring for CSHCN has been conducted over the past few decades, less attention has been given to the coping strategies implemented by the families (Beresford, 1994). Among the most common adaptive and maladaptive coping strategies being studied are social support, positive reappraisal, prayer, acceptance, information-seeking, withdrawal, resistance, avoidance, and disengagement (Gona et al., 2016; Heaman, 1995; Lai, Goh, Oei, & Sung, 2015).

Gratitude can be applied to the past, present, and future in a variety of ways (Harvard Health Publications, 2011) and may increase life satisfaction while also improving both mental and physical health (Emmons & McCullough, 2003; Jans-Beken et al., 2019; Suhr et al., 2017). Research has shown that gratitude led to increased social support which, in turn, increased well-being, improved physical health (Krause et al., 2017; Lin, 2016), and increased adaptive coping abilities (Lin, 2015). People who are more grateful are more likely to focus on the positive aspects of life and effectively implement active coping strategies (Lin, 2016; Watkins at al., 2003; Wood et al., 2010) especially when faced with daily stressors (Watkins & McCurrach, 2016).

Although women are typically more grateful than men, women are more likely to implement emotion-focused coping strategies such as avoidance or denial, which have been associated with increased psychological distress and decreased mental health while men frequently use problem-focused strategies such as planning (Abbeduto et al., 2004; Krause et al., 2017; Pepperell, Paynter, & Gilmore, 2018; Yue et al., 2017). Women are also more likely to be the primary caregiver in a family (Macedo et al., 2015) which increases stress and can lead to burnout (Panayiotopoulos et al., 2013; Semenova & Stadtlander, 2016). However, caregiving can be beneficial for those who view it as meaningful (Sanders, 2005) and may decrease mortality rates (Bonura, 2016).

Conversely, parents caring for a CSHCN who do not cope with stress and do not view the experience as meaningful are likely to suffer from mental, physical, and emotional health consequences (Witt et al., 2009).

Phenomenology as a Research Methodology

Phenomenology can connect paradigms and elicit a deeper appreciation of diverse worldviews (Duckham & Schreiber, 2016). In a phenomenological approach, the researcher describes the lived experiences of participants sharing a common phenomenon by obtaining details from each participant (Creswell, 2014). Interviews provide the essence of the experience among each participant (Moustakas, 1994) and help the researcher to better understand the meaning behind each experience (Patton, 2002). A unique characteristic of phenomenology is that this approach seeks to not only understand what participants experience but also the ways they interpret the experience.

Edmund Husserl and Martin Heidegger suggested two different phenomenological approaches (Duchkam & Schrieber, 2016). Husserl stressed the importance of bracketing, in which the researcher sets aside any presuppositions about the studied phenomenon (Belousov, 2016; Chernavin, 2016). He believed that truth could only be revealed when bracketing was consciously applied (Duckham & Schrieber, 2016; Husserl, 1970). The Husserlian approach claims that the researcher will develop a new understanding of the essence experienced by the participant when the personal understandings of the researcher are eliminated (Abalos, Rivera, Locsin, & Schoenhofer, 2016; Greenfield & Jensen, 2012).

Heidegger held a contrasting viewpoint and posited that bracketing limited the truth (Quay, 2016). He emphasized the importance of finding truth in existence (Wilson, 2014b) and asserted that humans and the word were an inseparable entity, as they exist as one (Jack & Wibberley, 2014). The Heideggerian philosophy, also known as interpretive phenomenology, places value on the researcher's subjective comprehension of the phenomenon, as themes are derived from lived experiences (Duckham & Schrieber, 2016; Wilson, 2014a). Heideggerian research appreciates the researcher's perspectives about the situations and supports the idea that the researchers achieve understanding by becoming part of the participant's lifeworld (Freeman, 2014a; Jack & Wibberley, 2014).

Review of Qualitative Methodology

In addition to phenomenology, there are four other primary qualitative designs: narrative research, grounded theory, ethnography, and case studies (Cresswell, 2014; Guetterman, 2015). Qualitative research is typically conducted in a natural setting, where the participants experience the studied event (Ross, 2017). The researcher plays a fundamental role in qualitative studies by observing the participants and conducting in-depth interviews (Granek, 2017; Wolgemuth et al., 2015). This approach also collects data from multiple sources (Creswell, 2014; Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017).

Narrative Research

Narratives provide insight into the experiences of an individual through chronologically presented details (Hinchman & Hinchman, 1997). After participants share stories about their lives, the researcher retells the stories (Creswell, 2014; Hickson, 2016). Individualized social and cultural patterns are discovered through personal narratives and life histories (Goldstein, 2017; Patton, 2002). Narratives are effective for research aiming to understand the life experience of an individual (Carless & Douglas, 2017; Creswell, 2014). Because this study sought to explore the lived experiences of a group of mothers raising a CSHCN, a narrative approach was not appropriate.

Grounded Theory

Researchers use grounded theory when the purpose is to develop a general theory of an action, process, or interaction specifically grounded in the participants' views (Corbin, 2017; Creswell, 2014). Grounded theory is not used to test or verify hypotheses (Sutcliffe, 2016). The interpretation of data is influenced by both the participants and the researcher (Rustin, 2016). The grounded theory approach was not appropriate for this study, as the goal was not to develop a theory.

Ethnography

Researchers use observations and interviews in ethnographic studies to study the shared patterns of language, behaviors, and actions of an intact cultural group (Creswell, 2014; Hansen & Trank, 2016). This study takes place in the natural setting of the cultural group and occurs over an extended period of time (Fujii, 2015). The researcher is typically immersed in the studied culture and endures intensive fieldwork (Mannay & Morgan, 2015; Patton, 2002). Based on the fact that ethnographic approaches are used to understand an entire culture, it was deemed inappropriate for this study, which sought to understand lived experiences.

Case Studies

Case studies are used to create an in-depth analysis (Creswell, 2014; Kavoura & Bitsani, 2014). Researchers often use this approach with an event, program, process, activity, or one or more individuals (Morgan, Pullon, Macdonald, McKinlay, & Gray, 2017). Comprehensive data collection is required and includes a variety of sources such as observations, documents, reports, interviews, and audio-visual material (Harrison & Mills, 2016). The purpose of this study was not to create an in-depth analysis; therefore, a case study was not appropriate for this study.

Summary

This chapter expanded on how the broaden-and-build-theory of positive emotions (Fredrickson, 1998; Garland et al., 2015) and the transactional model of stress and coping (Lazarus & Folkman, 1984; Ying et al., 2017) supported the studied phenomenon. The relationships between gratitude and each of the areas of coping, health, disease, and gender were also included (Emmons & Stern, 2013; Lyubomirsky et al., 2006). Because mothers caring for a CSHCN were the target population, details about women as primary caregivers were included along with stress, burnout, benefits, and consequences associated with caregiving (Crum et al., 2013; Grosse et al., 2009; Krishnan et al., 2017; Sam et al., 2016).

This chapter also highlighted ways that parents cope with raising a CSHCN. Due to the fact that parents encounter low-control situations and uncontrollable stressors, coping strategies must be adapted to the unique circumstances (Riley & Park, 2014; Tunali & Power, 2002). Further research is essential to determine what makes some families raising a CSHCN more resilient than others (Ferguson, 2002; Reddon et al., 1992).

Gratitude research has primarily focused on individuals suffering from chronic illness (Moosath & Jayaseelan, 2016; Sirois & Wood, 2017) and caregivers of older family members (Lau & Cheng, 2017; Willemese et al., 2016). There is an inadequate focus of research on both how mothers raising a CSHCN experience gratitude and the unique challenges they face as caregivers. This gap in the literature substantiated the importance of a phenomenological study where stress, coping strategies, gratitude, and caregiving were thoroughly examined. Chapter 3 provides detailed descriptions of the research methodology used for this study and includes the research design, target population, data collection procedures, and data analyses.

Chapter 3: Research Method

Introduction

The challenges posed by unique stressors (Burke & Hodapp, 2014) and consequences of unmanaged stress can cause mothers of CSHCN to experience gratitude differently (Lilly et al., 2012). Women have reported higher levels of PTSD symptoms than men, after both direct and indirect exposure to a traumatic event (Birkeland, Blix, Solberg, & Heir, 2017). Unmanaged stress can result in depression, anxiety, autoimmune disease, and cardiovascular disease (Beattie, Hall, Biro, East, & Lau, 2017; Sharma & Rush, 2014). Individuals practicing gratitude have experienced stronger immune functioning, decreased blood pressure, and improved self-care (Emmons, 2010; Lavelock et al., 2016).

For the purpose of this study, *gratitude* is operationally defined as appreciation, thankfulness, and affirmation of what is meaningful and valuable to oneself (Emmons & Stern, 2013; Sansone & Sansone, 2010). The mothers in this study were considered caregivers, with the term *caregiver* operationally defined as an individual serving as a personal advocate, performing medical and therapeutic tasks for a family member (APA, 2017) in addition to managing family needs, planning, scheduling, following up, and searching for applicable resources (Devault, 1999; Home, 2002). Finally, a *CSHCN* in this study refers to a child who has or is at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also requires health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998).

Previous research has focused on stress (Amirkhan & Marckwordt, 2017; Slavich, 2016), coping strategies (Lazarus & Folkman, 1987; Leung & Tong, 2017), gratitude (Armenta et al., 2017; Emmons & McCullough, 2003), and caregiving (Fonareva & Oken, 2014; Hillbrand et al., 2017). However, there remains a gap in the literature on the combination of stress, coping strategies, gratitude, and caregiving among mothers raising a CHSCH. It can become especially challenging for mothers raising a CSHCN to experience gratitude because of the stress associated with caregiving, as well as the consequences, which include decreases in both physical and psychological health and well-being, which are more prevalent in mothers than in fathers (Lilly et al., 2012). The lack of literature devoted to the lives of this population and the potentially devastating consequences of unmanaged stress justified the need for this phenomenological study (Beattie et al., 2017).

Researchers have focused on coping strategies used by parents raising a CSHCN and have outlined both positive and negative techniques such as acceptance, positive reinterpretation, withdrawal, and disengagement (Ekas et al., 2015; Gona et al., 2016; Lai et al., 2015; Obeid & Daou, 2015). While coping among parents is not specific to any single diagnosis within the category of CSHCN (Churchill et al., 2010; Stein & Jessop, 1989), little is known as to what makes some families more resilient than others in adapting to and coping with related stressors (Ferguson, 2002; Reddon et al., 1992). The lack of literature related to such resiliency substantiated the need for this study, as gratitude may play a positive role in coping with stress.

The purpose of this qualitative study was to explore stressors, coping strategies, and gratitude among mothers serving as caregivers to a CSHCN. This chapter explains the ways in which the phenomenological approach (Abalos et al., 2016; Moustakas, 1994) was used to develop a deeper understanding of the lived experiences of mothers raising a CSHCN and the role that gratitude plays in their daily lives, as women are at a higher risk of stress-related health risks (Dillon-Wallace et al., 2014; Murphy & Loria, 2017). This chapter includes sections on the following topics: (a) methodology, (b) research design, (c) phenomenological justification, (d) role of the researcher, (e) ethical protection of participants, (f) criteria for participant selection, (g) data collection, (h) protocol and procedures, (i) data analyses, and (j) coding procedures.

Research Design and Rationale

Qualitative, quantitative, and mixed methods were all considered for this study (Creswell, 2014; Park & Park, 2016). Researchers using qualitative methods explore issues in depth and gather detailed information from relatively small numbers of participants (Landrum & Garza, 2015; Patton, 2002). Quantitative methods use standardized measures and often include a higher number of participants (McCusker & Gunaydin, 2015). Qualitative research is used to explore and better understand the meaning that individuals assign to an issue or event, whereas quantitative research tests theories through the exploration of the relationship among variables (Christenson & Gutierrez, 2016; Creswell, 2014). Mixed methods combine both qualitative and quantitative data (Creswell, 2014; Turner, Cardinal, & Burton, 2017).

Researchers using the phenomenological approach examine a phenomenon from multiple perspectives (Adams & van Manen, 2017; Moustakas, 1994). Husserl (2014) described phenomenology as a means to capture the lived experiences of others without the need to interpret, theorize, or explain. Phenomenology involves an effort to understand and describe common themes among participants who experienced the same phenomenon (Creswell, 2014; Ellis et al., 2008; Gill, 2014). It is imperative for the researcher to examine the experiences through the perspective of each participant (Patton, 2002; Quay, 2016).

A qualitative phenomenological approach was used for this study because the aim was to explore how an event was experienced, rather than what was experienced (Adams & van Manen, 2017). This approach allowed for the essence of the meaning to be understood through the lived experiences (Douglass & Moustakas, 1985; Papaloukas, Quincey, & Williamson, 2017) of mothers who had personally experienced raising a CSHCN. The stressors, coping mechanisms, challenges, and gratitude associated with the experience were better understood through the firsthand accounts of each mother.

Research Questions

Based on a theoretical and conceptual framework consisting of Fredrickson's (2004) broaden-and-build theory of positive emotions and the transactional model of stress and coping (Lazarus & Folkman, 1984), the following research questions were addressed:

Primary RQ1: For which aspects are mothers raising a child with special health care needs most grateful?

Secondary RQ2: What are the major challenges/stressors faced by mothers raising a child with special health care needs?

Secondary RQ3: What major coping styles are employed by mothers raising a child with special health care needs?

Secondary RQ4: In which ways do gratitude, challenges, and coping styles contribute to quality of life among mothers raising a child with special health care needs?

Role of the Researcher

To best understand the perspectives of each participant, I set aside all prejudgments and biases as part of the epoché process (Moja-Strasser, 2016; Moustakas, 1994). I treated each quality equally in value so that hierarchies of importance were not created (Moja-Strasser, 2016). The epoché process was essential in allowing me to free my mind and view the experiences of the participants through a new lens (Moustakas, 1994; Overgaard, 2015).

As a speech-language pathologist since 2005, I have provided therapy to children and adults with varying abilities from diverse backgrounds. During the past 14 years, I have provided therapy primarily to children with special needs, and I have collaborated with their parents, most often the mothers, to promote the carryover of skills in the home setting. I brought certain biases to this study because of my experiences with mothers caring for a CSHCN. Because both researcher and participants bring some bias to research, it was critical to ensure that the data were interpreted based on the perspectives of the participants, rather than based on my own perspective as the researcher (Fields & Kafai, 2009; Fusch & Ness, 2015; Holloway, Brown, & Shipway, 2010).

Methodology

Target Population

This study focused on 15 mothers ages 25 to 75+ years who were raising a CSHCN. This population was selected based on the need for a better understanding of the stressors, coping strategies, and gratitude experienced by mothers providing care for a CSHCN. A phenomenological study of up to 10 participants is considered adequate to reach saturation (Creswell, 2014; Marshall, Poddar, Fontenot, & Cardon, 2013). This study included in-depth interviews with 15 mothers. This number was appropriate, as it was small enough to permit ample details to emerge and large enough to provide sufficient data from multiple experiences (Creswell, 2014; Malterud, Siersma, & Guassora, 2016).

Sampling and Sampling Procedures

Participants were recruited using purposeful sampling techniques, which allowed me to select information-rich cases to obtain a more in-depth understanding of the target phenomenon (Benoot et al., 2016; Patton, 2002). Purposeful sampling is a nonrandom means of selecting participants who are available and willing to provide details of their personal experiences as they relate to the studied event (Etikan et al., 2016). Extreme or deviant case sampling was also applied in an attempt to discover and better explain variations in the cases (Etikan et al., 2016; Patton, 2002).

This study included a nonprobability convenience sample, where participants were selected from a population in a nonrandom manner based on availability and accessibility (Kandola, Banner, O’Keefe-McCarthy, & Jassal, 2014; Teddlie &

Tashakkori, 2011). This method was inexpensive, quick, and convenient (Elfil & Negida, 2017; Teddlie & Tashakkori, 2009). Although nonprobability convenience sampling is one of the most common methods of sampling, it may not be as generalizable as other methods to a larger population (Setia, 2016; Tashakkori & Creswell, 2007).

After obtaining Institutional Review Board (IRB) approval, I gathered referrals to potential participants through both personal and professional contacts until I had recruited 15 participants. Saturation was attainable with 15 to 20 participants, as additional participants and data would not have provided new insights (Creswell, 2014; Lowe, Norris, Farris, & Babbage, 2018). Eligible participants (a) spoke English proficiently, (b) had at least one child with special health care needs, (c) were at least 25 years old, and (d) resided in Phoenix, Arizona.

Data Collection, Protocols, and Procedure

I collected data through semistructured, face-to-face interviews with each participant. The majority of the questions were open-ended so that the perspectives and opinions of the participants could be more thoroughly elicited (Creswell, 2014; Kallio et al., 2016). I conducted each interview at a time and place convenient for the participant and in a location where the participant felt comfortable expressing personal details related to the study.

The interviews lasted approximately 20 to 40 minutes and were audio recorded. Immediately following each interview, I used the recording to create a verbatim transcript (Neal, Neal, VanDyke, & Kornbluh, 2015). I asked each participant if she was willing to participate in a follow-up phone call should I require clarification or confirmation of the information I transcribed (Drabble, Trocki, Salcedo, Waker, & Korcha, 2016).

I provided interested participants with details about the purpose of the study and measures that would be taken to ensure confidentiality and anonymity, should they choose to participate (Gibson, Benson, & Brand, 2013). I explained to each potential participant that the study was being conducted to fulfill requirements for the PhD Health Psychology degree at Walden University. I clearly informed participants that participation was voluntary and that incentives or payment would not be offered (Doyle & Buckley, 2017). I provided informed consent forms in person for signatures, and participants had the option to exit the study at any time, at which point I would omit any data collected from the study (Oye, Sorensen, & Glasdam, 2016).

Data Analyses

I immediately processed and recorded the information obtained in the interviews in detailed notes (Creswell, 2014; Ranney et al., 2015). Data analyses began as soon as I collected the first data so that I could mentally establish themes and patterns, which allowed for greater awareness when subsequent themes arose (Creswell, 2014; Crowe, Inder, & Porter, 2015). I recorded specific highlights and observations on the same reflection template for each interview to maintain consistency and standardization (Castillo-Montoya, 2016; Creswell, 2014).

Once I had collected the raw data, I organized and prepped these data for analysis by transcribing interviews, typing field notes, and arranging the data into different types based on the source (Creswell, 2014; Tracy, 2010). In addition to the spoken words, I included and analyzed nonverbal language (Person, May, & Mayer, 2016). Through horizontalization, each statement, or segment of meaning, was assigned an equal value (Chan, Yuen-ling, & Wai-tong, 2013; Moustakas, 1994). After winnowing the data, I reflected on the general ideas and overall meaning of the data (Guest, MacQueen, & Namey, 2012; Stynes, Murphy, & McNamara, 2018).

I coded and bracketed the data into categories through both content and thematic analysis (Creswell, 2014; Elo et al., 2014). Through content analysis, qualitative data were systematically coded based on specific categories or themes (Dinçer, 2018; Fraenkel, Wallen, & Hyun, 2012). The meaning of the studied phenomenon was synthesized through thematic analysis, as I identified themes in the transcriptions (Ho, Chiang, & Leung, 2017).

The above-mentioned analytic scheme was believed to be the most optimal for this study because the goal was to reveal themes, patterns, and categories rather than statistical significance (Patton, 2002; Vaismoradi, Jones, Turunen, & Snelgrove, 2016). This also further substantiated the rich descriptions of the targeted phenomenon (Graneheim, Lindgren, & Lundman, 2017). Finally, this analytic scheme allowed me to organize and elicit the essence of the meaning from the data to provide prudent conclusions (Bengtsson, 2016).

Reliability and Validity

While quantitative research incorporates statistical methods to establish trustworthiness of the findings, qualitative research seeks methodological strategies to ensure reliability and validity (Levitt et al., 2017; Nobel & Smith, 2015). I clarified personal biases that may have influenced the findings by commenting on previous experiences, prejudices, and biases that may have contributed to both the approach and interpretation of the study (Creswell, 2013; Onwuegbuzie & Byers, 2014). I addressed reliability and validity through (a) data triangulation, (b) member checking, (c) use of rich and thick descriptions, (d) peer debriefing, and (e) an audit trail (Creswell, 2013; Noble & Smith, 2015; Thomas, 2017; Twining, Heller, Nussbaum, & Tsai, 2017).

Data Triangulation

Triangulation occurs as the researcher explores different perspectives on the same phenomenon (Fusch & Ness, 2015; Teddlie & Tashakkori, 2003). It involves combining a variety of qualitative data from multiple sources in order to promote validation of the data and the subsequent themes elicited from the data (Brown et al., 2015; Creswell, 2014). This process also makes it possible to find deeper meaning in the data, which provides a more complete understanding of the studied phenomenon (O'Cathain, Murphy, & Nicholl, 2010; Patton, 2002). I used data triangulation in this study by including data from multiple sources, and I applied theoretical triangulation through the use of various theoretical perspectives to interpret the results (Carter, Bryant-Lukosius, DiCenso, Blyth, & Neville, 2014; Onwuegbuzie & Leech, 2007).

Member Checking

Member checking is one of the most crucial techniques used by researchers to establish credibility (Harvey, 2015; Lincoln & Guba, 1985). Once the raw data had been polished, I offered a follow-up interview with each participant (Birt, Scott, Cavers, Campbell, & Walter, 2016; Liao & Hitchcock, 2018). I provided the interview transcripts, primary findings, and themes to each participant, who then had the opportunity to comment on the accuracy of the findings (Creswell, 2014; Varpio, Aijawi, Monrouxe, O'Brien, & Rees, 2017). This also allowed me to collect additional data that were needed to elaborate on certain categories (Iivari, 2018).

Rich and Thick Descriptions

I increased the validity of the results through the use of rich and thick descriptions along with quotes from the participants (Creswell, 2014; Freeman, 2014b). When I built rapport and trust with the participants, more details were shared, richer data were obtained, and validity was increased (Morse, 2015). Including detailed descriptions of the different perspectives related to the studied phenomenon enriched the results and also made them more realistic (Colorafi & Evans, 2016; Creswell, 2014). Such descriptions allowed the reader to substantiate my interpretations and critique the credibility of the study (Cope, 2014).

Peer Debriefing

I elicited the assistance of a peer debriefer to review the study and ask applicable questions (Creswell, 2014), as this process allowed for further interpretation that extended beyond my interpretations as the researcher (Connelly, 2016). The peer debriefer for this study was a physical therapist who specializes in pediatrics. She holds a Doctorate degree in physical therapy and has been providing services to CSHCN at a local agency for 7 years. As an outsider to the study, she held an impartial view and was not directly involved with any of the participants or data collection.

In addition to encouraging analytic discussions (Lincoln & Guba, 1985), peer debriefing strengthened credibility by challenging the methodology and findings (Hays, Wood, Dahl, & Kirk-Jenkins, 2016). It was advantageous to select an individual with comparable academic, professional, and personal experience to review the data (Baillie, 2015). Names and identifying information were removed prior to sharing transcripts with the peer debriefer to ensure the confidentiality of the participants.

Audit Trail

I maintained an audit trail throughout all research stages that included interview transcripts, notes reflecting my assumptions, data analyses notes, and final drafts (Cope, 2014; Lincoln & Guba, 1985). I also included inclusion and exclusion criteria along with explanations and justification for each aspect of the sample (Baillie, 2015). Another individual reviewed these materials, and the conclusions were then compared (Amankwaa, 2016; Connelly, 2016).

Researcher Bias

Since I was the data collection instrument for this study (Cope, 2014), it was critical to acknowledge that researcher bias would be present, both intentionally and unintentionally (Fields & Kafai, 2009; Morse, 2015). My cultural background and experiences naturally included a variety of biases, ideologies, and values (Chenail, 2011; Fusch & Ness, 2015). I addressed this issue by maintaining detailed notes and reflections in a reflexive journal (Hays et al., 2016; Rodham, Fox, & Doran, 2015).

Ethical Considerations

Ethics refers to the behavior and decision-making that are guided by moral principles (Ingham-Broomfield, 2017). Researchers who adhere to ethical standards by following rigorous procedures demonstrate a dedication to quality and safety (Arries, 2014). I strictly adhered to the ethical standards outlined by Walden University's IRB (2018b). An essential component of the IRB is to ensure that the human beings participating in the study are protected (Nichols, 2016).

Informed Consent/IRB Approval

Prior to the interviews, each participant was required to provide signed informed consent as set forth by Walden University's IRB (2018b). I secured the signed consent forms and all collected data in a locked, fireproof file cabinet in my home office. I only recruited potential research participants after Walden University's IRB granted written approval. Additionally, I did not collect data and research did not begin until I obtained such approval on February 8, 2019 (02-08-19-0341602).

Summary and Conclusion

This chapter described the qualitative research design and rationale (Creswell, 2014; Landrum & Garza, 2015). Specific information related to the target population, sampling procedures, data collection, and data analyses were also provided (Creswell, 2013; Teddlie & Tashakkori, 2003). The chapter ended with ways in which I enhanced the reliability and validity of the findings and I elaborated on the processes of data triangulation, member checking, rich and thick descriptions, peer debriefing, an audit trail, and researcher bias (Onwuegbuzie & Byers, 2014; Teddlie & Tashakkori, 2003).

There is a significant gap in the literature related to how mothers experience gratitude while facing substantial challenges associated with caring for a CSHCN (Chaij et al., 2014; Dardas, 2014). By examining benefits of gratitude (Randolph, 2017; Watkins, Uhder, & Pichinevskiy, 2015) along with barriers to achieving gratitude (Arrien, 2011; Davidai & Gilovich, 2016; Halberstadt et al., 2016), substantial data were obtained to emphasize the importance of gratitude among mothers of CSHCN and ways in which the mothers can overcome the barriers to achieving such gratitude. Results from this study provided insights into healthy coping strategies (Hamid & Musa, 2017; Lin & Yeh, 2014) that all mothers caring for a CSHCN can implement.

Chapter 4: Results

Introduction

The purpose of this phenomenological research study was to explore, discover, and better understand the contextual lived experiences of mothers raising a CSHCN. This inquiry was guided by Fredrickson's (2004) broaden-and-build theory of positive emotions (Joshanloo, Sirgy, & Park, 2018) and the transactional model of stress and coping (Jones & Lynn, 2018; Lazarus & Folkman, 1984). The interview questions were specifically written with the following research questions in mind:

1. For which aspects are mothers raising a child with special health care needs most grateful?
2. What are the major challenges/stressors faced by mothers raising a child with special health care needs?
3. What major coping styles are employed by mothers raising a child with special health care needs?
4. In which ways do gratitude, challenges, and coping styles contribute to quality of life among mothers raising a child with special health care needs?

Approval to conduct this study was granted by the Walden University IRB on February 8, 2019 (02-08-19-0341602). The study was conducted with 15 mothers, each of whom was raising at least one CSHCN. This chapter addresses the methods used to identify participants, data collection, participant demographics, findings, data analyses, composite description, and evidence of quality.

Piloting Study Questions

Piloting the interview questions served as a “dress rehearsal” (Moser & Kalton, 1992) and allowed me to carefully examine how the questions were perceived and make any adjustments prior to collecting data from the participants in the main study (Majid, Othman, Mohamad, Lim, & Yusof, 2017). This allowed me to check the language, understanding, responses, and ease of administration of each question (Singh, Bhalla, Giri, & Sarkar, 2015). After piloting the questions, it was determined that the wording and the order of the questions were appropriate, and modifications were not necessary. In addition to the eight main questions, a variety of follow-up questions and prompts were used to elicit more detailed responses (Appendix A).

Setting

The setting for the interviews was based strictly on the guidelines of the Walden IRB for ethical standards in research, which ensure that “all Walden University research complies with the university’s ethical standards as well as U.S. federal regulations” (Walden University, 2019b). Additionally, careful consideration was given to the size of the interview room as well as the features inside the room, as these aspects have been shown to influence a participant’s willingness to discuss sensitive issues (Okken, van Rompay, & Pruyn, 2012). The interview room was arranged in a way that enhanced the perception of spaciousness, which has also been shown to increase disclosure.

All interviews were conducted in a therapy room at a local clinic, which provided privacy and confidentiality. Before the interviews, each participant was provided with a detailed explanation of informed consent (Wolf, Clayton, & Lawrenz, 2018). It was clearly explained that participation was voluntary, and that participants could choose to withdraw from the interview at any time (Walden University, 2019b). In order to protect participant confidentiality, I replaced participants’ names with unique identifiers such as P1, as shown in Tables 1 and 2.

I provided the participants with phone numbers and websites for free support resources in the event that any of them experienced any discomfort during or following their participation in this study (Walden University, 2019c). To my knowledge, none of the participants experienced distress or discomfort due to their participation. It is unknown whether any of the mothers used the public mental health services provided. There were no personal or organizational circumstances that could have influenced the responses of the participants at the time of this study (McCambridge, Kypri, & Elbourne, 2014).

Participant Demographics

I adhered to the Walden IRB guidelines regarding confidentiality and informed consent procedures (Walden University, 2019b). All participants were English-proficient mothers of at least 25 years of age who were raising at least one CSHCN in Arizona. Table 1 provides information about the number of children each participant had along with the total number of CSHCN per mother. Also included in Table 1 are diagnoses, age, and gender of the CSHCN. Table 2 provides details about the therapies each CSHCN received at the time of the study.

Table 1

Participant Demographics—A

	Number/children	Number/CSHCN	Diagnosis	Age/CSHCN	Gender/CSHCN
P1	2	1	Down syndrome	7	Female
P2	2	1	Traumatic brain injury	14	Female
P3	1	1	Down syndrome	19	Male
P4	1	1	Autism	3	Male
P5	3	1	Learning disability	11	Male
P6	3	1	Autism	16	Male
P7	1	1	Batten disease	18	Female
P8	1	1	Cognitive impairment	17	Female
P9	4	2	Down syndrome	55	Male
			Cerebral palsy	31	Female
P10	3	1	Cerebral palsy	21	Female
P11	1	1	Autism	14	Male
P12	2	1	Cerebral palsy	54	Male
P13	2	1	PKAN disease	10	Female
P14	1	1	Muscular dystrophy	10	Male
P15	1	1	Autism	9	Male

Table 2

Participant Demographics—B

	Therapies received by CSHCN
P1	Speech, occupational, physical, music, on wait list for feeding
P2	Speech, occupational, physical, music, feeding
P3	Speech
P4	Speech, ABA
P5	Occupational, ABA
P6	Speech, occupational
P7	Speech, occupational, physical, music, feeding
P8	Occupational, music
P9	Speech, occupational, physical, music, feeding
P10	Speech, occupational
P11	Speech, occupational, physical, on wait list for feeding, ABA
P12	Speech, occupational
P13	Speech, occupational, physical, music
P14	Speech, occupational, physical, feeding
P15	Speech, occupational

Participant Profiles

Participant 1

P1 had a 7-year-old daughter with Down syndrome and a 10-year-old typically developing daughter. Her stressors included those related to providing maximum assistance to her child in the areas of dressing, bathing, and grooming. She was grateful for her daughters, for the fact that she and her family were healthy, and for having a flexible job that allowed her to rearrange her schedule to care for her child. P1 worked full time and was married. Her household included her husband and two daughters.

Participant 2

P2 had a 14-year-old daughter with traumatic brain injury (TBI) and a typically developing 3-year-old son. She reported stressors related to the anger and frustration that her child exhibited when she could not communicate her needs, wants, feelings, and ideas. Among the things for which she was most grateful were “the opportunity to embark on this journey” and the people that she had met on the journey. P2 worked full time and was married. Her household included her husband her two children.

Participant 3

As a mother of a 19-year-old son with Down syndrome, P3 identified stressors related to her child graduating from high school and issues related to transportation. She also reported increased stressors during times of transition, such as leaving elementary school for high school. P3 was grateful for a flexible job that allowed her to work around her child and for her child having many wonderful friends. P3 worked full time and had been a single mother since shortly after her son was born. She and her son lived alone in their home.

Participant 4

P4 had a 3-year-old son with autism and reported stressors related to the tantrums he threw when he could not effectively communicate. When asked about the things for which she was most grateful, P4 emphatically listed her child and said, “Life without him wouldn’t be life.” P4 was a stay-at-home mom and was married. Her household included her son and husband.

Participant 5

P5 had an 11-year-old son with a learning disability and attention deficit hyperactivity disorder. She also had two typically developing sons who were both over the age of 18 years. She reported stressors related to his constant activity, his struggles to sleep, and his aggressive behaviors toward her. She was most grateful for her siblings, who helped her tremendously, and for her children, whom she described as “my world.” P5 worked full time was single. Although her older sons helped out from time to time, it was just P5 and her CSHCN living at home.

Participant 6

P6 had a 16-year-old son with autism and two typically developing daughters over the age of 18 years. She noted stressors related to being recently separated and learning how to coparent. She also reported stressors related to the routine of each day, which she referred to as “both a blessing and a curse.” P6 was most grateful for her children, parents, siblings, and friends. P6 worked full time and was going through a separation from her husband. Her household included her three children and she shared custody with their father.

Participant 7

P7 had an 18-year old daughter with a rare terminal illness. She reported stressors related to her daughter’s frequent seizures, instability when walking, and struggles to swallow safely. Among the things that P7 was most grateful for were her friends, her parents, and those in the medical field who continued to help her daughter. P7 worked full time and was married. Her household included her daughter and husband.

Participant 8

P8 had a 17-year-old daughter with a moderate cognitive impairment. Her stressors included those related to any change in schedule, as her daughter was very routine oriented. Although she reported few stressors over the past few years, P8 expressed increased stressors at the time of the study due her daughter entering adulthood. P8 was grateful that her daughter had received excellent educational opportunities and was in good health. P8 worked full time and was married. Her household included her daughter and husband.

Participant 9

P9 was a mother of two nonambulatory children with special needs and two typically developing adult sons, both over the age of 50 years. Her 55-year-old son had Down syndrome, and her 31-year-old daughter had cerebral palsy. P9 reported stressors related to struggles to find help for her son’s daily needs, such as bathing, using the restroom, and dressing. As an older mother who had been a widow for more than 25 years, P9 faced unique stressors. Of the many things for which she was grateful, she often repeated her family, friends, God, and church members. P9 did not work and her household included both CSHCN for whom she was the primary caregiver and one of her older sons who did his best to help with his siblings.

Participant 10

P10 had a nonambulatory 21-year-old daughter with cerebral palsy. She also had a 29-year-old son and a 34-year-old daughter who were both typically developing and not living in the same home. P10 also had custody of her 3-year-old grandson who was undergoing evaluations to determine a possible diagnosis of autism. P10 described stressors related to her own health and the stress associated with the numerous doctor appointments and surgeries her child had had and continued to need. P10 was most grateful that her daughter had friends and therapists who genuinely loved her and that she could use an augmentative communication device to functionally and effectively express herself. P10 was a stay-at-home mom and was married. Her household included her daughter, grandson, and husband. In addition to being the primary caregiver for her daughter, P10 was also battling breast cancer.

Participant 11

As the mother of a 14-year-old son with autism, P11 described stressors associated with his struggles to communicate, as well as issues that she had been having with the landlord of her residence due to unsafe living conditions. She was grateful for the therapists who provided services for both her and her child. She was also grateful that she could attend each of his therapy sessions. P11 worked part time and was single. She and her son lived alone in their home.

Participant 12

P12 had a 54-year-old nonambulatory son with cerebral palsy and a 57-year-old typically developing daughter. She was grateful that he used his communication device so effectively and that he had a job where he could be around others, as he was extremely social. P12 expressed stressors correlated with being an older parent with an adult child who was completely dependent on her for all daily needs. P12 and her husband were both retired. Her household included her son and husband.

Participant 13

P13 was a mother with a 10-year-old daughter who had a rare degenerative neurological disorder. She also had an 8-year-old daughter who was typically developing. The majority of her stressors came from the numerous medical issues and doctor appointments that her daughter required. She also reported stress related to the regression that her daughter had shown in all areas. She was grateful for her respite provider, her family, her friends, and therapists. P13 was a stay-at-home mom and was married. Her household included her daughters and husband.

Participant 14

P14 had a 10-year-old nonambulatory son with Duchenne’s muscular dystrophy. She reported stressors related to stomach issues that her son frequently had, which often resulted in him coming home early from school or not going in at all. She was most grateful for her mom, who helped her a great deal with her son. P14 worked full time and was separated from her husband, with whom she shared custody. She and her son lived alone in their home.

Participant 15

P15 had a 9-year-old son with autism. Her primary stressors were related to his inability to effectively communicate and the struggles that she had experienced with finding a school where he would be treated with “kindness, patience, and respect.” Due to multiple negative experiences, her son was homeschooled at the time of the study. She was most grateful for her husband, the medical team that had helped her son for many years, and the child she was expecting by the end of the year. P15 worked full time and was married. Her household included her son and husband.

Data Collection

Data collection was conducted via semistructured face-to-face interviews with 15 participants, which took place in a private room in a centrally located clinic and lasted 20-40 minutes. The length of each interview depended on the responses of the participant, but no interview exceeded 40 minutes. Longer interviews, typically lasting more than 90 minutes, may cause stress for participants and ultimately affect data quality (Ranney et al., 2015). All interviews were digitally recorded and have been stored on the external hard drive of a password-protected computer (Chauvette, Schick-Makaroff, & Molzahn, 2019). I have been the only person to have access to the data and all files associated with this study.

The purpose of this study was to explore and describe the lived experiences of mothers raising a CSHCN. The aim was to provide descriptions of lived experiences in a way that readers can understand while maintaining the essence of the experience (Amos, 2016). To accomplish this, I asked the participants eight questions (Appendix A) about their experiences as a mother caring for a CSHCN, the associated stressors, gratitude, and coping strategies that they implemented.

A purposeful sampling approach was used to identify and select participants with information-rich experiences (Palinkas et al., 2015). All potential participants were screened and selected based on the required criteria: (a) mother of at least one CSHCN, (b) age of 25 years and older, (c) spoke English proficiently, and (d) resided in Arizona. Participants were recruited through both personal and professional contacts. I also distributed flyers (Appendix B) through a local clinic that provided a variety of therapeutic services to individuals with special needs.

Data Analyses

Once the interview concluded, I immediately processed and recorded the information in detailed notes (Creswell, 2014; Ranney et al., 2015). I began data analyses upon collecting the first set of data in order to mentally establish themes and patterns, which ultimately allowed for increased awareness when subsequent themes emerged (Creswell, 2014; Crow et al., 2015). In order to maintain consistency and standardization, I used the same reflection template for each interview to record specific highlights and observations (Castillo-Montoya, 2016; Creswell, 2014).

After collecting the raw data, I transcribed the interviews and typed field notes (Creswell, 2014; Tracy, 2010). Through horizontalization, each statement was assigned an equal value, and after winnowing the data, I reflected on the general ideas and overall meaning of the data (Chan et al., 2013; Guest et al., 2012; Moustakas, 1994; Stynes et al., 2018). I coded and bracketed the data into categories through both content and thematic analysis (Creswell, 2014; Elo et al., 2014).

The data were systematically coded based on specific categories and themes (Dinçer, 2018; Fraenkel et al., 2012). The meaning of the studied phenomenon was synthesized through thematic analysis, as I identified themes in the transcriptions (Ho et al., 2017). Throughout the data analyses, I listened to the audio-recorded interviews of each participant, read, highlighted, and re-read each interview transcript multiple times over the span of several weeks. I predetermined that key themes would be reported by at least 65% of the participants, and subthemes would be present in 50% to 64% of the responses.

Member checking was implemented to validate the information obtained in each interview (Harvey, 2015). Once the interviews had been transcribed, I gave the participants the opportunity to review their specific transcript for accuracy and encouraged them to make any changes that did not accurately convey their experiences (Varpio et al., 2017). When the member checking was completed, I reviewed the transcripts while simultaneously listening to the audio recordings once again.

One of my goals was to determine the meaning and significance of the words used by each participant (Amos, 2016; Leech & Onwuegbusie, 2007). To achieve this goal, I kept an open mind, carefully examined the data, and specifically sought to identify language nuances, intonation, and nonverbal cues (Leung, 2015). The next step included reduction of data (Moustakas, 1994) where I listed on paper the different explanations the participants provided about their experiences as a mother raising a CSHCN. I highlighted the relevant expressions and crossed out those that were repetitive and overlapping, which led to the development of themes.

After determining relevant expressions, I used a variety of colored highlighters to identify different elements, which led to the identification of both major themes and subthemes (Vaughn & Turner, 2016). In order to follow the guidelines of Moustakas (1994), I compared the elements of each transcript and included verbatim quotes from the participants to further substantiate each theme and subtheme (Neal et al., 2015). Continuing to follow Moustakas' (1994) steps for data analyses, I included verbatim quotes from the participants (Padilla-Díaz, 2015), which supported the individualized textural descriptions of the meaning and essence of each participant's experience.

I integrated the descriptions during the final step of data analysis, which enhanced the organization and elicitation of the meaning from the data (Bengtsson, 2016). This allowed for the presentation of prudent conclusions. The combination of the meaning and essence of the shared experience (Sundler, Lindberg, Nilsson, & Palmér, 2019) revealed nine major themes and two subthemes. Table 3 lists these themes as well as the participants from whom the themes emerged.

Table 3

Themes and Subthemes by Participant

Themes and subthemes	Participants who identified subthemes
1. Support of family and friends	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15
2. Feelings of gratitude	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15
3. Coping mechanism	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15
4. Life satisfaction/Quality of life	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15
5. Gratitude for flexible job	1, 2, 3, 9, 10, 11, 12, 13, 14, 15
6. Stress related to full dependency	1, 2, 7, 9, 10, 11, 12, 13, 14, 15
Subthemes of number 6	
Nonverbal challenges	1, 2, 4, 9, 10, 11, 13, 14, 15
Behavioral challenges	2, 3, 4, 5, 6, 11, 14, 15
7. High stress over the past 30 days	2, 3, 4, 5, 7, 9, 10, 11, 12, 13, 14, 15
8. Increased stress when describing child	1, 2, 3, 6, 8, 9, 10, 11, 12, 13, 14
9. Need to work on eating habits	1, 2, 6, 7, 9, 10, 11, 12, 13, 14

Themes and Findings

The participants were asked general questions (Appendix A) about their personal experiences, the stressors they encountered, things for which they were grateful, and things they felt they should be doing but were not. During the data analyses process, information from each interview was abstracted and categorized in order to determine themes and subthemes (Padilla-Díaz, 2015). The primary goal of identifying and presenting the key themes was to convey the essence of the lived experience (Alase, 2017). Discrepant cases were not included, as the data were consistent with the emerging themes and subthemes.

Theme 1: Support of Family and Friends

Although caregivers who receive support from family and friends have been noted to demonstrate increased resilience (Inci & Temel, 2016; Jonker & Greeff, 2009), support may be challenging to find due to strained relationships and feelings of isolation (Chukwu, Okoye, Onyeneho, & Okeibunor, 2019). This first major theme emerged as all 15 participants mentioned the importance of having friends and family as a support system. Even though not all of the participants had living parents, they each mentioned at least one family member and one friend from whom they received support and encouragement. They also described the benefits of venting to others.

> P1. I talk to my friends. I vent all the time about whatever I need to.
>
> P2. You know, I'm blessed. I get it from a lot of people. I have a really great support system. If I had to just identify one person though, it would definitely be my mom. She literally said, "This is your only job right now. You take care of

> her. I'll take care of the rest." and then she would do that and sit next to me the entire time.
>
> P6. I'm pretty lucky. I'm loved by my family and friends so I have a very good circle that is around me.

Theme 2: Feelings of Gratitude

Gratitude comes in a variety of forms and can be felt for many different things, situations, and people (Kardas, Cam, Eskisu, & Gelibolu, 2019). This second major theme emerged as each of the 15 mothers reported feeling grateful for at least one aspect in their life. Although a significant number of mothers reported being grateful for a flexible job, as in Theme 5, there was a great deal of variation in the other items for which each mother felt gratitude. These included a washing machine, therapists, medical professionals, a backyard, church, specialized grocery carts, and healthy children.

> P1. We didn't have one over the summer and it was awful! It was so awful! I would trade all my electronics in the world just so I never go without a washing machine ever again! She has blowouts almost every night and she doesn't recognize when she's pooping so we would go through probably five or six bed sets a week and I would have to save them all up and then go to the laundromat once a week to use the huge, like 80-pound washer.
>
> P3. I'm thankful we have a home and a backyard. We aren't stuck in our apartment for years and years, or the rest of his life.
>
> P10. I have a lot of gratitude toward the medical field. They truly are trying to help children with rare diseases and the pharmaceutical company has so many

> wonderful people that work for them and they reached out to us. Sometimes you're like, oh my God I just wish I could do this! You can have a pity party sometimes but I have more gratitude than I do bitterness for sure!

Theme 3: Coping Mechanism

Research has shown that coping strategies were influenced by the stressor as well as the environment in which the stressor occurred (Fairfax et al., 2019; Hastings et al., 2005). Despite not implementing gratitude as a coping mechanism, each mother listed at least one technique they used to cope with their stress, which led to this third major theme. Their coping mechanisms included going for a walk, playing video games, gardening, running, crying, going to the gym, and doing puzzles.

> P1. I play video games, a lot! I love playing video games! I feel like it gets my stress out. My older daughter is getting to the age where she's kind of playing video games with me, so we do like mommy daughter video game sessions. It's something I love doing!
>
> P2. You don't realize how much your kids pick up on your emotions, but it really does make a difference. When we are broken, and they see that, they definitely pick up those vibes. So, when I'm driving alone in the car, that's my therapy. I talk to myself. I build myself up. I cry.
>
> P15. I go outside into my garden. I started a garden because I noticed my stress levels going up so I just go out and work in my garden. I usually go out there for 20 minutes or so at a time and maybe three times a day.

Theme 4: Life Satisfaction/Quality of Life

Gratitude has been noted as a potential protective factor that may increase resilience in stressful and challenging times (Lee et al., 2018; Valikhani et al., 2019). Although each of the mothers discussed very stressful situations unique to raising a CSHCN, all 15 mothers made a comment about having a high quality of life or increased life satisfaction, which led to this fourth major theme. Each mother implemented some form of coping strategy and some also used prescription medications to facilitate their satisfaction with life.

> P1. Now that they're getting older, that's probably one of my favorite things. They fight light regular sisters. It's so much more normal than I ever though it would be!
>
> P2. So many good things have come out of my journey with her. It's a difficult journey but I wouldn't change it. It's tough but it's worth it so I wouldn't change it. I absolutely wouldn't change it!
>
> P9. The stress is just part of it. Stress is everywhere but this stress makes my life what it is and I wouldn't want it any other way.

Theme 5 : Gratitude for a Flexible Job

Work demands can interfere with the demands of caregiving and impact a person's well-being (Chandola, Booker, Kumari, & Benzeval, 2019). Individuals with flexible work arrangements have reported increased work life balance, lower burnout, and improved physical, emotional, and psychological wellbeing (Dizaho, Salleh, & Abdullah, 2017; Medina-Garrido, Biedma-Ferrer, & Ramos-Rodríguez, 2017; Uglanova

& Dettmers, 2018). The fifth major theme that emerged from this study was gratitude felt for having a flexible job. The participants commented on previous jobs that were not understanding when their child was sick, had an appointment, or there was a school holiday. The participants expressed gratitude and less stress with a job that was supportive and allowed the mothers to rearrange their schedule as needed to better care for their child.

> P9. I'm most grateful that I actually have a job now where I can rearrange my schedule if I need to. When I've been in the other jobs and other places, it becomes terrifying that you have to call it in or let someone know that you need to be away because your kid decided to get sick on the way out the door. I don't have to worry about that anymore so I'm very grateful for that.
>
> P12. He's been sick a lot more and that gets hard with work and trying to explain. At my job right now, I'm able to adapt things but at previous jobs it's been hard to explain.
>
> P14. I have a job that is flexible. It allows me to work around him and pick him up if needed.

Theme 6: Stress Related to Full Dependency of Child

Children with disabilities typically require extra help with daily living tasks and often continue to require this care as they age (Luijkx, van der Putten, & Vlaskamp, 2017; McCann, Bull, & Winzenberg, 2012). The sixth major theme of this study was the stress related to a child who was fully dependent for daily living skills. These included areas such as dressing, bathing, grooming, and eating. The mothers reported stress related to the extra time it took to get their child ready in addition to getting themselves ready, and in some cases, also helping another child to get ready. These tasks were noted to be especially challenging with older children, particularly due to the increased size or weight of the child.

> P2. She does require sufficient assistance with her daily grooming, showering, and everything. The best way to describe it is, ‘You live your life and you live hers.’ Morning routines are extremely stressful just because, it’s like showering, it’s like dressing two humans at the same time. I have to shower her, dress her, feed her, brush her, get her completely ready and then still get myself ready.
>
> P7. I don’t have to be at work until approximately 9:00 but because of her having to get up and me having to do everything for her, I have to get up at 5:00 and sometimes that actually gets stressful that I don’t get those extra three hours of sleep.
>
> P10. The mornings can be a little stressful. She can sometimes be difficult to wake up in the morning and she still struggles to be independent with dressing and going to the bathroom, brushing her teeth, and unfortunately, there’s time constraints in the morning so trying to tell her that we need to help her so that she can get off to school at a decent time can cause stress right there.

Subtheme 1: Challenges related to the child being nonverbal. A child may shut down or exhibit more extreme behaviors when they feel that no one understands them or that no one is willing to make an effort to understand them (Hartshorne & Schafer, 2018). Nine of the 15 mothers identified this subtheme, which emerged from descriptions of struggles and frustrations of not understanding what the child was trying to communicate. Although some of the children used an AAC device, they were unable to communicate at certain times when their device was not available, such as bedtime and bath time. The mothers expressed frustration in not understanding and also in seeing the frustration in their children when they were not understood.

> P4. You just know he’s having diarrhea. You don’t know why he’s having it. He could have diarrhea from eating too much food to having an ear ache. It all comes out that way so it’s a lot of a guessing game and a lot of frustration.
>
> P10. You know that your kid’s not going to tell you when things are wrong or when someone’s being mean to them. You have to really be a detective at times.
>
> P13. One time we found that she had been tied, like buckled, into a cube chair for 4 hours while she had a fever and because we were “picking her up soon”, they didn’t call and tell us. So, she just sat there and cried the whole time and we have had the experience where some people treat kids like that because they know they aren’t going to get told on. They know the kid can’t call them out on it.
>
> P15. I don’t know all the time what he wants. When I don’t understand, he’ll throw fits or tantrums. It’s harder for him to express how he’s feeling and as a mom, you want to know what’s going on and how to fix everything for him but I don’t know.

Subtheme 2: Frustration with behaviors. Parental stress may be higher in families with a child who demonstrates challenging behaviors (Argumedes, Lanovaz, & Larivée, 2018; Baker, Blacher, Crnic, & Edelbrock, 2002). This subtheme was identified by 9 of the 15 participants. Although behaviors were frequently related to the inability of the children to communicate as in Subtheme 2, this subtheme emerged as participants described stress directly related to the behaviors displayed when the children were upset or not understood. The behaviors were varied and included self-biting, throwing objects, and hitting the mothers.

> P3. He has a speech impairment so his inability to communicate causes a lot of aggression and frustration. He gets really physical, either biting or hitting and just mouthing off.
>
> P5. It's stressful when he might accidentally injure me. He's not doing it on purpose. He might throw something or start stomping and he'll push me. I've had him shove me all the way to the ground. He's so strong!
>
> P6. If he's not having a good morning, he'll spend the entire car ride kicking in the backseat and it's worrisome because he's pretty strong.

Theme 7: High Stress Levels Over the Past 30 Days

In addition to the varied ways in which individuals experience stress, the stressful events also vary in predictability, controllability, and pleasantness (van der Stouwe et al., 2019). This seventh major theme emerged as the participants described their past 30 days as stressful and very stressful. Twelve of the 15 participants identified this theme. The stressors described in this theme did not include those from Theme 6 or the Subthemes of Theme 6.

> P3. He's graduating high school. He's very sad about that. I'm having a hard time with that too because his needs won't be met at that level. He's going into another

> setting. He’ll be going to a Down syndrome program in the fall and he’ll be doing that probably for the foreseeable future; for years to come. He only gets three days there so the other two days I’m stressing about. What’s he going to do for those two days? Will he get a job? Will he like it? He won’t be around typical kids as much, now that he’s graduated high school.
>
> P7. I don’t know what the future holds and I’m scared that we’re entering the adult stage. She’ll be 18 in January. The unknown of the adult world is actually bringing me a lot of stress right now and it’s like that at every transition stage.
>
> P8. My daughter has a terminal illness so I think it might be a little bit different for some parents that maybe have a child who is like Down syndrome or something like that, where they’re basically healthy. I think it can be stressful obviously that way, but my daughter has seizures and she has a lot of difficulty walking, things like that, difficulty swallowing, so there’s always that added stress of having a seizure or choking on food, falling, things like that.
>
> P9. I can’t do transfers anymore. The kids are both so big now and can’t get them from their beds to their chairs, or in and out of the bath. Just trying to load them up in the van for appointments is too much. I don’t have the strength anymore.

Theme 8: Increased Stress When Describing Child

A study conducted by Lalvani (2015) found that parents of children with a disability believed that certain disabilities were viewed as less acceptable than others and these parents often advocated quite strongly for a label they considered to be less stigmatizing than what a medical professional had diagnosed. Other parents have reported feeling disregarding by others when describing the unique needs of their child and advocating for therapeutic services and education (Ryan & Quinlan, 2017). This eighth major theme was identified by 11 of the 15 participants. This theme emerged as the participants described increases stress levels when they described their child to someone who had not yet met the child.

> P8. When I'm talking to you and telling you about my daughter, I guess I get stress and anxiety just because it just reminds me more of her disabilities and what will probably happen because she has a degenerative disorder. That's kind of what causes stress when I'm talking to someone new about her disease and stuff like that. That stresses me out to think about how everything is going to degenerate even more.
>
> P11. I've talked to other parents about this and one of the things is that nowadays everybody's very into autism, very aware of what kids with autism should or shouldn't be like. So, a lot of times people think because they're aware about one type of disability, they're aware about all types of disability. Treating a kid with Down syndrome the same way you treat a kid with autism isn't going to be successful. It's hard to point out to people but I've had to do it with even school teachers.
>
> P13. You really want them to grasp the good. As a parent, you're that child's true advocate. You can represent that child. You can express what that kid needs, and likes, and dislikes. That's the stressful part. You really want to give them a broad picture but sometimes it's, at least for me personally, it's hard for me to. I tend to

> only want to say the good but I have to remind myself, ‘You’re going to work with her every day so these behaviors and these things, these challenges, are going to come out and I don’t want to do you or her a disservice by not letting you prepare yourself.’ I just fear the failure. Like, what if I don’t give you an accurate representation and then in the long run you and my child struggle because I failed to give you as much tools to use when assisting my child. It feels like a lot of responsibility.

Theme 9: Need to Work on Eating Habits

The diet of a child is highly influenced by the diet of the caregiver (Robson et al., 2016). High stress levels have been associated with unhealthy diets and, when compared with a control group, mothers of children on the autism spectrum were found to have higher reward-related eating habits both at the baseline and 2 years later (Radin, Mason, Laudenslager, & Epel, 2019). This final major theme was identified by 10 of the 15 participants and emerged as the mothers explained what they felt they should be doing but were not yet doing. While some of the participants described turning to food as a comfort, others described not eating enough. Each of the 10 participants reported that they were not eating a healthy diet, regardless of the amount consumed.

> P7. Food is definitely a comfort for me - so when things get rough, I like to eat and I like to eat alone.
>
> P11. I know I’ve gained weight and I don’t feel comfortable about that but I think a lot of that is just stress eating.
>
> P12. I get so busy sometimes and I forget to eat. I guess I worry so much about

> making sure he has everything he needs that I forget to do those little things for myself, like sit down and have an actual meal.

Additional Findings

There were some additional concepts and ideas that emerged throughout the interviews. Although they did not meet the criteria to be considered a theme or subtheme, they are worth mentioning. It is believed that these concepts can add value to the understanding of the phenomena of interest to the study (Castleberry & Nolen, 2018) and may provide new directions for future research.

Routines. While many of the mothers briefly discussed routines, P6 made a significant statement when she said that routines are “both a blessing and a curse.” Routines can include things such as eating the same breakfast food each morning or completing tasks in a particular order before going to bed each night (Cole, Kharwa, Khumalo, Reinke, & Karrim, 2017). Consistent routines have been associated with increased well-being for the child and all family members (McRae, Stoppelbein, O’Kelley, Fite, & Greening, 2018). However, even the slightest change to a routine can spark a tantrum or other challenging behaviors (Hartshorne & Schafer, 2018; Kharwa et al., 2017). Although routines are beneficial because they can effectively manage behaviors, it can be stressful for the mothers to consistently maintain routines while also planning for potential disruptions to such routines (McAuliffe, Vaz, Falkmer, & Cordier, 2017; Ooi, Ong, Jacob, & Khan, 2016).

Transitions. When discussing their stress levels over the past 30 days, some of the mothers described stress related to transitions, which are unique to this population.

These transitions occur when the children transfer from grade school, high school, and into adulthood (Gauthier-Boudreault, Couture, & Gallagher, 2017). According to the Individuals with Disabilities Education Act (IDEA), children between the ages of 3 and 21 years are entitled to a free and appropriate education (FAPE), where they may be provided with services or therapies to help them succeed academically (APA, 2019). The mothers expressed concerns related to new settings, new programs, different schedules, and more limited resources. Although some of the children were years away from turning 21, some of the mothers already feared losing support services and entering the unknown.

Older mothers. There were two mothers in this study who provided care for a CSHCN over the age of 50 years. One of the mothers was married and the other was a widow. It is common for a spouse to help care for a disabled older adult at home so that the individual is not institutionalized (Li & Dai, 2019) but one of the mothers did not have that option. One of her greatest fears was about what would happen to her children should something happen to her. Some research suggested that parents around the age of 65 years showed a decline in both health and psychological well-being (Magaña & Smith, 2006; Olsen, Floyd, Mailick, & Greenberg, 2018; Seltzer, Floyd, Song, Greenberg, & Hong, 2011). However, the transactional model of stress and coping (Lazarus & Folkman, 1984) suggests that these parents adjust to the stress and demonstrate a pattern of resiliency as they age (Namkung, Greenberg, Mailick, & Floyd, 2018; Song, Mailick, & Greenberg, 2018).

Advice to new mothers. It is not always known when a child will be born with a disability and some impairments occur later in life. Studies have suggested that mothers who gave birth to children with an unexpected developmental disability experienced profound and negative influences on their maternal functioning (Counselman-Carpenter, 2016). The mothers in this study were asked about the advice they would give to a new mom caring for a CSHCN.

> P1. Find a place where you can meet other moms with kids with the same disability that your child has. Yeah, we're all moms with kids with disabilities but it's really important to be friends with parents who are going through a lot of the same things.
>
> P2. Don't accept things because then you lose hope and then the chance is gone. No matter how slim the chances, you'd be amazed what holding on to that hope can do, the feeling it'll create and just the motivation you'll have because that hope is there. Once hope is gone, you've got nothing.
>
> P3. Don't be discouraged. Try to get as much as you can for yourself. Family support, outside support. Don't' be afraid to ask for help. I think I was just afraid to ask for help or I just didn't want to. I just wanted to do it all myself.
>
> P5. Fight for your child. Always fight for your child.
>
> P6. Just be that child's mother the best you can. Don't try to be the behavior coach, the OT, PT, or the doctors. Surround yourself with a good team and just be the kid's mom.
>
> P7. Take care of yourself if you can. You're going to feel isolated but don't isolate yourself so much that you don't stay in touch with your best friends. Stay connected and don't feel guilty spending time with yourself.

> P8. Don’t doubt them. Don’t discount them. Don’t count him out. I was told this when my child was a year old and it crushed me but it is the truth. ‘You can be your child’s biggest disability.’ You want to protect them and you want to keep them safe and you want to build this bubble around them but for them to grow, you’ve got to put them out there and push them to success.
>
> P9. You were chosen for a reason. Feel privileged that you were chosen.
>
> P10. Love them for who they are.

Coping Mechanisms Not Including Gratitude

The use of gratitude as a coping mechanism was significantly lacking in this study. The mothers all named at least one thing for which they were grateful but, when asked about ways they coped with stress, none of the mothers referenced the use of gratitude. Despite gratitude being one of the newer coping strategies, researchers have found that teaching individuals to be grateful has led to increased coping abilities in times of distress (Gabana, Steinfeldt, Wong, Chung, & Svetina, 2018; Harbaugh & Vasey, 2014; Krause et al., 2017; Lin, 2016).

When asked about things in their life for which they had gratitude, the mothers provided a variety of responses including: financial stability, health of their children, family, a working washing machine, medical professionals, therapists, and the “opportunity to embark on this journey.” The coping strategies implemented by the mothers were equally varied and included: crying alone in the car, “going with the flow”, going for a walk with her CSHCN, spending time with children, going to the gym, and puzzles. Gratitude has been shown to have a direct effect on quality of life (Valikhani et al., 2019) and, when practiced along with other healthy coping mechanisms, may provide additional benefits.

Evidence of Trustworthiness

While statistical methods are used to establish trustworthiness in quantitative research, qualitative research incorporates methodological strategies to ensure credibility, transferability, dependability, and confirmability (Korstjens, 2017; Levitt et al., 2017; Nobel & Smith, 2015). Unlike quantitative research that is predeterministic in nature and focused on objective measurement, qualitative research emphasizes lived experiences and narratives, which are not measured in the same way as quantitative data (Kei, 2018). This emphasizes the need for a more rigorous approach to enhance trustworthiness and highlight how the outcomes were determined (FitzPatrick, 2019).

As the primary research instrument, I held a unique role in this qualitative study and subjected my decisions, actions, assumptions, and conclusions to the critical assessments that would be applied to any other instrument (Raskind et al., 2018). Prior to this study, I clarified personal biases that may have influenced the findings through comments on my previous experiences, prejudices, and biases that could have potentially contributed to the approach and interpretation of my study (Creswell, 2013; Onwuegbuzie & Byers, 2014). Additionally, I implemented: (a) data triangulation, (b) member checking, (c) rich and thick descriptions, (d) a peer debriefer, (e) an audit trail, and (f) reflexivity (Creswell, 2013; Noble & Smith, 2015; Thomas, 2017; Twining et al., 2017).

Credibility. Credibility was obtained through the use of data triangulation, as I implemented face-to-face interviews, observations, and journaling in order to obtain a comprehensive view of the studied phenomenon (Cope, 2014). Using more than one method or data source enriches the understanding of a phenomenon (Connelly, 2016; Noble & Smith, 2015; Patton, 1999). I also applied member checking by providing the participants with the interview transcripts, primary findings, and themes, which they were encouraged to review and comment on the accuracy (Birt et al., 2016; Creswell, 2014; Varpio et al., 2017).

To further enhance the credibility of this study, I included notes in my reflexive journal that detailed the agreement and recognition of descriptions obtained from individuals who have shared the same or similar experience as the participants (Cope, 2014). I also describe my personal biases, which may have potentially influenced the findings (Nobel & Smith, 2015). Finally, the inclusion of rich and thick verbatim descriptions from the participants supported the findings and increased the credibility.

Transferability. This study included a small sample size, which is fairly common in qualitative research, as it allows for more in-depth responses from each participant (Vasileiou, Barnett, Thorpe, & Young, 2018). The small sample size also allowed for more in-depth member checking to ensure that the intended meanings of each participant were clearly and accurately portrayed (Kornbluh, 2015). The inclusion of contextual details related to the interview site, participants, and recruitment increased the transferability of this study so that it could easily be transferred to additional participants and settings (Rapport, Clement, Doel, & Hutchings, 2015).

The stressors, coping strategies, and perceptions of gratitude were exclusive to the responses provided by the participants in this study. Although this limited the transferability of this study, the rich and thick descriptions of the lived experiences (Kumar, 2018) of the mothers caring for a CSHCN may be of interest to additional comparable populations experiencing high stress levels. These detailed descriptions supported the conclusions drawn and increased the transferability to other people, settings, and phenomena (Amankwaa, 2016).

Dependability. The dependability, or reliability, of a study refers to the consistency of findings across replicated studies with the same participants, in the same context, and with the same methods (Chowdhury, 2015). The dependability of this study was enhanced due to the simple design, which can easily be replicated (Morse, 2015). The design method, participant recruitment, and ways in which the findings were derived were all detailed in the audit trail and can be duplicated by another individual (Connelly, 2016; Kornbluh, 2015). The process used for audio recordings and verbatim transcriptions of interviews along with highlighting and coding can also be replicated with ease.

The dependability of this study was further established through a peer debriefer, where questions about the process and findings of the research were shared (Moon, Brewer, Januchowski-Hartley, Adams, & Blackman, 2016). This allowed for an additional, outside perspective for both the analysis and interpretation of the findings. In addition to reviewing the documents for consistency and authenticity, the peer debriefer also evaluated the accuracy and whether or not the data supported the interpretations and conclusions (Amankwaa, 2016; Lincoln & Guba, 1985).

Confirmability. Confirmability provides evidence that the interpretations are grounded solely on the data and not the preferences or views of the researcher (Korstjens, 2017). Confirmability was increased through the inclusion of my assumptions and beliefs, which explained how the findings were useful while still considering the influence that my position as the researcher may have had on them (Moon et al., 2016). This research began from a neutral premise and the themes emerged from an inductive process of both data collection and interpretation (Ellis, 2016). The detailed methodological section provided additional details related to the data and ways in which the themes emerged (Moon et al., 2016).

To enhance confirmability, I maintained an audit trail throughout each research stage, including clear descriptions of each research step from the beginning of the study to the development and presentation of the findings (Amankwaa, 2016). This included interview transcripts, notes reflecting my assumptions, notes related to data analyses, and final drafts (Cope, 2014; Lincoln & Guba, 1985). I have also documented detailed notes and reflections in a reflexive journal (Hays et al., 2016; Rodham et al., 2015).

Summary

Chapter 4 presented the findings from this phenomenological study in which I explored the lived experiences of mothers raising a CSHCN. The purpose was to explore how mothers raising a CSHCN experienced gratitude. Face-to-face interviews were conducted with 15 mothers who were asked 8 primary questions specific to their unique lived experiences. Data analyses followed Moustakas' guidelines and began immediately with detailed notes, a reflection template, transcription, and coding (Castillo-Montoya, 2016; Creswell, 2014; Crow et al., 2015; Dinçer, 2018; Ranney et al., 2015).

Analysis of the transcriptions revealed nine major themes: (a) support of family and friends, (b) feelings of gratitude, (c) coping mechanisms, (d) life satisfaction/quality of life, (e) gratitude for flexible job, (f) stress related to full dependency, (g) high stress over the past 30 days, (h) increased stress when describing child, and (i) need to work on eating habits. Additionally, two subthemes emerged in Theme 3: non-verbal challenges and behavioral challenges. All above themes answered the research question and emerged solely from the data rather than my preferences or views as the researcher (Korstjens, 2017). Chapter 5 will include an interpretation of the findings, limitations, recommendations, and implications for positive social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative phenomenological study was to explore and better understand the lived experiences of mothers raising a CSHCN and the ways in which they experience gratitude. It can be challenging for the mother of a CSHCN to maintain positive feelings of gratitude because of the stress associated with caregiving and its consequences, which may include decreases in physical health, psychological health, and well-being (Lilly et al., 2012). These consequences of caregiving stress have been shown to be more prevalent in mothers than fathers. A secondary purpose was to identify potential barriers to experiencing gratitude, which, when implemented as a coping strategy, may decrease the negative effects of daily stress and improve mental health (Krejtz et al., 2014).

The conceptual framework for this study was guided by two theories: Fredrickson's (2004) broaden-and-build theory of positive emotions and the transactional model of stress and coping (Lazarus & Folkman, 1984; Pogrebtsova et al., 2017). The synthesis of Fredrickson's (2004) broaden-and-build theory of positive emotions and the transactional model of stress and coping (Lazarus & Folkman, 1984) provides the foundation for developing a better understanding of gratitude among mothers of CSHCN, who experience increased challenges and stressors (Krakovich et al., 2016). Specifically, these two theories strengthened the framework of the study by detailing the associations between emotions, coping, and health (Gloria & Steinhardt, 2016).

A phenomenological approach was used for this study because the intent was to obtain subjective information related to the lived experiences of each individual participant, as well as to explore the meaning assigned to the experience (Adams & van Mannen, 2017; Ellis, 2016; Quay, 2016). Face-to-face interviews were conducted with 15 mothers and lasted 20-40 minutes. The analysis of the participants' rich and thick descriptions revealed nine major themes: (a) support of family and friends, (b) feelings of gratitude, (c) coping mechanisms, (d) life satisfaction/quality of life, (e) gratitude for flexible job, (f) stress related to full dependency, (g) high stress over the past 30 days, (h) increased stress when describing child, and (i) need to work on eating habits. Additionally, two subthemes emerged related to Theme 3: nonverbal challenges and behavioral challenges.

Interpretation of the Findings

Findings from this study add to the existing literature and are consistent with data obtained from additional populations. Data are lacking on the role of gratitude among mothers caring for a CSHCN, and although parents of a CSHCN typically require more replenishment to sustain their health, they often put the needs of their children first and fail to care for themselves (Boston University, n.d.; Huang et al., 2013; Kuhlthau et al., 2014). Results from this study may be used to provide more information specific to the lived experiences of each mother by illuminating gratitude as a beneficial coping mechanism (Nezlek et al., 2017). In addition, information about how to practice gratitude and its associated benefits can be disseminated through a variety of platforms including newsletters, brochures, classes, blogs, and applications.

Theme 1: Support of family and friends. Decreased stress has been documented among parents who maintain contact with other parents raising a child diagnosed with a similar disability through the exchange of social, emotional, and practical support (Abbasi, 2017; Kerr & McIntosh, 2000). This support from family and friends may also increase the resilience of caregivers (Inci & Temel, 2016; Jonker & Greeff, 2009). P2 elaborated on how blessed she was to have unconditional support from her mother, and P1 expressed the importance of finding at least one parent with a child who had a similar diagnosis with comparable strengths and weaknesses.

Theme 2: Feelings of gratitude. Feelings of gratitude include a confirmation of goodness in life as well as an acknowledgment that the sources of such good things lie outside the self, to at least some extent (Emmons & Stern, 2013). Gratitude can be applied to the past by recalling positive memories, the present by appreciating the good in situations, and the future by maintaining an optimistic perspective (Harvard Medical School, 2011). Each mother reported feelings of gratitude and a majority were for a flexible job, as detailed in Theme 5. Additionally, P7 was grateful for her church and P12 was grateful for the therapists who helped her and her child.

Theme 3: Coping mechanisms. Coping among parents is not specific to any single diagnosis within CSHCN (Churchill et al., 2010; Stein & Jessop, 1989). Coping styles vary among individuals and result in different effects on the outcomes of stressors, which primarily include functional status, emotional well-being, and health behaviors (Glanz & Schwartz, 2008). P5 explained that going for a walk either alone or with her child helped her to clear her mind and relax. P9 coped by putting puzzles together, which she then glued, framed, and gave to others as gifts. P14 enjoyed a glass of wine when she was overwhelmed.

Theme 4: Life satisfaction/Quality of life. Gratitude has been shown to decrease material desires, increase life satisfaction, and play an integral role in the maintenance and structure of social relationships (Bryan et al., 2018; Emmons & McCullough, 2003; Lambert et al., 2009). In addition to predicting quality of life among individuals with arthritis (Eaton et al., 2014), gratitude has also predicted both life satisfaction and psychological quality of life in both healthy and unhealthy samples (Rash et al., 2011). P1 explained that she had been told about how horrible everything would be and that she did not experience those negative aspects. She was thrilled with how normal life was for her and her daughter. P2 said that, even if God came down and told her that her she could have her daughter's disabilities removed but that she would not have experienced all that comes along with the diagnoses, she still would not change a thing. She commented that her life, her daughter's life, and the lives of her family were enriched because of the journey.

Theme 5: Gratitude for flexible job. In households where the mother and father both worked full time, 54% of parents reported that the mother dealt more with management of the activities and schedules of the children, with 6% of the fathers doing more, and 39% sharing the responsibility equally (Pew Research Center, 2015). It was also reported 47% of the mothers did more when the children were sick, compared to fathers at 6%, and equal sharing at 47%. Individuals with flexible work arrangements have reported increased work-life balance, lower burnout, and improved physical, emotional, and psychological wellbeing (Dizaho et al., 2017; Medina-Garrido et al., 2017; Uglanova & Dettmers, 2018). P9 described the stress and challenges she had experienced in previous jobs that did not allow schedule changes. P12 explained how appreciative she was to have a job that allowed her to adapt her schedule to care for her son, who had been getting sick more often than in the past.

Theme 6: Stress related to full dependency. Mothers providing care for a chronically ill child often struggle to balance domestic responsibilities with those associated with the unique needs of the child, which may lead to increased stress resulting in both chronic and acute physical disorders, depression, isolation, financial turmoil, and self-accusation (Macedo et al., 2015). Children with disabilities typically require extra help with daily living tasks and often continue to require this care as they age (Luijkx et al., 2017; McCann et al., 2012). P2 described significant stress from providing full assistance to her daughter for all daily living skills while also caring for herself and her younger son. P7 expressed frustration over waking up hours earlier than she would typically have to because her daughter was unable to groom herself or independently perform any of the morning routines necessary to get ready for school.

Subtheme 1: Nonverbal challenges. Children who are nonverbal and do not have any other communicative modality are often unable to exchange feelings, thoughts, and ideas with others (Metsala, Galway, Ishaik, & Barton, 2017). A child who is not understood by others may exhibit more extreme behaviors or shut down completely due to frustration (Hartshorne & Schafer, 2018). P13 detailed the horrible ways in which her daughter had been treated by an individual who knew that they would not be “told on” due the child being nonverbal. P15 described how badly she felt each time her son threw a tantrum because he could not effectively communicate his wants and needs.

Subtheme 2: Behavioral challenges. The degree of challenging behaviors exhibited by the individual receiving care influences the severity of impacts on the caregiver (Fairthorne et al., 2016). Parents may experience increased stress when caring for a child who demonstrates challenging behaviors (Argumedes et al., 2018). P3 said that her son bit and hit when he got mad, especially because he lacked the ability to functionally express his anger and frustration. P5 explained that her son did not intentionally hurt her but that he had pushed her when he was upset.

Theme 7: High stress over the past 30 days. Chronic and unmanaged stress have been correlated with the development, preservation, and exacerbation of serious physical and mental health ailments as well as premature mortality and accelerated biological aging (Holt-Lunstad et al., 2010; Slavich, 2016). In addition to the varied ways in which individuals experience stress, stressful events also vary in predictability, controllability, and pleasantness (van der Stouwe et al., 2019). P7 described many stressors related to the unknown as her daughter entered the adult world. P8 explained stressors related to the severity of her daughter's terminal illness and the numerous health issues associated with it.

Theme 8: Increased stress when describing child. Previous research has found that parents of children with a disability believed that certain disabilities were viewed as less acceptable than others, and these parents often advocated quite strongly for a label that they considered to be less stigmatizing than what a medical professional had diagnosed (Lalvani, 2015). Other parents have reported feeling disregarding by others when describing the unique needs of their child and advocating for therapeutic services and education (Ryan & Quinlan, 2017). P8 explained that her stress increased when she described her child because it reminded her of how real the situation was and brought to light the fact that her daughter's health was progressively deteriorating. P11 described the stress associated with the diagnosis of her son and the ways that others automatically associated him with other individuals with the same diagnosis.

Theme 9: Need to work on eating habits. Stress can result in skipping meals or engaging in emotional eating, which frequently involves the consumption of unhealthy foods (Araiza & Lobel, 2018; Leow, Jackson, Alderson, Guelfi, & Dimmock, 2018). High stress levels have been associated with unhealthy diets and, when compared with a control group, mothers of children on the autism spectrum were found to have higher reward-related eating habits both at the baseline and 2 years later (Radin et al., 2019). P7 explained how she ate when she was stressed and indicated that it provided comfort for her. P12 acknowledged that she often forgot to eat because she was constantly ensuring that her son had everything that he needed. Considering that the diet of a child is highly influenced by the diet of the caregiver (Robson et al., 2016), the stress-related eating responses of the mothers may impact their health as well as the health of their children.

Conceptual Framework

The broaden-and-build theory (Fredrickson, 1998, 2004) was used to frame and explore the phenomenon of gratitude among mothers raising a CSHCN who face unique challenges, as this theory emphasizes the ways in which stressful experiences provide a means for broadening the appraisal, which facilitates personal growth and transformation (Garland et al., 2015). Studies have found that gratitude interventions elicited the acquisition of positive resources including optimism, connection with others, and life satisfaction (Fredrickson, 2004; Kerr et al., 2015). Each of the mothers reported a strong connection with at least one other individual and, although the mothers described numerous stressors, each mother was satisfied with her life and would not change her situation because she felt that the unique challenges associated with the child were part of what made her life and her child so special.

The transactional model of stress and coping (Lazarus & Folkman, 1984) was applied to the mothers in this study to specifically focus on the appraisals given to constant stressors experienced in daily life with an emphasis on the coping mechanism chosen for each stressor (Riley & Park, 2014). While many of the stressors were similar among the participants, the coping strategies were varied. Each mother reported at least one coping mechanism that was implemented on a regular basis. These included gardening, painting, running, playing video games, and having a glass of wine. Although each mother acknowledged the importance of effective coping mechanisms, the primary reason for not engaging in them regularly was related to not having enough time.

Limitations of the Study

Although each participant was assured that all data would remain anonymous, unintentional biases may have been present as a result of social desirability, in that participants may have feared being portrayed negatively (Navarro-González et al., 2016). In order to address the potential limitations and enhance the trustworthiness of this study, I clarified personal biases and previous experiences that may have influenced the approach and interpretation of the results (Creswell, 2013; Onwuegbuzie & Byers, 2014). Additionally, I implemented: (a) data triangulation, (b) member checking, (c) use of rich and thick descriptions, (d) peer debriefing, and (e) an audit trail (Creswell, 2013; Noble & Smith, 2015; Thomas, 2017; Twining et al., 2017).

Recommendations

Although unmanaged stress has been associated with a variety of neuropsychiatric disorders (Albrecht et al., 2017), cardiovascular disease (Esler, 2017), depression, isolation, and physical disorders (Macedo et al., 2015), implementing positive coping strategies can be advantageous for psychological adaptation and stress reduction (Kourakos, 2017). Each of the mothers in this study listed at least one thing for which she was grateful. However, none of the mothers reported using gratitude as a coping mechanism. Future research could investigate the influence that gratitude-based coping has on stress levels and well-being when added to an already current positive coping strategy. Intervention based research could focus on training mothers with CSHCN about how to effectively implement gratitude as well as how to measure the effects it has on stress and related health outcomes.

Participants only included mothers because the current literature documents women as the primary caregivers in families regardless of ability, disability, or age of the family member receiving care (Osafo et al., 2017; Sharma et al., 2016). Research also suggests that women have increased stress-related health risks when compared to men (Cohen & Janicki-Deverts, 2012). Future research could focus on how men who assume the role of primary caregiver experience gratitude. Future research could also address a qualitative comparison of the stressors of parents with nonverbal CSHCN versus CSHCN who are verbal as well as CSHCN with behavioral challenges versus CSHCN without behavioral challenges. It may also be beneficial to examine the challenges of providing care and advocating for CSHCN at different stages of life, such as infant, toddler, teenager, and adult.

A review of multiple phenomenological studies revealed the mean sample size of 21 participants (Guetterman, 2015). Due to the small sample size of this study, the needs of the mothers were quite varied and inconsistent. Each mother reported a very different need. Examples included larger seats in shopping carts, support groups for siblings, alternative means of transportation for therapies and activities, more vocational training, and more resources for each life stage of the child. It is recommended that future research have larger sample sizes and a specific focus on the needs of mothers raising CSHCN.

Implications

For this qualitative phenomenological study, 15 mothers raising a CSHCN participated in face-to-face interviews and were asked about their experiences as they related to the research questions. The conceptual framework for this study was guided by Fredrickson’s (2004) broaden-and-build theory of positive emotions and the transactional model of stress and coping (Lazarus & Folkman, 1984), which strengthened the framework of this study by detailing the associations between emotions, coping, and health (Gloria & Steinhardt, 2016). This study was guided by four research questions:

1. For which aspects are mothers raising a CSHCN most grateful?

2. What are the major challenges/stressors faced by mothers raising a CSHCN?
3. What major coping styles are employed by mothers raising a CSHCN?
4. In which ways do gratitude, challenges, and coping styles contribute to quality of life among mothers raising a CSHCN?

It was originally posited that findings from this study could produce sustainable social change by affirming gratitude as an effective coping strategy (Nezlek et al., 2017) and could provide details related to preventative care that multiple populations might implement. Although the mothers in this study did not specifically report using gratitude-based coping, each mother named at least one thing for which she was grateful, without hesitation. In spite of unique and sometimes extreme stressors, the mothers saw positive aspects in their lives. The findings from this study indicated that women faced with many stressors can still be grateful and experience a high quality of life.

Previous research has shown that gratitude influences perceptions of stress and may ultimately decrease stress levels while increasing well-being (Lee et al., 2019; Wood, Maltby, Gillet, & Linley, & Joseph, 2008). The findings from this study support such research and may also be applied to other populations, especially those in highly stressful environments. This is important because it may facilitate a quick recovery from both acute and chronic stressful situations. Studies have also shown that grateful individuals are typically more hopeful about the future (Krause, Emmons, & Ironson, 2015), and each mother in this study talked about specific things that she was looking forward to in the future.

Conclusion

Gratitude is an effective coping strategy with numerous benefits (Valikhani, Ahmadnia, Karimi, & Mills, 2019) that can easily be implemented by a diverse group of individuals. As this subject continues to gain more attention, research from just the past 6 years has already shown a significant, negative association between gratitude and anxiety (Zhang, Mou, Tong, & Wu, 2018), depression (Lin, 2015a; Tullbure, 2015), high-risk behaviors (Ma, Kibler, & Sly, 2013), and PTSD symptoms (Van Dusen, Tiamiyu, Kashdan, & Elhai, 2015). Additionally, a significant, positive association has been documented between gratitude and well-being (Hill et al., 2013), life satisfaction (Chen, Wu, & Chang, 2017), hope (Loo, Tsai, Raylu, & Oei, 2014), and self-efficacy (Mills et al., 2015).

This study contributes to the current literature by identifying the ways that mothers caring for a CSHCN experience gratitude and highlighting unique stressors faced by this underrepresented population. The current literature primarily focuses on caregivers for family members with illnesses such as dementia (Chen et al., 2019; Fonareva & Oken, 2014), brain injury following combat (Brickell et al., 2019; Hahn et al., 2019), stroke (Badaru et al., 2019; Christensen, Golden, & Gesell, 2019), and those at the end of life (Lewis et al., 2019; Maura et al., 2019). Findings from this study were different because the focus was solely on mothers raising a CSHCN, who were specifically studied because women caregivers are more likely than men to experience decreased physical and mental health in addition to diminished well-being (Björquist et al., 2016; Musick et al., 2016; Sirois & Wood, 2017).

At some point in time, the majority of people throughout the world are likely to encounter situations and stressors that they cannot control (Riley & Park, 2014). Stress is highly influenced by the perceptions that an individual has toward that stress (Jones, Mendenhall, & Myers, 2016), and those with a positive outlook are typically happier, are more satisfied with life, have fewer health problems, and have more energy (Crum et al., 2013; Jans-Beken et al., 2019). It is encouraging to think about gratitude being implemented to help others improve multiple areas of their lives, free of cost, and in any location, as gratitude has the potential to help individuals of all ages, all ethnicities, and all abilities.

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Appendix A: Guiding Interview Questions

1. Explain and describe for me your experiences over the past 30 days as a mother caring for a child with special health care needs.
2. How would you describe your child to someone, like a new teacher, who has not yet met him or her?
3. In general, how would you describe your overall physical health and mental health today or within the past few days?
4. When you feel overwhelmed, what are some of the strategies you use?
5. Explain and describe for me the primary strategies you use that make you feel good.
6. What does the term gratitude mean to you?
7. Can you tell me what specific resources have been most effective for your raising a CSHCN?
8. Is there anything else you would like to add before we conclude the interview?

Appendix B: Invitation Flyer

Invitation Flyer

Would you like to share your story about your experiences as a mother caring for a child with special health care needs?

You may be eligible for this study if you:

- Are a mother of at least one child with special health care needs
- Are at least 25 years of age
- Speak English proficiently
- Live in Arizona

What's the Purpose?

The purpose of this study is to describe the experiences of mothers raising a child with special health care needs. The study will focus on your personal experiences and will address stressors, coping strategies, gratitude, and challenges you face.

What Will You Be Asked to Do?

If you agree to take part in this study, you will be asked to complete a form about your child, who will not be identified, and then participate in one audio recorded interview that will last approximately 20-40 minutes. The interview will be an interactive discussion about your experience as mother caring for a child with special health care needs. The interview will take place in a private room at the clinic at a time that is convenient for you.

All information will be confidential and used solely for the purpose of understanding the experiences of mothers caring for a child with special health care needs.

This research project is part of a dissertation study being conducted by Keli Kleindorfer, a doctoral student at Walden University. You may already know the researcher as a Speech Language Pathologist, but this study is completely separate from that role.

If you are interested in participating, please contact Keli Kleindorfer at
xxx-xxx-xxxx or xxx.xxxx@waldenu.edu
Thank you for your time and consideration!