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Perceptions of Well-being and Coping Mechanisms from Caregivers of Individuals with Autism

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Walden University
2019

Abstract

Perceptions of Well-being and Coping Mechanisms from Caregivers of Individuals with

Autism

by

Barbara Ann Simmons

ASN, Darton State College, 2010

MSN, Walden University, 2014

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Caregivers of individuals with autism often report increased levels of stress and a lack of social support to help them cope with various stressors as they provide care. Without coping mechanisms or social support, as individuals with autism present various behavioral and emotional challenges, caregivers can experience a decline in well-being. Thus, the purpose of this qualitative study was to explore the processes that caregivers of individuals between the ages of 9-18 diagnosed with autism use to cope with stress and social support in Southeast Georgia. Grounded theory was used to describe the perceived thoughts caregivers have about stress and well-being and how they gain control over their situation through adaptation. Individual semi-structured interviews were used to collect data from 20 caregivers of children (ages 9-18) with at least a moderate to severe autism spectrum disorder. Findings reveal that caregivers used problem-focused coping in the identification of stressors that impacted them physically and emotionally. The degree to which stress impacts a caregivers' life is dependent on the way caregivers respond to the stressor. Because coping strategies play a role in response to stress, those strategies led to the development of a theoretical model that aim to understand the processes that generate a response to stress. Data were coded and organized into themes using open and axial coding procedures; a theory was then generated using selective coding, yielding a theory of caregiver coping processes. The improved understanding of the challenges that caregivers face as they provide care for individuals with autism holds potential to minimize the negative outcomes of stressors and harness the potential for more positive coping mechanisms to improve caregiver well-being and promote positive social change.

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Dedication

This study is dedicated to all those who have assisted and supported me on my academic journey and ultimate goal of becoming a researcher in the field of nursing. To my children, Elishia, Keyshia, Jontavius, and Kempton, who have always provided a constant reminder throughout the years that I can do anything. To my loving grandchildren, Khalil, Kirstyn, and Kaelynn, as their love, comfort, patience and positive attitudes helped to make the stress of this journey bearable. I also dedicate this project to our caregivers and families in Southeastern Georgia, whose time and participation in the project will be beneficial to the larger autism community and future families in Georgia raising and caring for individuals with autism. Your support is greatly appreciated along my journey.

Acknowledgments

I am grateful to everyone who listened, critiqued, prayed for me, and supported me along the way, especially my children Elishia, Keyshia, Jontavius, and Kempton. I am also appreciative of the guidance I received from Dr. Eric Anderson (committee chair), Dr. Margaret Harvey (committee member), and Dr. Janice Long (URR). Also appreciated are my previous committee chair Dr. Janice Belcher and Dr. Debra Wilson (URR). I would never have been able to complete my dissertation without the help, advice, and support of each one of my dissertation committee and family members.

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Chapter 1: Introduction to the Study

Introduction

Due to the social and behavioral challenges presented by individuals with autism, caregivers can face increased fatigue and stress as well as a decline in mental well-being based on the severity of autism that the individual cared for presents (Autism Society, 2014; Centers for Disease Control and Prevention [CDC], 2016; Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014). Ranging from 8.2 to 24.6, the prevalence per 1,000 children shows that more people are being diagnosed with the disorder, and as of 2016, one in 68 children were identified with autism across the United States (CDC, 2016). As the prevalence of autism continue to rise, informal caregivers face the challenges of caring for individuals with autism. With various changes and disruptions in their everyday lives, caregivers have reported consistently high levels of caregiver burden (Cadman et al., 2012; Myers, Mackintosh, & Goin-Kochel, 2009).

This qualitative research study was conducted to explore the experiences of caregivers as they provided care to those with autism spectrum disorders. In addition to dealing with the communication, learning, and behavioral challenges presented by the individual with autism, caregivers often face other challenges with the social interactions and comorbidities that occur in addition to autism. The prevalence of individuals diagnosed with autism across the United States is discussed in this chapter as well as a background on autism spectrum disorders and the challenges that caregivers face as they provided care for the individual.

Background

Autism is a complex condition that has often been associated with children versus adults. This association can be attributed to studies that have been focused on interventions toward the learning and communication disabilities of school-aged children. Individuals diagnosed on the autism spectrum typically experience various life-changing effects that caregivers strive to manage (Autism Society, 2014). Although there has been progress toward addressing the needs of autistic individuals, care can be challenging because of the nature of the behaviors that the individuals present (Benton & Johnson, 2014; Cadman et al., 2012). According to the American Psychiatric Association (2015), autism has been identified as a complex neurological disorder that affects communication, learning, and social functioning, though this is dependent on the severity of autism. With the 2013 DSM-5 manual, a severity rating for the disorder was added with three levels of severity (see Appendix A): Level 1 requires support (repetitive behaviors that may interfere with daily functioning), Level 2 requires substantial support (high levels of distress or frustration may occur for the autistic individual), and Level 3 requires very substantial support (it is very difficult to redirect the autistic individual; Autism Speaks, 2017). Lower functioning autism refers to individuals who fall into the severe categories of autism spectrum such as Level 3, and multiple impairments may be found in all areas of development. Autistic individuals face various challenges ranging from issues adjusting to sensory problems to difficulties in behavior. As these challenges arise families and caregivers are also affected by these challenges.

Psychosocial and behavioral challenges can impact the mental well-being of caregivers by causing an increased level of stress, decreased well-being, and a sense of lack of support. As a result, caregivers may experience isolation in providing care to the autistic individual (Autism Society, 2014). Autism remains as an incurable condition that has no boundaries, and caregivers face multiple behavioral and psychosocial challenges that are exhibited by the individual with autism that contribute to a decline in well-being for the caregiver. There has been a focus on the development of interventions on coping with the autistic individual, but measures must also be implemented that will ensure an enhanced understanding related to the challenges that are faced by caregivers as they provide care to the individual. An interdisciplinary approach must be taken to address not only these challenges, but focus must also be placed on other conditions that exist as health care professionals gain a better understanding of the needs of the caregiver and the individual with autism. Thus, this study helped examine factors that may contribute to caregiver stress such as caregiver gender, severity level of autism, status of caregiver (informal/holding a job), primary responsibilities of caregiving, and supports used to cope with challenges (Autism Society, 2014). For this study, caregiver perceptions of social support and coping mechanisms were explored among caregivers of individuals with autism in Southeast Georgia.

Caregiver stress and the negative outcomes that can decrease the well-being of those caring for individuals with autism have been described by various researchers. For example, Sullivan et al. (2011) stated that the collaborated efforts of health care professionals can make a significant contribution that will increase the well-being of

caregivers and autistic individuals. Crais et al. (2014) also conducted a review on the perceptions of primary care providers' and their hesitancy to screen autistic individuals who fell between 12 and 18 years of age. The results were beneficial to communities and providers as they strived to ensure that the needs of the caregiver were met. Additionally, the autistic individual may receive and optimal level of care when the caregiver is at an optimal level. In reviewing levels of care, Raina et al. (2004) linked care to the negative impacts on caregiver well-being. Findings of the study revealed that variations existed in the way caregivers adapted to stressors. A more recent study conducted by Huang et al. (2014) indicated how caregiver stress was influenced by certain behaviors that were manifested in those diagnosed with autism, showing how caregivers experienced stress at different levels depending on the severity of autism of the individual.

In another study, researchers described the impact of caregiving on parents of children on the autism spectrum (Hoefman et al., 2014). It was found that caregivers experienced problems such as depressive moods and financial problems when they attempted to combine the daily routines of life with caregiving. As parents met the high care demands of children with autism, it required a large amount of time, effort, and patience. Meeting these demands often resulted in psychological distress, depression, anxiety and other mental or physical problems among parental caregivers (Hoefman et al., 2014).

Based on the findings of these studies, health care providers do not have as much information or as many treatment options available for individuals at the opposite end of the autism spectrum. Due to this gap in knowledge, additional research was warranted

that will provide a more enhanced understanding of the processes the caregiver use to adopt effective coping mechanisms that will improve well-being for the caregiver.

Problem Statement

Due to the social and behavioral challenges presented by individuals with autism, caregivers can experience fatigue, stress, and a decline in mental well-being based on the severity of autism the individual has (Autism Society, 2014). The assertion has also been made that there are psychological stressors that stem from the inability to socialize, and this inability can also evoke a sense of isolation for the caregiver (Autism Society, 2014). Despite previous research that caregivers require increased support compared to other disorders (Bromley, Hare, Davison, & Emerson, 2004; Muller, Schuler & Yates, 2008), coping mechanisms and the well-being of caregivers must be addressed (Khanna et al., 2011).

Previous qualitative studies have been focused on addressing the experiences faced by those providing care for persons with autism; however, findings are inconsistent (Estes et al., 2009; Weiss & Lunsky, 2011; Zhou & Yi, 2014). There has also been a lack of qualitative research on the processes caregivers use to adopt coping mechanisms that will enhance the well-being of caregivers of individuals with autism (Ji et al., 2014). There is a lack of knowledge related to the challenges that the caregivers of individuals on the opposite end of the spectrum face (lower functioning autism) and ways of helping caregivers to manage those challenges. Identifying factors that contribute to stress and a lack of social support can enhance the well-being of the caregiver as they learn to adopt

coping mechanisms and receive adequate social support (Seymour, Wood, Giallo, & Jellett, 2013).

Purpose of the Study

The purpose of this grounded theory study was to explore the processes that caregivers of individuals between the ages of 9-18 years diagnosed with autism used to cope with stress and social support in Southeast Georgia. This study provided an enhanced awareness of the concepts used to improve the understanding among health care professionals about necessary approaches that will enhance the well-being of caregivers. The goal of the study was to discover a substantive theory (Glaser & Strauss, 1968/2009) to identify the stress and coping mechanisms that caregivers for individuals with autism face and the processes they use to enhance their own well-being as they care for those with autism.

Research Question

For this grounded theory research, the questions of inquiry contributed to the examination of the perspectives that each participant had regarding the factors that contributed to distress in their daily lives. Other research questions were focused on generating a theory that would aid in explaining the processes that participants viewed as an influence to the perceptions of caregiving stressors. The following questions stemmed from the central question and explored the related factors and challenges that caregivers faced:

Research Question 1: How do caregivers of individuals with autism perceive their well-being?

Research Question 2: How do caregivers of individuals with autism use coping

strategies to maintain an optimal level of well-being?

Research Question 3: What beliefs influence caregivers of individuals with autism

in adopting effective coping strategies?

Theoretical Foundation

Grounded theory was chosen as the appropriate methodology to generate a theory

from the study. Grounded theory was developed by Glaser and Strauss (1968/2009)

through the constant comparison of collected data. The method is differentiated from

variations that were developed by Strauss and Corbin, (1998) and Charmaz (2006).

Glaser (2009) described Charmaz's (2006) method as a full conceptual description that

does not allow for the true emergence of theory, but rather theory is derived from

preconceived ideas that have no objective data for comparative analysis or triangulation.

As theory was generated and the processes of interest were described as it

occurred, theoretical sensitivity was incorporated in the review of other studies related to

this research study. Theoretical sensitivity provided a guide during this study as theory

emerged during the collection of data. In the collection of data, this exploration focused

on creating meaning from those perspectives to develop a framework of a theory that

would explain the processes that caregivers used to cope with stress. This study used a

qualitative research method that used surveys and 45 minutes to 1.5-hour interviews with

approximately 20 participants to promote an in-depth exploration of the daily experiences

of caregivers of individuals (ages 9-18) with autism spectrum disorder and their

perspectives on social support and well-being.

Nature of the Study

Using a qualitative approach with a grounded theory as described by Corbin and Strauss (2015) aided in identifying themes and categories that described the challenges faced by informal caregivers as they provided care to individuals with autism. Focusing on social support for caregivers and the psychosocial characteristics that influenced caregiver behaviors, surveys and interviews consisting of approximately 20 participants were conducted to collect data. By using interviews with open-ended questions, I sought to gain a better understanding of the factors that may contribute to increased levels of stress and a decreased level of well-being for caregivers. A semi-structured interview guide was used to help me to focus on the processes being studied. Grounded theory allowed for the emergence of themes and categories as theory was generated. This aided in explaining how practice can implement interventions that will aid in improving the issues that have been identified.

Because the purpose of the study was exploratory to generate a new theory that would explain the processes used to adopt effective coping mechanisms, a grounded theory qualitative study provided the most effective tool to help improve understanding of the unique perspectives of those providing care to an individual with autism. Reflexivity was an important element of grounded theory (Creswell, 2009), so memos were used in the exploration of my thoughts and reactions while engaging in the comparative analysis of data, participant interviews, data collection, and interpretation (see Patton, 2015). Memos allowed for immersion in the data and guided the direction of the research that led to the development of theory (Patton, 2015). Purposive theoretical

sampling was used in the selection of caregivers who provide care to individuals on both ends of the autism spectrum that was inclusive of various levels of communication skills, behavioral issues, and ages 9-18. This type sampling was based on the participants' potential contribution to the development of theory (Creswell, 2013). The final number of participants was determined by the number of participants needed to reach saturation of the data. Once saturation was obtained, line-by-line coding was used to analyze data.

Definitions

Caregiver stress: Lazarus and Folkman (1984) defined stress as a relationship between the individual and the environment and is appraised by the person as a burden that exceeds their resources to adopt effective coping strategies that will eliminate the likelihood of their well-being in danger. *Caregiver stress* refers to an individual who provides care and experiences tension during the provision of that care. The meaning of stress is derived from factors that disrupts a balance in their life.

Coping: As caregivers experience increased levels of stress during care for those diagnosed with autism, there are also various methods of coping that can decrease the negative effects of stress. For this study, coping refers to the way caregivers respond to an event that causes stress. In responding to stressful events, it requires adopting effective strategies that will lessen the threat of stress. When effective coping strategies are used, caregivers can manage stress that exceeds their resources (Lazarus & Folkman, 1984).

Informal caregiver: This term refers to family members and friends who are involved in the daily task of providing care to someone who is ill. This individuals task

goes beyond the scope of providing physical care. The informal caregiver also manages financial, legal, and coordinated formal care as well.

Assumptions

In this study, one assumption was that the processes used by caregivers to adopt coping strategies to enhance their well-being could best be understood by exploring the perspectives of caregivers who had experienced the challenges of providing care to an autistic individual. It was also assumed that the participants in the study would be able to adequately recall past experiences of the processes they had used and would be able to convey those experiences through interviews. In choosing grounded theory, it was also assumed that the chosen method would be a successful means of understanding caregiver processes. The belief was that in abstractly exploring the concepts a richer theory would emerge versus a description of the experiences for this unique group of participants. The theory that would be true to the experiences of caregivers who provide care to autistic individuals rather than a theory that has been co-constructed by the participants and the researcher. Another assumption was that caregivers faced unique challenges as they provided care to an individual diagnosed on the autism spectrum and that those challenges were worth exploring aside from interventions for the autistic individual and the development of new programs. Reliance was placed on the chosen participants in the study to provide the context of their experience within the overall caregiving experience. The final assumption in this study was that the participants would be honest and open as they shared their experiences.

Scope and Delimitations

The study addressed the perceptions that caregivers of individuals with autism have of the meaningfulness of well-being for themselves, the influence their perceptions have had on the choices they make, and how their perceptions of the meaningfulness of their well-being affected their behavior in the daily routines of life. Because the perspectives of the caregivers are the focus of the study, an attempt was made to verify that the responses about the experiences of providing care were accurate descriptions provided by the participants of the study.

Limitations

In acknowledging limitations in this study, sample sizes were relatively small as samples were limited to a select few families and caregivers of autistic individuals in the state of Georgia. Due to the characteristics of the sample size, generalizability of the findings will not occur (Creswell, 2013). The findings of the study may not be representative of all caregivers of individuals diagnosed on the autism spectrum because the study will be limited to a selected county in Southeast Georgia. The present study was also focused on a selected age group that is not representative of all individuals found on the autism spectrum. Studies have shown that limitations exist in small sample sizes, selection bias, and issues with generalizing results. Because generalizability was not being sought, weaknesses were addressed by ensuring that enough detailed data had been gathered to saturate the emergent themes within the study. Open-mindedness was a goal so that the emergence of themes would occur with influence from me (Creswell, 2013).

Limitations can also exist due to problems stemming from the interviewing protocol. Problems can arise if the interviewer allows for the responses to potential open-ended interview questions get too far off-topic. To address this issue, an interview guide was employed. The potential for interpersonal dynamics can also exist whereby the interviewer may influence the quality and quantity of responses. In qualitative studies, the building of rapport, empathy, respect, and trust with the interviewee plays an important role during the interview process (Patton, 2015).

Significance

As the prevalence of autism continue to rise, formal and informal caregivers of individuals on the autism spectrum face the challenge of caring for these individuals. In addition, factors such as stress, fatigue, and decreased mental well-being increases as care is provided (CDC, 2016; Moodie-Dyer et al., 2014). On a continuous basis, caregivers of persons with autism constantly experience change and disruption in their everyday lives (Myers et al., 2009). Caregivers have reported a consistently high level of caregiver burden which included a decline in mental well-being and inappropriate behaviors in caring for those with autism (Cadman et al., 2012).

The study filled a gap by identifying ways of coping that affected informal caregivers who provided care for autistic individuals between the ages of 9 and 18 in Southeast Georgia. In addressing the challenges of stress, social support, and coping mechanisms where minimal research has been focused on caregivers of individuals with autism, the study supported the theoretical perspectives of adaptation mechanisms that will address increased stress levels, and how a lack of or absence of support can affect

caregivers. By addressing these problems, a more enhanced understanding can be gained on how decreased stress levels, adequate support, and appropriate care can enhance well-being for the caregiver. Additionally, by implementing a holistic approach, evidence was provided to ensure that caregivers would receive needed support so that they can provide the best possible care for individuals with autism (see Crowe & Salt, 2015).

Significance to Practice

Results of the study can be used as a guide in establishing strategies that can reduce stress levels such as anxiety or financial difficulties that are experienced by caregivers. In developing techniques to adapt to stress, key factors (behavioral or emotional) that have contributed to increased stress levels, fatigue, and decreased well-being can be reduced or alleviated. Bringing about an awareness of these issues will also create an ability for caregivers to achieve new insights on these challenges as they seek needed support.

Significance to Theory

In both natural and social sciences, research aims to describe, understand, and explain reality (Patton, 2015). Qualitative inquiry is empirical research to the extent that the inquiry deal in the data of experience (Schwandt, 2001). The challenges that are faced by caregivers as they provide care to the individual with autism was addressed empirically by providing and understanding into what processes are used to cope with stressors and how the caregiver transition through those processes to reduce the chance of experiencing negative outcomes during the provision of care for the individual with autism (see Patton, 2015).

Significance to Social Change

Evidence-based knowledge provided by research aids in positive outcomes (Dykens, Fisher, Taylor, Lanbert, & Miodrag, 2014). The implications for positive social change include a better understanding of the challenges that caregivers face as they provide care for individuals with autism, minimizing the negative outcomes of stressors, and creating the potential for more positive coping mechanisms that will improve caregiver well-being. The gradual influence of evidence-based knowledge provided by research will bring about outcomes that will guide change in a positive manner (Dykens et al., 2014) as the caregiver seek resources to improve their well-being.

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Summary

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Although the challenges that caregivers of individuals with autism face has been linked to increased levels of stress, a lack of knowledge remains about how the perceptions of adopting coping mechanisms to enhance caregiver well-being, how these perceptions influence the choices that the caregiver makes to improve their well-being, and the potential effects that stress and social support may have on the caregiver. Although current research addresses some of these issues, either the underpinnings or format of existing studies have not given meaning to the unique perspectives of the caregiver from various regions, particularly in the Southeast region of the United States. Before discussing the perceptions that caregivers have of the influences that stress and social support have on the meaningfulness of well-being in their lives, Chapter 2 addresses the differences in how caregiver stressors and the meaningfulness of well-being

is defined and the perceived influence the outcomes of research may have on the

perspectives of the caregiver.

Chapter 2: Literature Review

Introduction

The purpose of this study was to explore the social support and processes that caregivers of individuals between the ages of 9-18 years diagnosed with autism used to cope with stress in Southeast Georgia. Grounded theory was used for a constant comparison of data and theoretical sampling to obtain relevant data to generate a theory. Meaning was inductively derived from the collection of data from the caregivers' processes that they shared in interviews. The purpose of the literature review was to provide a more in-depth understanding of the challenges that caregivers face as they provide care to individuals with autism. This literature review demonstrated the importance of studying the perspectives of the caregiver and how positive coping mechanisms can enhance their well-being. Based on the literature, some factors influencing caregiver stress and well-being are the autistic individual's behavioral challenges and caregiver perceptions of appropriate social support (Cappe, Wolff, Bobet, & Adrien, 2011; Weiss & Lunsky, 2011). Findings in literature provided a lens for understanding how the caregivers perceived stress and social support and how processes used to cope with these stressors influenced the caregiver's behavior to maintain an optimal level of well-being (Seymore et al., 2013).

In this chapter, the literature review reveals a lack of adaptation mechanisms and emphasizes the need to expand research on how caregivers adopt coping mechanisms to meet challenges while providing care for individuals with autism. Before beginning the review of relevant literature, a brief explanation will be given on the organization of the

review, planning in the search for literature related to the topic, and how literature was used in grounded theory approaches.

Literature Search Strategy

In the selection of a grounded theory design, a full review of literature was delayed until the collection of data and the analysis of the data had been almost completed. It has been suggested by Glaser and Strauss (1968) that literature should not be relied on until the researcher has reached the point of generating theory. This deferment of a full review of literature is aimed to alleviate any preconceptions of concepts and influences that may contaminate the collection of data. Core variables are the basis of theory development, and a premature review of literature has the possibility of introducing preconceived ideas into the theory (Glaser & Strauss, 1968). These preconceived ideas can prevent the researcher from recognizing the main concepts that emerge from the data. Once theory has been grounded and generates from the data, then a review of literature is conducted through the integration of ideas (Glaser & Strauss, 1968).

To develop a background in the literature, a search related to caregiver stress and autism was initiated. Some of the studies consisted of surveys, questionnaires, and interviews with caregivers to gather enough information that would be representative of the phenomenon under study. A search was conducted through various databases such as CINAHL, Medline, ProQuest, and Google Scholar. Key terms to search for literature included *autism spectrum disorder* OR *autism, caregivers* AND *stress, challenging*

behaviors AND *autism, caregiver burden, parental stress* AND *caregiver stress, social*

support, isolation, parenting styles, emotions, stigmatism, and coping mechanisms.

Most of the peer-reviewed journal articles and dissertations reviewed in this study

were conducted through comprehensive searches using other databases and sources such

as PsycARTICLES, PubMed, SAGE, and eBooks. Some terms and phrases that were

used in the search began to show up repeatedly: *caregiver stress, coping, social support,*

and autism. To expand the search, sources from the references in articles and discussion

in articles were examined. Researchers (Corbin & Strauss, 2015; Glaser & Strauss,

1968/2009) who played a key role in the referenced studies contributed to a further

understanding of the challenges faced by caregivers of autistic individuals.

Theoretical Foundation

In using a grounded theory approach, the review of literature was not used in the

construction of a theoretical framework to interpret the processes under study (Glaser &

Strauss, 1968). Using an existing theory as a lens to guide the study would have

contradicted the chosen methodology, because grounded theory is used to generate a

theory directly from the data (Creswell, 2013; Timmermans & Tavory, 2012). Relevant

literature was incorporated into the study during the interpretation stage, versus

incorporating literature prior to the beginning data collection. A preliminary literature

review was conducted to provide general background information on the topic area,

helping to justify the need for the study. Previous literature that justifies this study

included: (a) research about how the meaningfulness of addressing increased stress levels

and coping mechanisms has been defined and studied, (b) contextual factors that may

play a role in shaping perceptions of caregivers regarding social support, (c) the potential

impact the perceptions of stress and social support have on the meaningfulness of

adopting effective coping mechanisms, and (d) implications of perceptions of the

meaningfulness of improving well-being for the caregiver.

For this study, Glaser and Strauss's (1968/2009) grounded theory served as a

framework to explore and seek understanding of caregiver needs and how to support

coping mechanisms that will improve their well-being while providing care to individuals

with autism. The grounded theory design was developed in 1967 by Barney Glaser and

Anselm Strauss, and it is an inductive approach that generates an explanation of the

processes, actions, or interactions that are formed by the perspectives of a large number

of participants (Creswell, 2009, 2013; Strauss & Corbin, 1998). When grounded theory

was first developed, Glaser focused arranging qualitative methods into a systematic code,

thereby generating "middle-range" theories and maintaining a process that is empirical.

Strauss contributed to grounded theory by outlining symbolic interactionist and pragmatic

aspects. Through the influence of Strauss, grounded theory places emphasis on people as

active agents in a continually evolving process that shapes the world in which people

live. Additionally, as emphasis is placed on change, processes, variability and

complexities of life, these emergent processes give meaning to actions as they occur

(Glaser & Strauss, 1968/2009).

Grounded theory is a general methodology that researchers use to develop theory

that has been grounded in data that has been systematically gathered and analyzed

(Strauss & Corbin, 1998). The primary factor that distinguishes the methodology from

other qualitative approaches to inquiry is the emphasis on theory development (Strauss & Corbin, 1998). Another defining factor of this methodology is the emphasis that is placed on continuous comparative analysis throughout the data collection process, which allows for verification of developing theory and hypotheses. Within this model of qualitative inquiry, the researcher has the responsibility to give voice to the experiences of the participants and also to interpret their experiences (Strauss & Corbin, 1998).

The defining processes of the methodology for this study included the identification of common themes related to the central phenomenon of the study, discovering and categorizing responses provided by the participants into abstract concepts, identifying the patterns of relationship to stress and coping mechanisms, and exploring of the outcomes of those concepts into a framework that has been generated by a theory (see Creswell, 2013). Furthermore, the next section shows that grounded theory has been used in the past to understand stressors and related coping strategies associated with caregiver stress (Lazarus, 1984; Wang, Michaels & Day, 2011). Additional specifics of grounded theory relating to the study and adaptations from the methodology will be discussed in the following sections of this chapter.

Literature Review

Before the collection of data and the analysis of that data, a preliminary literature review was conducted in regard to grounded theory. The purpose of this literature review was to examine previous research on the challenges faced by caregivers and related topics so that gaps could be identified in existing research and a basis could be established for research and the development of interview questions. Grounded theorists

(Glaser & Strauss, 1968, 2009) have advocated the delay of a full literature review until the analysis of data has been completed, which avoids using preconceived ideas that may force the researcher's data into a preexisting category (Charmaz, 2006). This delay may also encourage the articulation of the researcher's ideas based on data. However, researchers should have some background in the technical literature without a review of all the literature (Strauss & Corbin, 1998). Using a process of inductively incorporating related literature in the final section of the study helped to compare and contrast the results from the study (Creswell, 2009). Additionally, being aware of the concepts that repeated in the literature and appeared to be significant stimulated theoretical sensitivity (Strauss & Corbin, 1998).

Caregiving in Autism

Although various support groups and organizations are available to caregivers while providing care for an individual with autism (e.g., Autism Speaks, Autism Society), previous grounded theory studies have indicated various behaviors and challenges from family caregivers of individuals with autism. For example, Zhou and Yi (2014) conducted a grounded theory study using transcribed interviews and observational notes of caregivers of individuals with autism to investigate the caregiving styles of parents in China. Results of the study revealed that parental stress and parenting self-efficacy were factors that influenced the functional improvement of children with autism. Based on participant reports of anxiety, hopelessness, anger, and powerlessness after learning of a child's diagnosis of autism as well as facing various daily behavioral challenges, findings showed an association between parenting cognition and parental behaviors. Another

grounded theory study, conducted by White, McMorris, Weiss and Lunsky (2012), illustrated the experiences of crisis in families of individuals with autism based on online survey responses from individuals who had a family member diagnosed with autism. Twenty-eight themes developed and were categorized into three main components of crisis: antecedents, behaviors, and consequences. Furthermore, Altiere and Kluge (2009) used semi-structured interviews to gather the perceptions and experiences that the families of children with autism faced. Results showed that five challenges emerged from the experiences of the families: development, questioning, devastation, solutions, and growth. Findings provided important considerations for professionals and families on the importance of acceptance and the need for positive support.

Despite previous studies on caregiver experiences, few articles have addressed the daily challenges that caregivers (parents) of a child with autism face. However, Ludlow, Skelly, and Rohleder (2012) explored the experiences, challenges, and coping mechanisms of 20 parents of children with autism. Six core categories included difficulties changing routines, dealing with challenging behaviors, judgements from others, lack of support, impact upon the family, coping, and the importance of appropriate support. Findings from the study placed emphasis on the parents' belief that they required additional support.

Caregivers often experience stressors that are associated with caring for an individual with autism (Weiss & Lunsky, 2011), which makes it important for health care professionals to identify at an early stage when caregivers are either approaching or are in a state of crisis so that they can respond in an appropriate manner. Results showed a

negative correlation with helpful coping mechanisms. This correlation was found in

family hardiness, and parent empowerment, positive adjustment to caregiver quality of

life, and positive parenting experiences. Significant moderate-sized correlations were

found between all variables and crisis severity, with the exception for positive parenting

experiences ($p = .08$) and socioeconomic status ($p = .88$). These correlates positively

correlated with known stressors such as the severity of aggressive behavior presented by

the individual with autism, negative life events, problematic coping and outcomes such as

caregiver burden, worry, and mental health problems. Findings of the study met

assumptions that caregivers at marked levels of distress (all p's $\leq .01$) who were

approaching or in crisis were significantly different from caregivers with lower levels of

distress (both $p \leq .001$) in nearly all the dependent variables. The study indicated that

access to a quick way of measuring where families are in terms of distress and crisis can

be helpful in research and the clinical field (Weiss & Lunsky, 2011).

Additional research has shown the experiences of families who live with autistic

individuals who demonstrated aggressive behaviors (Hodgetts, Nicholas, &

Zwaigenbaum, 2013) and the need for better interventions. Hodgetts et al. (2013)

conducted semi-structured interviews with the parents of nine males diagnosed with

autism who demonstrated aggressive behaviors. Through the constant comparison of

data, the researcher discovered three processes that were central to the study. These

processes negatively influenced the daily routines and well-being of family members,

support and services, and financial strain. The emergence of themes was inclusive of

isolation, exhaustion, safety concerns, home expenses, respite needs, and limited

professional supports and alternative housing. Findings of the study showed that the negative outcomes of aggression on support and service systems constituted an important step in tailoring resources that will best meet the needs of families caring for autistic individuals who are aggressive (Hodgetts et al., 2013). Additionally, Ji et al. (2014) suggested that family functioning, adaptation strategies, social support and sociodemographic characteristics were considered statistically significant (*p*-value of < .05) in correlation with each other and contributed to impacting the quality of life for families and caregivers. This indicates a need for effective interventions that would enhance the coping strategies of these individuals as they continued to provide care for the autistic population.

Finally, more research may need to be conducted on the association of anxiety with autism spectrum disorder. For instance, Ozsivadnian, Knott and Magiati (2012) conducted an exploratory study using a series of five focus groups with 17 parents of children and adolescents with autism spectrum disorder and anxiety. Although much research has been conducted on autism, relatively little is known about autism-specific factors that could have a role in the increased prevalence of anxiety disorders in children with autism spectrum disorder. Parents shared similar descriptions of various triggers and behavioral signs that were associated with anxiety in their child. Many parents reported that due to their children having increased difficulty in verbally expressing their worries, they showed anxiety through changes in their behaviors. Impacts from anxiety was reported as being more substantial than the impact of autism (Ozsivadnian et al., 2012).

Caregiver Stress and Coping

Studies have provided insights into the meaning of being a caregiver of an individual whose autism is severe on the autism spectrum (Hellzen & Asplund, 2002). For example, Hellzen and Asplund (2002) showed the relationship between the caregiver and the autistic individual as they received care. Focus was placed on the well-being of the caregiver and their ability to manage stress levels during provisions of care for the autistic individual.

A few studies have explored the various ways caregivers have used coping strategies. Phelps, Hodgson, McCammon, and Lamson (2009) examined how a child diagnosed with autism can contribute to multidimensional implications on the lives of families and their overall functioning. The Effects of the Situation Questionnaire was used to gather qualitative data from a sample of 80 caregivers. Results showed that seven thematic content areas emerged from the data: psychological, familial and social implications, services, spiritual benefits, economic challenges, and focus on the future of having a child diagnosed with autism. Conclusions of the study offered valuable insights into how helping professionals may attend to the biopsychosocial, and spiritual dimensions of those who provide care for a person with autism.

Another study, conducted by Kuhaneck, Burroughs, Lemanczyk and Darragh (2010), showed perceptions of effective coping strategies for the parented stress of 11 mothers. Primary questions of inquiry included "What stressors, if any, have you experienced raising a child with an autism syndrome disorder?" and "Can you describe the strategies you have found most effective in dealing with these stressors?," and "Have

any strategies been ineffective?" Six themes related to maternal coping included "me time," planning, sharing the load, knowledge is power, lifting the restraints of labels, and recognizing the joys. Themes such as lifting the restraints of labels and recognizing the joys supported recent findings regarding the positive aspects of raising a child with a disability and provided a framework from which pediatric therapist could assist mothers to cope effectively.

An older qualitative study conducted in South London by Tavable and Tavable (2009), investigated the effects of using a mental health questionnaire for adults affected by depression. Using convenience sampling, twenty general practitioners agreed to participate in a semi-structured interview and focus group before and after questionnaires were introduced to them. The inductive principles of grounded theory were used throughout the study as data was collected. Detailed coding of the transcribed text allowed for researchers to complete an in-depth analysis. Triangulation of the chosen methods allowed for the participants to reflect, modify and add to their contributions in different ways and at different times. The chosen methods were used to increase the reliability of data collection and reduce potential bias in the study. Additionally, using semi-structured formats and topic guides in the study ensured the coverage of emerging themes that were revisited in subsequent groups and interviews. In the results of the study major themes that emerged in the study included control and responsibility, doctor-patient relationship, and support for the doctor. These themes were influenced by the practitioners' experience and perceived time spent dealing with depression in their patients. Use of the questionnaires allowed for more experienced practitioners to

relinquish control, encourage patient involvement, and offer alternative sources of help for the individual.

Quantitative studies aim to explore consequences that can rise from the use of different coping strategies. Such studies have focused on classifying different coping mechanisms. Other studies have focused on examining emotion-focused coping. This type coping involves the process of reducing stressors by managing emotions that accompany the perception of stress that are experienced by the caregiver. Lazarus and Folkman (1984) identified emotion-focused coping as an exercise of self-control, use of positive reappraisals, escape-avoidance or disclaiming. Caregivers who used emotion-focused coping strategies tended to experience more stress and disturbances in most areas of their lives. The caregivers also experienced more guilt as they attempted to adjust to their child's diagnosis of autism (Cappe et al., 2011). Emotion-focused coping includes the use of religion, humor, self-distraction, positive reframing and acceptance. Seymour et al. (2013) found that such strategies severely affected the maternal emotional well-being of the caregiver and also increased their levels of stress. In an earlier study conducted by Hastings (2005) positive reframing was found to be beneficial as a strategy in reducing the effects of stress for the caregiver.

Researchers in another study (Bluth, Roberson, Billen, & Sams, 2013) sought to develop a new stress model. In developing the model, the characteristics of autism syndrome disorder were described and the literature supported stressors that were found in families of children with autism. The stress model included such things as resources for parents (mother & father) and the outcomes derived from caregivers using these

resources. In the promotion of positive outcomes researchers applied the stress model using a mindfulness intervention to strengthen the relationship of parents. In defining the term mindfulness, a broad definition was used to identify the term as an awareness, circumspection, discernment, and retention. Mindfulness refers to a state of consciousness that involves the individual cognitively bringing an awareness and attention to an immediate experience. In using Perry's stress model, it was found that parents of children with autism experienced a higher level of stress than parents of children with down syndrome, intellectual disabilities or developmental delays. Couples who parented children diagnosed with autism reported a higher rate of divorce and separation than couples found in the general population and parent of children with other disabilities. Limitations existed in the model due to the design having been applied to a limited population. Additionally, generalizability was also limited in this study. Suggestions of the study are that future research be conducted in regard to differences in parental perceptions of child characteristics, couple relationship outcomes, and positive individual parental outcomes. Due to mindfulness interventions aiding in decreasing the effects of stress associated with having a child with autism, it was also suggested that future research be conducted to study how mindfulness operates within the stress model in comparison to a control group.

The results of each reviewed study showed variations ranging from caregiver coping strategies to social support and increased levels of stress for caregivers who provided care to individuals with autism. As various participants were interviewed in the studies, many caregivers may have developed some type of coping mechanism, while

others may have experienced difficulty in coping with different stressors such as increased stress levels, behavioral challenges, lack of support, social isolation, and decreased well-being that imposed challenges on the caregiver. These impacts are inclusive of the caregivers' biopsychosocial domains. Stigmatism also found to affect the family and caregivers' ability to maintain social roles in the community, which as stated by Schaff, Toth-Cohen, Johnson, Outten, and Benevides, (2011) can contribute to the caregiver socially isolating themselves.

Summary and Conclusion

This chapter provided a preliminary review of current literature on caregiving for an individual with autism. The literature review explored qualitative research on the experience of caregiving and quantitative research on the prevalence of stress, a lack of social support, and well-being. Autism is a lifelong disorder and prevalence of the incidence of autism has grown in the United States. Those who provide care for an individual diagnosed on the autism spectrum may face the challenges of increased stress levels and behavioral challenges that are presented by the individual with autism. Declines in caregiver well-being that are exacerbated by such factors as stress and social support may also impose challenges as the caregiver cope with the physical and emotional demands that are encountered in providing care. As the population of caregivers that provide care to those with autism face unmet needs to maintain their own well-being, this area of caregiving for persons with autism has been relatively unexplored from a qualitative standpoint. Even positive interventions designed to aid caregivers in

quantitative studies have been unsuccessful in meeting the widespread needs of those providing care for the autistic individual.

For this reason, a grounded theory methodology was chosen to provide a foundation on which to base future research in the field. Understanding the underlying challenges that caregivers face and how they currently process those challenges is an important step in understanding how to provide support to caregivers during the provision of care for those with autism. Chapter 3 provides an overview of grounded theory, which will be inclusive of a background of the method and the general steps involved in using the method. The next chapter also describes how the grounded theory methodology was applied in the study.

Chapter 3: Research Method

Introduction

The purpose of this grounded theory study was to explore the social support of caregivers of individuals between the ages of 9-18 diagnosed with autism spectrum disorder in Southeast Georgia and the processes they use to cope with stress. Caregivers face behavioral and psychosocial challenges that are exhibited by individuals with autism spectrum disorder that contribute to a decline in caregiver well-being (Werner & Shulman, 2015). These factors can include stress, social isolation, and a perceived lack of support. An interdisciplinary approach must be taken to address these challenges to enhance the well-being of the caregiver of individuals with autism in different geographical locations and age groups (Phelps et al., 2009). More research must be conducted on the issues regarding the caregiver and interventions for effective coping mechanisms that will enhance optimal well-being (Cadman et al., 2012). In this chapter, the research design and the rationale for the design will be discussed. Emphasis is also placed on the role of the researcher and an explanation on the methodology for this study along with qualitative approaches that were used in the collection and analysis of research data, issues of trustworthiness, and ethical procedures.

Research Design and Rationale

A qualitative approach with grounded theory was used to provide a general explanation of stress, social support, and well-being based on the perspectives of the participants. In using this approach, the research questions helped explore the related factors of stress, social support, and well-being:

Research Question 1: How do caregivers of individuals with autism perceive their well-being?

Research Question 2: How do caregivers use coping strategies to maintain an optimal level of well-being?

Research Question 3: What beliefs influence caregiver behaviors in adopting effective coping strategies?

Grounded theory allows for a focus on the views of the participants in the study (Creswell, 2009, 2013). The selected setting was one that is natural and familiar to the participants. Multiple stages of data collection were used and categories of information were refined so that interrelationships could be defined. As participants shared their thoughts, responses were recorded throughout the interview process. As trust was built between me and interviewees, participants could be more relaxed as they expressed their views in regard to the challenges that they faced.

The use of qualitative research addressed the challenges that were faced by caregivers of individuals with autism. Due to the current gaps in literature relating to the stressors impacting caregivers and lack of support, a quantitative approach would not have addressed the issue in this study. Focusing on the lack of accessible resources for the autistic individual and the psychosocial characteristics that influenced caregiver behaviors, surveys and semi-structured interviews were conducted to collect data. With surveys and interviews, I gained a better understanding of the factors that might contribute to increased levels of stress and a decreased level of well-being for the long-term caregiver. Forty-five minute to 1.5 hour sessions can range from unstructured

interviews where participants control the content of the interview to interviews that use

questionnaires that have been carefully designed (Grove, Burns, & Gray, 2013), which

guided the interview times for the current study. Each interview included informed

consent, collection of demographic data, and guided interview discussions.

Another design considered but not chosen was narrative research, which is

focused on individual stories (Creswell, 2013). This approach is used to tell the story of

an individual or groups of individual experiences (Creswell, 2013). Interviews are used to

develop themes through chronology. Underlying challenges to this approach are inclusive

of the large amount of information the researcher would need to gather from each

participant to have a clear understanding of their life. In addition, researcher bias must

also be considered as an analysis is conducted. Therefore, this design was not chosen for

this study.

Grounded theory provided a more unified theoretical explanation, as it moves

beyond the boundaries of describing to generating and/or discovering theories for what

has emerged. This design also helped in explaining how practice can implement

interventions that will aid in improving the issues that have been identified. Using

grounded theory, the researcher can focus on the processes or actions to be taken such as

the development of programs to provide more positive social support for caregivers of

individuals with autism. Therefore, due to a current theory not being available to explain

or understand the processes addressed in this study, a qualitative design was selected to

explain the support that this selected group of caregivers need (see Creswell, 2013).

The important concepts of grounded theory include categories, codes, and coding. As the method is consistently used throughout the study, the three elements incorporated were: (a) theoretical sensitivity, which includes coding that will provide and explanation of the subject under study and generate strong theoretical concepts that will emerge from the data; (b) theoretical sampling that involved deciding on who to interview so that their contribution will help to generate theory; and (c) the comparison of data between the subject under study and the context of the subject to generate a strong theory.

Role of the Researcher

My role as the key instrument was to collect data through interviewing participants. Open-ended interview questions designed by me were used rather than questionnaires and other instruments developed by other researchers. My perceptions of the challenges that caregivers faced as they provided care to autistic individuals was shaped by personal experiences. Prior to beginning this research, I worked at an advocacy resource center in Southwest Georgia servicing individuals with intellectual and developmental disabilities. I served first as a developmental disability professional, then as the nurse administrator for the agency, assisting in the assessment of clients; facilitating individual service plan meetings with clients, staff, and support coordinators; and assisting in meetings for those who required exceptional rate Medicaid waivers due to a decline in health. I was also involved with administrative activities and decision-making on a health care level and worked closely with direct care staff, residential directors, executive, and compliance officers. This understanding of the context and role enhanced my perception and sensitivity of the challenges encountered by caregivers of

autistic individuals and assisted in working with the participants. Although I am not connected to any current agencies where the study was conducted, prior background experience derived from another agency provided a better understanding of the population under study.

The development of sensitivity in regard to the subject matter also helped in building rapport, which was important in conducting interviews and surveys to make the environment more comfortable for the participants and increase the probability of the participants sharing meaningful information that aided in the development of theory. My experience also helped enhance any insights from participants.

Methodology

Grounded theory was used to obtain a general, abstract framework from a process that was grounded in the responses of the participants in the study. Grounded theory is a theory that has been generated from data that has been systematically obtained and analyzed through a constant comparative process (Creswell, 2013), which in this study involved surveys and individual interviews. Surveys validated interviews and were administered prior to the beginning of each interview where the targeted population of caregivers who provided care to an individual with autism spectrum disorder (ages 9-18) discussed the phenomenon of interest. Surveys consisted of demographic information and three open-ended research questions: (a) How do you describe well-being in terms of your own health (physical health, mental health)?, (b) What are the coping strategies used to maintain your own well-being? (e.g., talking to people, time by myself, hobbies) and,

(c) What do you believe would help you use more effective coping strategies in caring for an individual with autism?

Two key characteristics of grounded theory are the constant comparison of data with emerging categories and theoretical sampling obtained from different groups of participants to increase the similarities and the differences of information (Creswell, 2009). In theoretical sampling, the researcher purposefully interviews participants who can contribute to the developing theory. Initially a homogeneous sample is interviewed, and as the theory begins to develop, a more heterogeneous sample who can confirm or disconfirm the conditions under which the model is maintained are interviewed (Creswell, 2013).

This study was limited to caregivers who were over 18 years of age and were currently providing care for an individual with autism between 9-18 years old in Southeastern Georgia. Participants also had to speak English, understand all interview questions, and to answer in a unified manner. Participants were able to complete a survey that provided demographics and were able to attend scheduled interviews. Requirements for the study excluded those who had been diagnosed with an intellectual or physical disability. The number of interviews required for the study can be estimated as a priori. Recruitment was continuous until no new information was generated. As transcripts and field notes were reviewed at the end of each interview, issues from each participant was reviewed as a measure to assess saturation of data.

Participant Selection Logic

The targeted population was caregivers of individuals with autism between the ages of 9 and 18. As focus is placed on this age group of individuals with autism, caregivers can face an increased level of stress due to the externalized behaviors of the individual with autism (Van Bourgondien, Dawkins, & Marcus, 2014). The demographic location for this study was restricted to Southeastern Georgia. Samples were recruited from response to flyers, outreach to local autism parent groups, and social media. The chosen site for this study was in natural and familiar surrounding such as the participant's home, library, or a chosen location by the participant where distractions were limited. Participant selection was limited to informal caregivers who currently provided care to individuals between the ages of 9 and 18 who had been diagnosed with autism, Asperger's disorder, or pervasive developmental disorder (American Psychiatric Association, 2000).

A small sample of 20 to 30 participants helped in developing a well-saturated theory for this study (see Creswell, 2013). Sampling was purposeful as individuals were selected. There are approximately 100 caregivers in the county who care for individuals 9-18 years of age. Interviews consisted of an estimated recruitment of 20 participants. As emerging information indicated the value of a change, samples were added as the fieldwork unfolded. This type of sampling informed an understanding of the problem and central phenomenon (Creswell, 2013). In grounded theory the subjects may not be located at the same site (Creswell, 2013). In this case, selection of these individuals can provide richer information that will aid in the development of categories as information is

gathered. This gathering of contextual data was beneficial as the study enters into the axial coding phase of the study (Creswell, 2013).

Data were collected with open-ended questions in surveys and interviews. An interview protocol was created and used to redirect conversations back to the subject of interest to stay on course and allow for richer responses to be gathered from the participants (see Appendix D). During interviews, data collection also included the severity of autism as I asked the caregiver to describe the severity of the individual's autism, if known. As the participants voiced their perspectives, with permission I tape recorded the interview so that it could be transcribed for analysis. Additionally, expressions, body posture, and other nonverbal signs were collected to validate and expand on verbal information that had been recorded. Institutional Review Board (IRB) approval (approval no. 02-01-18-0331671) was obtained before data collection. Participant consent was also obtained before data collection from individuals who were willing to volunteer and provide information that will help in facilitating data collection.

Instrumentation

I was the key observer during the collection of data. Surveys (see Appendix B) were estimated to be 15 to 25 minutes long and were administered prior to conducting interviews. Journaling was also used to record the observation of noted expressions, reactions of the participants (body posture, nonverbal signs), and any significant events that took place during data collection. The questions focused on the perceptions of stress and social support and beliefs that may influence the way in which caregivers chose coping mechanisms that will either improve their well-being or allow for them to identify

to the challenges that are faced while providing care to the individual with autism. I used Excel to code and construct explanations of the data. No data were collected until IRB approval was obtained and permission obtained from the participants of the study.

Data Collection

The main sources that were used in the collection of data were: (a) tape-recorded interviews, (b) survey data, (c) journal entries, (d) field notes, and (e) constant comparison of data from the onset of interviews. Each interview allowed me to document participant perceptions to increased stress levels, social support, meaning of caregiver well-being, and coping mechanisms that are used to deal with the challenges that are presented. This allowed an opportunity for me to gain an understanding on the perspectives of caregivers as they faced the challenges of providing care for individuals with moderate to severe developmental delays on the autism spectrum. It also allowed for me to give voice to the perceptions of the challenges caregivers face and the aspects of supports found beneficial by the caregivers as they care for the autistic individual.

Caregiver interviews as well as observation and journaling were conducted as participants expressed and clarified their views regarding the role of caregiving. This allowed both observation of certain aspects of participant behavior and enabled reporting to be done in ways useful to social science and not harmful to participants. In the event that participants needed debriefing or more support beyond each interview, a number was made available for contacting the Care and Counseling Center of Georgia or the Georgia Crisis & Access line for counselor referrals. The interviews were conducted in a quiet and natural setting without distractions and in which there would be little risk of a

perceived threat to the caregiver. An interview protocol was used that contained key research questions and subquestions. Prior to each interview, consent to participate in the study was obtained from the participants.

The synthesis of concepts found in the literature were instrumental in the process of deciding where to look while gathering and analyzing data in the initial phase of data collection. A few concepts that I explored during data collection were the caregivers' understanding of autism, the challenges that they faced while providing care for the autistic individual, and the interaction of the caregivers' internal coping mechanisms and the external supports they seek for help. The emergent nature of this process required flexibility in questioning as data were generated; questions that I asked and how those questions were asked varied for each interview. Thus, I was able to direct each discussion according to the emergence of themes and possessed theoretical sensitivity for the meaning of a developing theory during the emergence of those themes. In addition, if after the interviews were conducted and data was not saturated, I continued recruitment and additional interviews were conducted.

Once an understanding of concepts had been gained and a sense of the collected information along with its meaning had been formed, I was able to focus and test the assumptions of the study. During the data collection process, participants were given the opportunity to provide additional data or review my preliminary conclusions (Grove et al., 2013). Once assumptions were tested, an inquiry was made about the meanings each concept has with individuals. Interview questions (see Appendix D) were centered around the research questions and was used with theoretical sampling.

Data Analysis

Data analysis explored the main concerns of collected data: (a) coded caregiver nodes for perceptions of stress, social support, coping mechanisms, and well-being; (b) coded interview nodes; and (c) a comparison of the coded nodes for stress levels, social support, coping mechanisms, and well-being with the coded nodes from each interview session conducted with caregivers. Data analysis and data collection was done in a logical order with all preliminary data analysis informing the further collection of data. Early in the data collection process I recorded theoretical notes to compare with the data, related interview responses to one another, developed new concepts, and linked concepts to ones in the literature. Throughout the study these theoretical notes were integrated into longer analytic memos that aided in furthering the focus of the study. This data analysis process continued during and after data collection until some kind of pattern for data analysis emerged that accounted for what was being studied.

In addition to the use of memos, the ongoing process of coding interview transcripts was central to the analysis of data. This required reading and rereading the data to highlight and label important, descriptive, or informative issues that emerged, for later sorting and categorization (Creswell, 2013). Rereading the data enabled me to identify and discover processes and the properties and dimensions that characterize them. The ultimate goal was to develop a theoretical framework that accounted for the experience of caregivers of individuals with autism. The rich description that emerged depicted the experience and the meanings that attributed to supports and well-being for the caregiver and were a significant contribution to the literature. Grounded theory

provides a comprehensive explanation of a process by including variation rather than assuming there is one answer to a research question that will fit what is under study (Patton, 2015).

In the initial examination of data, I looked for patterns and information that would help in the determination that all questions had been answered. Once this determination had been made, journal entries were entered into the EXCEL spreadsheet for the purpose of coding. This process assisted me in finding patterns of adopted coping strategies that were used among the caregivers. It was hoped that a process of follow-up feedback would provide insights on the participant's' beliefs toward any influences that contributed to their ability to adopt effective coping mechanisms that would improve their well-being while providing care to the autistic individual. The categories were considered 'saturated' when it was apparent that no new ideas or concepts seem to be emerging, and when no additional negative cases were found that disconfirmed or invalidated the proposed framework for analysis (Patton, 2015).

Strauss and Corbin's (1990) Paradigm

Open or line-by-line coding was the first step in data analysis of a grounded theory framework. As defined by Strauss and Corbin (1998), open coding involves a breakdown of data so that it may be examined, compared, conceptualized, and placed in categories. As open coding begins, initial impressions will be formed from the collected data so that it may be coded or labeled (Strauss & Corbin, 1998). Coding of the data was used to identify any conceptual reoccurrences and similarities in the patterns of responses from participant experiences of challenges faced. As the similarities in the emerging

concepts were identified, they were placed in categories. As focus in the study was narrowed during the initial coding process, it allowed for me to decide which direction to take in the further collection of data so that the analysis could continue.

In axial coding, data was placed back together in a different way so that connections were made between formed categories (Strauss & Corbin, 1998). Finally, as selective coding begun, core categories were selected and linked to other categories. Selective coding allowed for a more descriptive narrative to develop so that a framework for the study would emerge from the ideas and perspectives shared by the participants of the study.

Issues of Trustworthiness

Credibility

In qualitative research, validity is used to determine whether the findings are accurate from the standpoint of the researcher, the participant, or the readers of an account (Creswell & Miller, 2000). Credibility refers to the accuracy of how collected data reflects the multiple realities of what is under study. Some strategies that I used to check the accuracy of the findings and ensure internal validity included:

1. Triangulation of data - data was collected through multiple sources to include surveys and interviews, previously conducted studies and document analysis. The use of multiple resources aided in shedding light on the emerging themes in the study.

2. *Member checking* - At the end of the interviews I summarized what had been said and solicited the participants' views of the credibility of the findings and interpretations.

3. *Clarifying researcher's bias* - I was self-reflective in order to create an honest narrative regarding any pre-conceived ideas and how those ideas might influence the interpretation of findings.

4. *Clarifying* – Research bias is very important and should be disclosed from the outset of the study. This strategy allowed for me to understand my position and any biases or assumptions that could impact the inquiry. I commented on past experiences, biases, prejudices, and orientations that could shape the interpretation and approach to the study.

An important step in grounded theory research is to develop open coding categories and then, through axial coding to interrelate those categories. An important verification step takes place through this process (Creswell, 1998). I posed questions that related categories and then I returned to the data and looked for evidence that would support developed categories, or refute the questions, thereby verifying the data (Creswell, 1998). After a framework of the developing theory was written, the literature was used as a supplement in validating data. The literature was also referenced to validate the accuracy of findings or provide examples of how a difference exist in the findings of the study and published literature.

Transferability

Transferability is a primary strategy that was utilized to assure that external validity would provide descriptions that are rich, thick, and detailed. This ensured that others who are interested in transferability will have a solid framework for comparison (Patton, 2015). Three techniques to ensure reliability were employed in the study. First, the researcher provided a detailed account of the focus of the study, the researcher's role, the participants position and basis for selection, and the context from which data would be gathered (Patton, 2015). Second, triangulation of multiple methods of data collection and analysis were used, which strengthens reliability as well as internal validity. Finally, data collection and analysis strategies were reported in detail in order to provide a clear and accurate picture of the methods used in this study (Patton, 2015). As each phase of the research project was completed, it was subjected to examination by an external auditor who was experienced in qualitative research methods.

Dependability

In grounded theory dependability refers to the researcher confirming that collected data represents the changing conditions of what is being studied and that there is consistency across time, researcher and the techniques used in the analysis of data. This process occurs by someone else who will perform an audit of the data and confirm that grounded theory methodology procedures have been followed and have been used correctly.

Confirmability

Confirmability involves the testing of the objectivity of the research study. This examination is inclusive of a detailed audit trail which involves another researcher confirming the findings of the study.

Ethical Procedures

Creswell (2013) concurs that ethical issues can arise throughout the qualitative research process. It is recommended by the author (Creswell, 2013) that researchers take into consideration ethical issues that involve our role as researcher, and in light of the purposed study, show sensitivity to the chosen population due to the vulnerabilities that exist. Participants for this study were recruited after approval had been acquired from the Walden University IRB. Approval aided in ensuring that all participants were protected from harm. This protection was inclusive of a full disclosure of the intentions of the study, participant and data confidentiality, and participant anonymity. After communicating by means of flyers and social media, a brief study description was included in invitation letters to prospective participants. This description included procedures for obtaining informed consent, an introductory letter, and legible instructions that were understandable to the participant. Included in this information was a form of consent, purpose and nature of the research study, procedures that would be used, any risk for participating in the study, safeguards against risks and discomforts, benefits of study, level of confidentiality, agreement to maintain confidentiality of the participant, contact information of the investigator, consent of voluntary participation, duration of the study, and number of participants involved.

I acquired informed consent from each participant. Before each interview was conducted, I informed participants of the purpose of the study so that they would have a full understanding of all expectations and procedures to be used in the study. Participants were informed that they could voluntarily withdraw from the study at any time without consequences. In past studies agencies have offered minimal incentives in the amount of $25. For this study, no monetary compensation was offered for participation.

The collection of data was kept confidential, personal information and identifiers were coded so that participants would not be identified. An alias such as Participant 1 or 2 was used instead of actual names. Interviews were recorded using an audio recorder and transcribed for accuracy. All collected data will be kept in a fireproof safe in the researchers' home for a total of 5 years, after which it will be destroyed using proper measures such as shredding. The only parties that will have access to data collected are the researcher, participants (for member checking), and members of the dissertation committee.

Summary

This chapter provides an explanation of the reasons for using a qualitative plan in this research study. It discusses the specific qualitative method used, in this case, grounded theory. Additionally, my role and background are revealed to enable readers to understand potential researcher bias in this study. Information about the data sources and ethical considerations are provided and methods of data collection and analysis are described. Finally, an explanation of how trustworthiness of the study can be enhanced through various strategies has been provided in this chapter. Once IRB approval had been

obtained from the educational institution and permission of access to caregivers had been

granted, demographics, data collection, data analysis, evidence of trustworthiness and

results of the study were discussed in Chapter 4.

Chapter 4: Results

Introduction

The purpose of this grounded theory study was to explore the processes that caregivers of individuals between the ages of 9-18 years old diagnosed with autism use to cope with stress and social support in Southeast Georgia. In this chapter, an introduction of participants is provided, along with the themes that are central to the shared experiences of each participant. Analysis of experiences was gained from data collected using surveys and interviews to answer the following three research questions: How do caregivers of individuals with autism perceive their well-being? How do caregivers use coping strategies to maintain an optimal level of well-being? What beliefs influence caregivers of individuals with autism in adopting effective coping strategies? From each question, three subquestions were developed: How did these caregivers describe well-being regarding their health? What coping strategies did these caregivers used to maintain their well-being? What factors did caregivers believe would help them use more effective coping strategies in caring for an individual with autism?

The focus of this chapter is data collection, the process of data analysis, and the results of this study. In this chapter, a discussion of the demographics of each participant is shared along with the methods used for data collection. A description of the various strategies used to ensure trustworthiness of the study will be provided. Next, an overview of the analysis phase will proceed with a discussion of the results. Finally, this chapter will address each research question and conclude with a summary of all findings.

Research Setting

Individual interviews were conducted from February 28, 2018, to July 14 in the participants' homes. The home environment provided a comfortable and familiar setting where participants were able to relax and express their views as they shared their experiences without a compromise in confidentiality. Most interviews averaged 45 minutes in length and were tape-recorded, transcribed, and placed in a Microsoft Word Document for review and comments. Afterward, transcribed data were manually coded and entered into an Excel spreadsheet as a triangulation method for coding and analysis. Before data collection began, Walden University's IRB approved this research study.

Demographics

A total of 20 participants who provided care to individuals with autism participated in this study. All recruited participants met the criteria for participation in the study. Meeting criteria meant that the participants were (a) 18 years of age or older, (b) spoke English, and (c) cared for an individual who was 9-18 years old with autism. Each participant was assigned a pseudonym to maintain confidentiality (Participants 1 through 20). Demographics for each participant consist of gender, the severity of child's level of autism (if known), an age range of participant, the age of the child, primary challenges that caregiver faced, and use of outside support. Approximately 45% of the participants were 30-39, 25% were 40-49, another 25% were 20-29, and the remaining 5% 50-59. Additionally, out of 95% of caregivers who used outside support, approximately 75% of the participants stated that they were currently employed and experienced challenges

using outside support. Demographics for each participant are shown in a demographic chart (see Appendix C) with an assigned pseudonym.

Data Collection

Data collection occurred in the homes of 20 participants (17 females and three males) in the form of surveys and individual interviews. This number was representative of the caregivers of a total of 20 children diagnosed on the autism spectrum (from mild to severe). Children ages ranged from 9 to 18 years old, with one child transitioning to the age of 19 on his next birthday in fall 2018. The data collection process began on February 28, 2018 and extended to July 14, 2018. During this timeframe, participants completed a demographic survey 15-25 minutes before the interview. Recruitment of participants was through purposeful sampling. Participant recruitment took place in Southeast Georgia. Interviews averaged approximately 45 minutes to 1.5 hours with an average range of 45 minutes for most interviews. Before conducting individual interviews that were semi-structured, three participants completed surveys and rescheduled the interview process for a later time due to currently scheduled engagements. All participants gave their signed informed consent before completing a survey. An interview schedule was used as a guide for topics to cover in the interview. Core research questions included:

1. How do caregivers of individuals with autism perceive their well-being?

2. How do caregivers use coping strategies to maintain an optimal level of well-being?

3. What beliefs influence caregivers of individuals with autism in adopting effective coping strategies?

With the consent of participants, interviews were tape-recorded and transcribed verbatim. Six steps took place in the process of analyzing the transcripts. This process involved (a) becoming familiar with the data, (b) identification of initial codes, (c) search for emerging themes, (d) review of themes, (e) defining and naming themes, and (f) reporting of themes found in the data (Vaismoradi, Turunen, & Bondas, 2013). During the analysis process, I used Microsoft Word for transcribing documents and Excel spreadsheets for the management of collected data. Before data collection, I requested and obtained IRB approval from Walden University and permission to research in the homes of participants, the library, or at a location of the participants choice where confidentiality would be maintained.

During this process, there were a few variations from the original data collection plan. After discovering that a local agency was not responsive to further attempts to gain access to the site, I sought and received IRB approval for a change of study methods from focus groups to individual interviews in a chosen location by potential participants age 18 years and older who provided care for an individual (9-18 years old) diagnosed on the autism spectrum. The original sample size proposed for this research study was approximately 20-30 participants. After interviewing the first 17 participants, I returned to the field to complete three rescheduled interviews. At this stage, I reached saturation early in the data collection phase as no new theoretical insights or properties emerged under the main categories during the data collection process. A more in-depth discussion of this process will be provided in the next section.

Data Analysis

During analysis, I began by using an inductive process of constant comparison during which I went back and forth between the data collection and the analysis. This process allowed for an in-depth examination of all data to form the foundation from which all categories and the generation of a theory would emerge. Transcripts were first read in full to get an overall sense of data. Categories in the data were identified, informed in part by the focus of questions asked (e.g., "perceptions of stress," "seeking support resources"), and from what emerged in the data. A list of codes was developed and structured according to categories and subcategories. A selection of participant quotes was also selected and assigned to codes. In reporting results, selected quotes are used to illustrate the findings of this study. Identifying information has been removed from data to protect confidentiality.

Open Coding

The first phase of analysis was focused on open coding, in which a line-by-line examination of the data was performed to identify ideas and events that represented the phenomenon under investigation. I began the open-coding phase by listening to the taped files of each interview, reading through the transcribed transcripts to gain an understanding of what the participants were saying, and then going through the transcript of each interview, line by line, and identifying codes that emerged from the data. With the emergence of each new code, I looked for its attributes and dimensions and based on those I combined the codes to organize and refine them into categories and subcategories according to their relative importance based on the phenomena explored.

The initial interview questions were used to determine the organization of some of the coding. For example, I was able to place *repetitive behaviors* under the category *caregiver perceived stressors* because that is the section that I was exploring when I asked the participant to describe what situations or events brought about stress while taking care of persons with autism. By the end of the open coding process, a total of 490 individual codes emerged.

Axial Coding

The second phase of the analysis process led to axial coding. During this process, I made connections between the categories and subcategories. *Well-being* emerged as the central category because it seemed important in understanding caregiver perceptions of the meaningfulness of well-being and the ability to respond to and cope with stressors and support. This factor connected the way that meaningfulness of well-being and coping strategies were defined concerning the understanding to be gained by individuals, health care providers, and the community.

All categories were organized based on a paradigm model. Connections were made using (a) causal conditions, (b) a phenomenon, (c) context, (d) intervening conditions, (e) strategies, and (f) consequences (Strauss & Corbin, 1998, p. 127). After making connections, 12 categories and their subcategories were analyzed and arranged according to their relationship with each other. For example, one of the categories I identified was the *caregivers' perception of stress* (phenomenon). The subcategories were *situations/events leading to increased stress* such as *concern for child's safety* (causal conditions), *constantly redirecting* (intervening conditions), *difficulties faced*

(consequences), *lack of structured routines* (consequences)*, challenging behaviors* (action/interaction strategies/context), and *desire to seek resources and support* (strategies). Figure 1 represents an example of the relationship made between the main category and its subcategories based on the Strauss & Corbin's (1998) paradigm model.
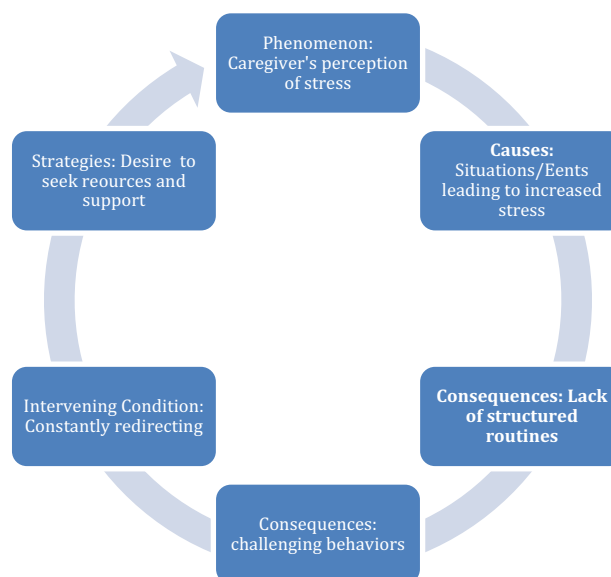
Figure 1. Example of Strauss & Corbin's (1998) paradigm model.

After organizing all collected data into categories and subcategories, I returned to the field and continued to collect data on the three interviews that participants rescheduled due to prior engagements. After transcribing and coding the final set of interviews, I discovered that new codes were not emerging from the newly collected data, and all data was related to existing codes. In seeking variations in participants, I recruited and interviewed caregivers who worked full-time, were unemployed, single caregivers, married caregivers, and sibling participants. Although I incorporated some variation in the sample, no significant difference developed in the data. No discrepant cases were found, as each participant seemed to be motivated by the meaningfulness of finding an

equal balance between caring for a child on the autism spectrum and maintaining their well-being, which was used to help refine the emerging theory and to gain a deeper understanding into the perspectives that each participant shared. Once a formulation of the categories occurred and I reached saturation, I moved to the final analysis phase: selective coding.

Selective Coding

During this phase of the analysis, I identified the central phenomenon, which was *wanting a balance between life and caregiving.* The 12 categories were rearranged into five larger categories and further defined by integrating all other categories to form a storyline for the emerging theory. The five major themes will be described in the Description of the Five Primary Themes section.

Evidence of Trustworthiness

There are several important strategies to ensure the trustworthiness of the results of a study (Creswell, 2013). I used at least two strategies for verifying the trustworthiness of qualitative research (Creswell, 2013). In this study member checking and triangulation were used to enhance the credibility of findings in this study.

Credibility

The credibility of this study was increased by investing sufficient time to capture the perspectives of participants so that an understanding could be gained on the targeted phenomenon. Credibility was accomplished by manually coding data to ensure that findings were rooted in data that provided a voice for caregivers.

Variations occurred in the performance of member checking. Initially focus groups were to be conducted and at the end of each session data would be summarized by acquiring the participants' views of the credibility of findings and interpretations. After gaining IRB approval to conduct individual interviews, with the completion of data collection and analysis, I was able to review the analysis of data collected from participants and receive their feedback on whether the interpretations made sense to them. Additionally, I rechecked whether the interpretations were accurate for describing their shared perspectives. My review with each participant consisted of the caregivers' process based on the five main categories generated from the data. An examination of the data occurred by reflecting on relevant literature in the field. Through reflections, prior research can aid in providing a context for interpreting and triangulating the data. I was able to compare the results of the study to other studies so that potential similarities or differences could be noted.

The final strategy I used to ensure the credibility of the study was to conduct a self-reflection of my own bias by setting aside any preconceived ideas that might influence an interpretation of findings. I also disclosed any biases that may have formulated from past experiences, prejudices, and orientations. In the next section, I will discuss the data analysis process and provide a foundation for the results of the study.

Transferability

I increased the transferability of my research by spending time in the field collecting participants' stories about their perceptions of the meaningfulness of well-being and the strategies used to cope with stress and social support. Doing so enabled me

to increase the quality and transparency of this study. I also provided in-depth descriptions of the research design, sampling scheme, data collection and analysis, and the research results.

Dependability

A review of researcher memos taken throughout the data collection process was used to increase the dependability of this study. Memos were used to explore any biases, reactions, or thoughts during the interview process and the data analysis stage. Explanations about the interpretation of data are also recorded.

Confirmability

During the interview process, the constant writing of memos provided an audit trail that helped in increasing confirmability for this study. I used spreadsheets to keep track of data along with Microsoft Word documents for transcription of each interview to provide evidence of archived data. Archived data was achieved through data management using Microsoft Word tables and transcripts that will be stored in a locked safe for at least 5 years.

<div align="center">

Study Results

</div>

At the conclusion of the data collection process, all data, including interviews, were transcribed verbatim and analyzed. During the analysis process, the identification and coding of significant participant statements took place. Five major themes emerged from the codes: (a) caregiver perceived stressors, (b) caregiver perceptions of well-being, (c) strategies to cope, (d) desire to help self and others, and (e) feelings about social support. After the themes were determined, I arranged them for discussion based on

Strauss & Corbin's (1998) paradigm model, which consisted of connections being made using casual conditions, a phenomenon, context, intervening conditions, strategies, and consequences.

Description of the Five Primary Themes

The five main categories that described the central phenomenon were: caregiver perceived stressors, caregiver perceptions of well-being, strategies to cope, desire to help self & others and, feelings about social support along with one central phenomenon a balance between life and caregiving. These themes represent the details of the perceptions of caregivers that emerged from the interviews and are supported by quoted statements from the participants. An illustration is presented in Figure 2 as it related to the central phenomenon, a balance between life and caregiving located at the bottom with the five main themes stemming from the central phenomenon.
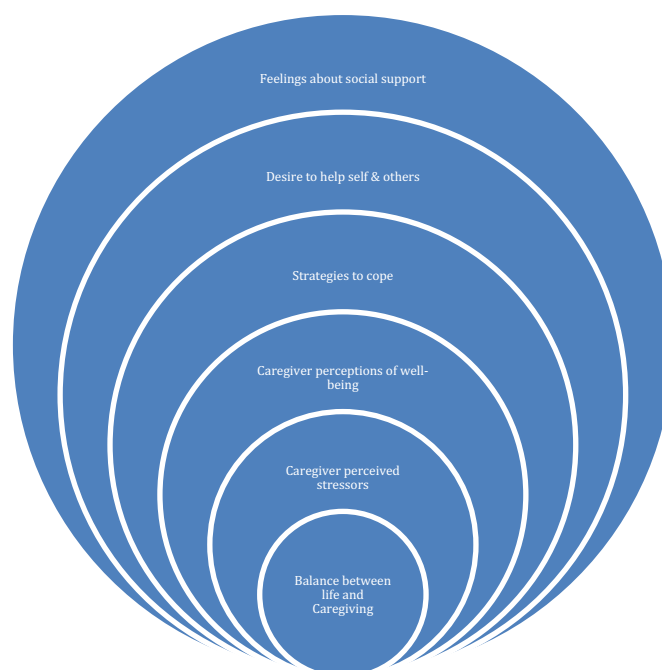
Figure 2. Central phenomenon and five main themes.

The central phenomenon of the five main themes presents as a relationship to each other. The linking of the five themes is that of me spending a substantial amount of time exploring the data and developing a deeper understanding of the context as the phenomenon in question, caregiver processes used to cope with stress and social support was approached. I identified the five categories as five separate and distinct themes; it is important to note that the themes are more accurately a mixture of events and participant experiences that, together, inform the context of those experiences and take on slightly different expression as a theory emerge.

Another important note to recognize is that this analysis of the caregiver processes is a reflection of the participant's understanding of the challenges they face as the expressed statements merged through the interviews. Because the objective of this study was to explore the processes that caregivers of individuals between the ages of 9-18 years diagnosed with autism use to cope with stress and social support in Southeast Georgia, the primary focus of the interview data for the analysis of events were intentional. Other data sources, such as literature reviews, have also been used to provide evidence to support, balance, and extend the analysis driven by interviews with caregivers. In the initial process, insights into understanding the coping processes of caregivers were gained through peer-reviewed articles. An overview of this material appears in Chapter 2, and no attempts will be made to recreate a summary of that material in this chapter. Finally, more than 16 years of experience providing direct and indirect care to families and individuals on the autism spectrum gives me firsthand experience, knowledge, and opinions on these issues. I took extra precautions in limiting the degree to which my

knowledge would cloud and bias the analysis; there is no claim that I have objectively held myself beyond the scope of this data.

Participant Views

Participant recruitment for this study occurred through a variety of means. Some were recruited through responses from posted flyers and social media; some were known by participants who had consented to participate and were recruited via a snowball technique, and associates familiar with my research journey suggested some. A demographic table (Appendix D) gives an overview of the background of the 20 participants who agreed to participate.

Through conduction of individual interviews that were informed by all stages of the research process - five primary themes: caregiver perceived stressors, caregiver perceptions of well-being, strategies to cope, desire to help self & others and, feelings about social support, along with one central theme balance between life and caregiving appeared to underlie the five main themes. Through a grounded theory methodology, the five themes emerged as the primary conditions within which the perspectives of well-being, perceived stressors, coping strategies, desire to help self and others, social support and the outcomes of seeking a balance in caregiving coexist. As circumstances required the adaptation of effective coping strategies to maintain a balance between caregiver well-being and providing care to an individual on the spectrum, these perspectives facilitated aspects of the caregivers' experiences of adopting effective coping strategies as they provided care.

Caregiver perceived stressors were identified as the first theme because it overarches the other four themes that emerged during data analysis. All properties that fell under this category portrayed the caregiver's experience with events and situations that contributed to caregiver stress. Participants described these factors regarding how such events contributed to increased levels of stress as they provided care. An example of the subcategories that were related to this category was *challenging behaviors* (child having outbursts, tantrums)*,* difficulties faced, change in child's routine/environment, unpredictable/repetitive behaviors, concern for safety, fear of the unknown, seeking resources, communication, child being uncooperative, and lack of finances. When asked to describe situations or events that contributed to stress, responses supported statements such as those made by the following participants in describing factors that caused stress:

> I would say that the meltdown moments are what cause me to experience stress. Especially when he cannot get his way, and the tantrums began. It is at this time that he does not have a concern for his safety or the safety of others, so I have to make sure that he does not injure himself. Patience is important at this time because I have to let him wind down at his own pace. It is stressful because I feel as if I have no control over the situation. (Participant 10)

Initially, I made a note about situations that caused stress; then I went back to my memos about meltdowns and found that when caregivers referred to meltdowns, they were speaking about the child having a temper tantrum. I returned to search the transcripts even more so that I could gain a deeper understanding of the caregivers' meaning of meltdown. A more in-depth search of transcript 16 showed that tantrums

were the referencing point that referred to the meltdown moments that caregivers spoke

of as participant 16 stated that "sometimes the issue of behaviors can be a challenge.

When my child began to have tantrums, he sometimes hit himself repeatedly"

(Participant 16). During the interview process, caregivers stated that behaviors that

displayed actions such as the child repeatedly hitting or slapping self during the tantrum

phase led to other concerns of safety which will be discussed further in this chapter.

The occurrence of tantrums were repeated often as participants described

perceived stressors while providing care. Although it was noted that some participants

referred to their child having meltdowns, I placed this term at a lower level due to the

infrequency of occurrences mentioned as a perceived stressor. I continued to search the

transcripts for situations or events that caused stress until I was satisfied that the

referenced tantrums occurred more frequently than meltdowns.

I intended to develop a synthesis of concepts that would shed light on the events

that occurred and give voice to each caregiver perception. Although caregivers may be in

similar situations, perspectives of the situations are portrayed differently. During the

analysis, I focused on exploring the various ways in which each caregiver expressed the

perceptions of their current experiences. I went back to the transcript of Participant 5 and

searched a little deeper. After considering the rest of her words, it became obvious that

she was talking about a fear of the unknown as a contributor to her perceived stress of

which she stated, "You may have to come back to a certain task, so I would say the

unknown can be stressful and frustrating at times" (Participant 5). Participant 6 stated that

not knowing was a contributing factor to increased stress when he stated: "in first

knowing, it is like all right, we know something is not neurologically typical with our child." After being observant of events that contributed to his child's behavior, participant 6 commented that "It let us know what we are facing. However, then, it also helped lessen the stress of the worry. Each person with autism expresses it differently. Depending on which behavior he is presenting on a certain day, it differentiates between all right, is this autism or is this just him being a child at this age. Do we need to deal with the child part, or do we need to deal with the autism part, or is it a combination of both."

During the analysis of transcripts, I realized that the concept of perceived stressors had the potential to influence my view of the experiences that caregivers shared. For example, I began to recall some of the aspects of perceived stressors as described by some of the caregivers as I embodied my former role as a developmental disability provider. I was able to separate myself as Participant 7 described his experience by stating, "One of the situations that bring about stress while caring for your child is constantly redirecting. That can be a bit stressful when you are continuously trying to redirect, and the individual is not easily redirected" (Participant 7).

As I continued to focus on perceived stressors, a deeper search into the interviews showed that communication was another contextual concept that evoked a sense of stress in the caregiver as Participant 8 stated:

Sometimes communication becomes difficult as my son tries to express his feelings. This difficulty alone brings about stress because I worry about his social interactions and whether or not others are bullying him when he goes to school. I

also worry about safety because there are times when he will take off and begin to run. He loves the outside, so at times he does not understand boundaries and timeframes. Living in a locked house has now become a routine for both my sons to keep my child safe. Ensuring that we are at the bus stop on time to get him is also important because once he comes off that bus, he takes out running. (Participant 8)

I returned to transcript 14 and found that communication continued to be a contributing factor to the perceived stress felt by caregivers. In a review of my memos, I found that caregivers felt that it was important to try to figure out what their child was trying to communicate. This assessment allowed caregivers to find ways to meet the needs of their child. Participant 14 stated that "Communication with my child can sometimes become difficult. Not being able to communicate with him becomes stressful when he cannot tell me what is wrong and I cannot figure out what is causing him to react."

I searched my memos for notations on shutdown modes and found that caregivers referred to their child as not communicating when they did not want to complete a task. Participant 9 stated that "The fact of knowing sometimes you cannot do anything about their condition, like for instance, when they are in a shutdown mode, and you cannot figure out what's going on. It gets quite stressful sometimes." Participant 19's statement related to shutdown modes as the caregiver referenced communication issues by stating the following: "When I do not know what is wrong, it becomes overwhelming to try to figure out what is wrong." Searching the transcripts further allowed me to gain a deeper

understanding as caregivers referenced "shutdown mode" as it related to the various

behaviors the child presented. Caregiver expressions of shutdown moments appeared to

be an underlying factor that contributed to behaviors that stemmed from poor

communication. Participant 2's statement supported the shutdown moments about

behaviors and task when she stated that: "Helping him with his homework or getting him

to do things on his own without him getting angry or mad about it can get stressful

sometimes."

Safety was another perceived stressor that evoked stressful situations in

caregivers. A deeper search of the transcripts revealed that safety impacts the caregivers

in different ways, and causes additional stress that forces others in the household to share

the burden of providing safety for the individual. This concept appeared to be an elusive

target for a few of the caregivers as they tried to learn ways to implement a plan that

would meet the needs of everyone in the household. One tool that caregivers relied on

consistently was the ability to embrace measures that would keep their child safe. Such

measures have been inclusive of relocating locks based on the height of the child, setting

protocols to keep the door locked at all times and ensure that a buddy system is in place.

Other safety skills included keeping household chemicals and medications out of the

child's reach and keeping home clutter free. Such findings were supported by statements

provided by the following participants:

There are times when my child will try to get out of the house, so safety is my

biggest stressor. Making sure that the doors are locked. We had to relocate the

locks on the doors by placing them higher to keep our child from unlocking the

door and running away. (Participant 11)

Probing of the transcripts and literature (American Psychiatric Association, 2015)

revealed that the child with autism typically has trouble trying to generalize certain social

skills (safety). Due to this, measures such as keeping the child in eyesight or arms reach

was supported by Participant 17's statement that:

When my child becomes bored inside the house, and he tries to get outside, I have

to ensure that he is always where I can see him. Because he will get in a hurry and

run out of the house when he has an opportunity. He lacks a sense of danger to

know that he could get hit by a car or even stumble and fall. It becomes stressful

when you have to continually keep him in eyesight and also tend to other duties in

the home and away from home. (Participant 17)

I continued to look for issues related to environmental situations and events that

caused stress from other participants. In this search I noted Participant 12's supporting

statement concerning the environment and how sensory overloads can impose increased

levels of stress on the caregiver and child:

I have to make sure that I keep the unfamiliar sights and loud sounds at a

minimum as much as possible because it causes anxiety for my child. Certain

sounds tend to overload my child, and because of this, I try to keep the inside

environment peaceful and more stable to prevent any behavioral episodes. By

trying to keep the environment inside our home quiet also helps to reduce the

amount of stress and anxiety I feel when interrupted moments cause my child to

act out. (Participant 12)

Participant 12 also stated that in "seeking outside sources that will provide activities that

are age appropriate" also contributed to the amount of stress she experienced as she

attempted to meet the needs of her child socially.

Because the child with autism can become continuously focused on certain items,

caregivers felt that it leaves their child unaware of the possible dangers in their

environment. Participant 3 shared insights in regard to environmental factors in the home

and how the concern for safety increased stress and anxiety by stating:

When multiple things are going on in the household such as cooking time, and

cleaning, you have to multitask to ensure an eye is kept on him and also others in

the house. It causes stress and anxiety and can delay processes in my mind

especially when he gets out the door or is playing in the kitchen when I am

cooking. (Participant 3)

During the interview process, I noted that repetitive behaviors imposed a concern for

safety on a few parents as Participant 16 voiced her perceptions on how the display of

certain behaviors posed a threat to her child's safety when she stated that: "The outbursts

bring up the issue of keeping him from injuring himself, so I worry about safety. It causes

me anxiety and fear."

During the analysis of transcripts, it was found that environmental threats outside

the home also posed potential threats and increased the likelihood of triggering sensory

overloads for the child. In consideration of uncomfortable behaviors this perceived stressor was supported by the following statements:

> Trips to the doctor can sometimes be stressful because it is a different environment and can cause anxiety and confusion for him. Often I try to reach out to the nurses ahead of the appointment in hopes that they can arrange an exam room that will have some familiar surroundings to keep my child from acting out. It becomes overwhelming for me because sometimes I may not be able to call ahead or the nurses may not have time to prepare the environment. (Participant 13)

Structure within the home and in routine schedules also held significance for caregivers as they shared their experiences. The occurrence of unstructured routines was found to be the root of specific behaviors that caused caregiver stress as Participant 4 responded that "if a structured environment is not maintained, it causes anxiety for me as well as for my child."

An analysis of the perceived stressors voiced by caregivers was taken into consideration as a few participants spoke about repetitive behaviors and safety during the times when such behaviors were presented. Participant 20 and Participant 4 shared these concerns in the following statements:

> Repetitive behaviors such as banging his head or slapping himself when he becomes upset are stressful. Because you do all you can to keep him safe not only during this time but all the time. Often this behavior shows when he becomes angry or frustrated with something. (Participant 20)

and,

> When my child has repetitive behaviors like rocking back and forth when visitors
>
> come to the house, it becomes stressful. Because these individuals are not familiar
>
> to him, he will pace back and forth into the room. Sometimes he will flick his
>
> hands back and forward and continue to ask the same question over and over
>
> again "who is that? (Participant 4)

Another probe into the memos focused on sleep habits of the caregiver and how a lack of sleep affected their ability to implement measures that would decrease the stress that caregivers felt. Caregivers stated that patterns of sleep for them were interrupted by their child's sleep patterns. Based on caregiver responses I noted that when sleep patterns of the caregiver were interrupted (due to interrupted moments of sleep for the child), it caused stress for the child and the caregiver. I found that the caregivers' perceived that when deprived of sleep it causes a decline in their health and less alertness to focus on the needs of their child.

This perception was significant in the way caregivers adopted coping strategies to intervene when their child was acting out or when other stressful events occurred during the caregiving process. This perception was supported by statements from Participant 15 on how such events of stress impacted her physical well-being as she stated that: "Because my child has poor sleeping habits, a lack of sleep for myself can sometimes be stressful for me when he has had a bad night." Participant 15 concluded that "when moments like this occur, a lack of sleep for myself cause me not to function on the next day fully. It causes anxiety as well."

Financial aspects were also perceived as potential stressors in the lives of a few caregivers and were supported by the following statement made by Participant 18 as she expressed that:

Being a single parent, sometimes it is stressful financially. When my child becomes ill, and I have to stay home with him because of lack of support. When he is not feeling well, he cannot effectively communicate what is wrong. It becomes overwhelming as I try to figure out what the problem may be. Not having the necessary support physically and financially to help me with my child is also another situation that causes stress.

Caregiver's perceptions of well-being were the second theme because all properties that fell under this category pointed to the caregiver's psychosocial and physical experiences of when they first begin to recognize a difference in their well-being. This theme introduced the internal and external complexities that entangle with health implications for the caregiver and the pressures of social convention and conformity. During the interviews, caregivers described how stressful situations lessened the wholeness they felt regarding their well-being. Responses centered on how they perceived their well-being from a physical and mental point of view, including the factors that were contributing to impacting their well-being. Examples of the subcategories that fell under this category were *feelings of depression, anxiety, loneliness, stress, feelings of being overwhelmed, maintaining well-being, and current health conditions.* When asked to describe well-being regarding their health, caregiver responses were demonstrated by statements such as those made by the following participants, in describing well-being:

I try to keep a schedule or calendar to reduce stress. Physically, I have diabetes, and high blood pressure and the stress of caring for my child contributes to my levels increasing. Mentally I have sought help from a psychiatrist. There have been times when I felt depressed. Also, because he will walk off the school bus, and we cannot find him, it increases my worrying and stress. I worry about him becoming an adult. When seeking help for these issues, I worry about separation anxiety because he is only used to me. Seeking assistance from other places also cause anxiety and worry for me. (Participant 2)

A more in-depth probe into the transcripts revealed that feelings of being overwhelmed, tired, stressed and feeling alone led to what the caregiver has perceived as a decline in their physical and psychological well-being. As caregivers experienced what has been perceived as a decline in well-being, responses show that a realization of such factors caused the caregivers to find ways to either improve or decrease the stressors felt.

Participant 14 expressed that stress and worry impacted her from a physical and psychological standpoint when she stated that:

I feel stressed on many occasions because communication is the only concern when dealing with my child. Often, I worry about how I will be able to meet his needs if I cannot identify what is wrong. I worry about his safety during times that he will not calm down because something is wrong or he cannot get his way in certain situations. All of these things cause me to become overwhelmed from a mental standpoint and tired physically. There are times when situations arise, and I feel I am all alone in this. (Participant 14)

Another example of a statement in this category was made by Participant 1 about the
challenges she faced that led to her seeking counsel:

> Raising a child with autism has certainly caused much stress over the years. Five
> years ago, I was diagnosed with breast cancer. I am a survivor, and I have no
> health issues currently. I attend counseling two times per month and pay privately
> to maintain my mental health. That has been very helpful. I am a big believer in
> self-care. (Participant 1)

Participant 3 spoke of sacrificing his freedom and likes when he shared how he
began taking care of his brother. His statement supports the concept of well-being and
how feeling whole can be broken due to the social issues within an individual's
environment:

> When I began working with my brother and taking care of him, it was very
> stressful, and I felt anxiety as I learned a new thing, to not only care for myself,
> but for my brother. It allowed me to understand what it was to be an adult and
> have to sacrifice things like my friends, my social life, sports and activities that I
> could do in my spare time, to understanding that priorities take priority.
> (Participant 3)

Participants 4 reflected on the current health issues she faced and related the outcome of
those conditions to stress by stating "recently I was diagnosed with diabetes, so I try to
reduce stressful situations in my own life." Participants 5 and 6 shared their perspectives
of what well-being meant to them and the strategies they used to maintain well-being
when they stated the following: "Maintaining low-stress levels as much as possible is

essential in keeping my well-being. Choosing healthier options for meals and receiving a good report from my primary care doctor are all critical" (Participant 5). Participant 6 shared that: "Not feeling overwhelmed, feeling well-rested, being in good spirits and optimistic helps me to remain balanced and in good health" (Participant 6)

Further analysis of the transcripts showed that some caregivers felt that their well-being was good physically and mentally. Responses supported the perception that finding ways to care for self was critical in being able to care for the individual with autism. In the next statement, the participant felt that his health was good, but that constant redirecting of the individual contributed to feelings of being drained. Participant 7 stated, "I describe the well-being of my health physically and mentally as good. Sometimes, a little shy of good, I feel mentally drained, especially when you have to redirect constantly."

Due to the various responses related to well-being and feelings of being drained, overwhelmed and tired, I went back to my memos to note that the behaviors of the caregiver and how they responded to the child also played a role in how the caregiver perceived well-being. I also noted that the way caregivers responded was also a significant factor in how the caregiver learned to cope with various challenges. The next three statements support the concept of caregiver perceptions of well-being. Factors that influenced these perceptions were shared by Participant 8 when he stated:

Sometimes I become physically tired and drained. It is difficult in providing care and having to work. It becomes exhausting sometimes when I have to run behind my child because he has gotten out of a door that has been unlocked. Because he

moves so quickly, coming in, and taking a few seconds to regroup and relock the door can make a difference in compromising or maintaining his safety. Mentally I am good as I maintain myself by keeping the faith. (Participant 8)

Participant 9 stated "physically, I become exhausted. Not having time to rest properly tends to make me feel drained and tired". Moreover, Participant 10 shared that "Although I have no health issues at this time, I sometimes feel tired and overwhelmed. I am sometimes stressed out because of the behaviors that my child have on some days". Participant 11 shared that "sometimes I feel tired and overwhelmed." Participant 12 also stated that "sometimes I became a little frustrated and secluded during times when my child began to show behaviors because the environment is different or I cannot pinpoint what is wrong with him."

As I continued to probe the transcripts, a more in-depth search revealed more participants who felt that the caregiving role and the challenges faced shaped how they perceived their health by stating that: "Regarding my health, I have sometimes felt tired physically and mentally. I experience times of frustration and feel overwhelmed" (Participant 13). Participant 15 provided another supporting statement in regard to perceived well-being by stating that: "In describing my well-being, I sometimes feel stressed and tired. At times, things become a little overwhelming when I have not received an adequate amount of rest." Participant 16 expressed that "I am exhausted physically and mentally on many days. Sometimes just worrying whether my child will be okay can become exhausting and can cause me to experience stress." Each participant

shared how the certain task within the caregiver roll contributed to how they felt about well-being.

A search of the transcripts revealed that communication and worry also played a role in this process as Participant 17 stated the following: "Physically I get tired from sometimes having to ensure that home is safe and clutter free for the safety of my child. Mentally I get drained from the constant worry and care I have to provide for my child." For participant 18 communication was a factor when she stated that "I feel drained and stressed. I worry a lot whenever my child is sick and cannot communicate what is wrong". Factors such as feeling exhausted and worry were contributing factors for participant 19 when she shared that "I would describe well-being as having little stress mentally and physically, but of course, we know that that is not always possible. Physically I sometimes become exhausted. Mentally I worry about my child."

Participant 20 expressed that due to current health conditions, the task of avoiding stress was difficult. However, a further search of transcripts showed that efforts to avoid too much stress were necessary for the caregiver to maintain or improve well-being. Shared perceptions regarding strategies to avoid or decrease these factors will be discussed further with other themes. However, in regard to reasons for avoiding increased stress Participant 20 shared the following: "I have high blood pressure, so I have to work extra hard in avoiding things that will place stress on my body. Mentally things can sometimes become draining."

Strategies to cope was the third theme that emerged from the analysis and connected to the central phenomenon. This category centered on properties that involved

the caregiver's ability to improve their well-being by not only seeking counsel but also to find ways to address the factors that contributed to influences on their well-being. Processes that the caregivers used to select coping strategies encompassed situational factors that influenced how they coped with stressors. Examples of the subcategories that represented this category were: *responding to challenging behaviors, beliefs that influence coping, understanding coping strategies, and spirituality*. Influencing beliefs were a major contributing factor in this category. The expression of these beliefs also captured what the caregivers believed affected their ability to adopt effective strategies in maintaining their well-being. Examples of additional codes that described this well-being category were: *meditation and prayer, reading scripture, going to church, counsel with a pastor, and understanding coping strategies.* When asked to describe strategies used to maintain well-being, and beliefs that influenced the ability to cope, caregiver responses were supported by the following statements made by caregivers:

> To cope I pay for counseling at least twice a month and exercising helps to relieve some of the stress that I experience. Taking time out for self helps me to think things through so that I will be able to cope more effectively with situations. (Participant 1)

During the interview Participant 1 also stated that "If I do not adequately take care of me and engage in activities that will reduce my stress levels, and eat a well-balanced diet, I will not be able to provide sufficient care for my child." Additionally, Participant 1 felt that "as parents, we would have better-coping strategies if there were more support and better access to more available resources for our loved ones."

A further look into transcript 8 showed that faith was a critical factor that a few caregivers relied upon as they sought a way to feel whole and gain the strength to continue providing care for their child.

> I go to church; I try to take time out to meet my own needs by praying and enjoying the services at the church. I like to work on cars, so sometimes when I have the opportunity to do this, it helps to relax me. It also allows me time to take my mind off things. (Participant 8)

Based on some responses, caregivers understood the importance of learning how to cope with the different challenges that presented as care was provided to the child. Participant 16 stated that:

> I understand that if I do not take the time out to meet my own needs and take care of myself, I will not be able to take care of my child. Admitting that having a child with autism impacts me emotionally. It helps in preparing me for what lies ahead. It prepares me in learning how I will cope with challenges, such as keeping his safety first by removing objects and things that may cause injury.

Participant 2 felt that "learning patience and taking one day at a time" would help her to use more effective coping strategies as she provided care for her child. Coping strategies used to maintain well-being for Participant 2 were stated as "I talk with my mother sometimes. I was going to a professional counseling agency and talking with a counselor once a month with the options of coming there twice a month depending on how I felt."

A few participants expressed how other activities aided in the ability to cope with the daily challenges that were faced. Such beliefs for coping were supported by Participants 3 and 4 as they stated the following:

Working and playing sports help me to use better-coping strategies as I provide care for my brother. More training in the area of providing care for a child on the spectrum would be helpful in learning ways to cope with the different issues. (Participant 3)

Participant 4 added the following:

Going to movies, going to the salon. Having girl time and the opportunity to talk and express how I feel helps me. I also attend church. I have to be able to live my life and do the things I enjoy however I always make sure my son is good *first.* (Participant 4)

Participant 4 also stated that "more money and resources are needed. I do have to say that the resources are out there, but many people do not know about that. Also, there are events and seminars I would like to attend, but there is never enough time."

In addition to becoming involved in other activities, the belief that talking with someone was found to be a factor that allowed for caregivers to learn ways to embrace the situation as they learned how to cope with the various challenges faced. These beliefs were supported by the following statements made by Participants 5 and 6. Participant 5 said, "Talking to family and friends, going to the spa, attending the movies, concerts and praying are ways I cope with the challenges that we face will caring for our son." Participant 6 expressed his perceptions by stating:

While sharing thoughts with my wife, both of us take time to connect without our sons. My wife allows me to go to and participate in activities that are restful and enjoyable. Additionally, more ready access to health care providers & educators that serve autistic individuals would be good. Affordable programs that provide autism support and support programs that are close to where I live would help decrease some of the stress.

A broader search of transcript 6 showed that connecting to the family was an important part of support. I also found that as families connect with their children, they also learn to embrace their child by accepting the diagnosis of autism as they learn how to cope with the different challenges that may present.

Many participants felt that becoming engaged in activities that they enjoyed allowed time for themselves so that they could gather their thoughts. A continued search of the transcripts and memos showed that by taking time out for self, caregivers were able to feel a sense of renewal, and were strengthened as they returned to the role of caregiving. The following statements were supportive of this perception as Participants 7, 9 and 10 stated that: "The coping strategies I use to maintain my well-being is listening to music in my own time" (Participant 7). Participant 9 shared "I love to paint and plant vegetables as a hobby. It helps to relax me"; and Participant 10 voiced that "I take time out for me so that I can relax. Listening to music helps me to relax. Sometimes just taking a walk and listening to my music helps me to relax also."

In expressing beliefs that influenced how she coped with the daily challenges of providing care for a child diagnosed on the spectrum, Participant 10 stated that "having

someone to talk to so that I can express how I feel. Having more support during the challenging times would also help. More information on what to expect is needed because no two people are alike." Participant 11's statement was supportive of the renewing of mind and body when she stated that: "I try to regroup by meditating and exercising. Sometimes a little me time is good because it allows me the time to do the things I want to do." Participant 11also stated that "having better access to programs and family support groups" would help her to use more effective coping strategies during the journey of caregiving.

In regard to the perspective of renewing self, Participant 12's statement was also supportive as she stated that "Having time for me to wind down is important. Taking walks and having time to meditate so that I can pull my thoughts together is helpful to me." Participant 12 also shared that having "better resources that provide support for families and programs that are offered outside of a routine work schedule so that my child will have activities that will help to engage him in the social environment, such as exposure to other children" would help her to learn how to cope better when different situations arise.

Feelings of having a balance and wholeness were supported by Participant 13 as she stated that "I try to keep myself balanced by seeking support from a family member who will watch my child for an hour or two so that I can have some me time. Seeking counsel at least once a month to share how I feel and to try and find ways to resolve these feelings" is how she copes on a routine basis.

Participant 14 stated that "I exercise three to four times a week, have daily prayer and scripture reading to strengthen me. I also read poetry to relax my thoughts and spend my time talking about how I feel." Participant 15 shared that "keeping daily schedules and routines help to keep my child calm. In turn, this also prevents me from experiencing stress and feeling overwhelmed." Participant 15 believed that "having time for self so that I can think on issues at hand and how to prevent certain behaviors, admitting when help is needed, and learning how to deal with different behaviors is important in developing coping strategies that will allow for me to take care of my child."

Participant 17 stated that to cope:

I take time out to relax. When my child is in school, I exercise during the week. I also pray and meditate so that I can strengthen myself. I find time to meet my needs by resting and doing activities that I enjoy such as listening to soft music. (Participant 17)

Participant 18 shared that in learning to cope "I try to get some rest myself. I try to be very observant of his needs and what occurs in his daily routines";

Moreover, Participant 19 voiced that "I exercise 3 times a week. Talking with someone about how I feel helps to release some of the worry and anxiety that I experience. Attending church services and reading also helps me to relax."

As I returned to transcript 20, I found that having someone to talk to was a measure that many of the caregivers relied upon as they learned to build supportive relationships and express the emotions that they felt. Further evidence showed that expressing emotions was a means of learning how to improve well-being and develop

strategies that would better prepare caregivers as they learned to cope. This final analysis was supported by Participant 20 as she expressed that "sometimes having someone to talk to help to strengthen me. I know that my child needs me, but taking time out for self so that I can regroup help in maintaining my own emotions."

The desire to help self & others was the fourth theme that emerged from the data. This category captured the caregiver's determination to reach a sense of wholeness in life as the caregiver sought to strengthen self and find avenues to help others along the course of providing care. Examples that described this category were: *take care of self, talk about the situation, seeking programs and support, seeking information/more knowledge, become involved, be observant, ask for help, and do not isolate self.* Statements that fell under these categories were voiced by Participant 1 when she shared her feelings regarding various programs and groups; she commented that:

> when seeking resources that will provide support and care providers when I have
>
> to work, often the support is not adequate. I find that support coordinators do not
>
> follow through on updating the service plans for my child because they do not
>
> keep the job long enough to make a difference. (Participant 1)

Participant 5 talked about her initial response to a lack of knowledge about her child's disorder and the situations that were challenging. A further search of the transcript revealed that learning as much as possible about the child's disorder aided in adopting strategies that would help to meet the needs of the child and the caregiver. Becoming more knowledgeable also allowed for the caregiver to decrease factors that affected well-being. This was supported by Participant 5 in the following statement:

I would say when dealing with the various challenges that our child presents with the diagnosis; we are still learning every day about different things that could come to be and also as far as time management because it takes more time. (Participant 5)

During the interview process, some caregivers agreed that feeling helpless at some point in their journey was because of not being familiar with their child's condition.

Participant 5 shared the following:

I can only speak for myself. Initially, of course, I wanted nobody to know. I did not want my child labeled because, again, reverting to what I knew of children with special needs growing up, they were in one half of the other end of the school, while the mainstream kids were on the opposite side. So just me becoming more knowledgeable because my initial reaction was, oh my gosh, he cannot have this. He cannot have this attachment to his school record. It dismisses the fact that I did not know I was not educated about how things have changed and that it's ok to let people know because you never know who might be able to help you in various capacities to cope with the condition. (Participant 5)

In helping self and others, it was found that spending quality time with family was important as Participant 6 stated the following:

Even though you face challenges it is still important as a husband and wife unit to connect, but also it's important to connect as a family like going out to eat dinner or take a family trip to do something as a family unit together. (Participant 6)

By not allowing autism to consume the caregiver's life, this statement supported findings as participant 6 expressed that family support aided in maintaining a balance in life.

I returned to the transcript of participant 20 to find that as caregivers expressed a desire to improve circumstances for themselves and others, the building of relationships was a basic need that was essential in maintaining well-being. Participant 20 commented that "I would tell others to be very observant of their child. Learn about their child's disorder, and seek help when needed. I would remind people to be understanding and know that they do not stand alone during this time." In providing this statement, caregivers recognized that admitting and seeking help was an avenue that provided the means to build relationships with others who could help them to overcome the challenges they faced while providing care for their child.

During the interview process, Participant 2 stated that she utilized online support as a means to reach out to others for information that would aid her in the process of coping with daily challenges while caring for her son when she stated that

> Reaching out to many parents on Facebook gave me someone to talk about the situation. We talk about our child and how they react. We also try to find out if any parents have information about the conditions they face. We also talk about things that we can do to help cope with the situations we face. (Participant 2)

A deeper search of transcript 4 revealed findings that self-care was important in ensuring that the best care would be provided for the child. In helping self and others, self-care was a factor that enabled the caregiver to manage their expectations while focusing on what would be a realistic way to achieve the task of providing care in the

least stressful manner that was possible. This was supported by the following statement

provided by participant 4 when she stated:

> To reduce the stressors that I feel, I try to plan for events that will occur at home
>
> versus people just showing up unannounced. Planning helps me to prepare so that
>
> my child will know what to expect. If I had the opportunity to help someone else,
>
> I would tell them to take care of self and meet their needs so that they will be
>
> strong enough to meet the needs of their child. Become involved in activities and
>
> events that will help them to learn how to cope with the different behaviors that
>
> their child may have. Be very observant of the needs of their child and know what
>
> to expect with the disorder. (Participant 4)

In maintaining needed support, Participant 7's statement supported findings that

adequate support aids in helping the caregiver not to disconnect from people. The

statement also supported findings that social networks can help in providing the

emotional support that is needed in the caregiver role:

> The biggest support I find is in the people that are close to me. Talking to these
>
> individuals help to strengthen me. What helps me a lot is doing something that
>
> will calm my mind. Music tends to be the medicine for calming my mind. I would
>
> inform others not to fold under pressure. Find a strategy that will help you deal
>
> with the situation as it can be very frustrating and overwhelming at times.
>
> (Participant 7)

I returned to written memos to find that a few caregivers relied on the assistance

of religious organizations to provide a listening ear. Maintaining support gave caregivers

a sense of security as they connected to members of the clergy in their search for help. This sense of security was supported by the following statement provided by participant 8 when he stated:

> I take time out to meet my own needs by using prayer and meditation. Going to church allows me to have time to talk with my pastor about the challenges I face. Hobbies such as working on cars help me to relax and prepare me for whatever problems I may have to face. As a caregiver you have to be observant of your child, know how to deal with the different things that will arise and learn about the disorder. Don't just close yourself off, get help because you are not alone. (Participant 8)

Participant 9 found comfort in seeking support from a local provider agency as she found ways to cope with the daily challenges by stating that:

> I participate in meetings sponsored by a provider agency that send support staff out. These meetings help me to cope with the situation so that I can provide better care. I would encourage others to talk with someone about the feelings they have. Don't close yourself off because help can be found. (Participant 9)

In addition to reaching out to others for support, finding objective measures to cope with stressors was also a way in which caregivers faced daily challenges. This was evidenced by statements made by Participants 10 and 11:

> Whenever I began to feel stressed, I take the time to plan things out so that the behavioral responses from my child will not affect the way I cope. I talk with others and seek help to be able to continue to carry out my caregiving

responsibilities. I would tell people not to close themselves off from others.

Develop a support network and express how they feel about the situation.

(Participant 10)

Participant 11's statement was very supportive of seeking help and was inclusive of being observant of various things that will increase the probability of causing behaviors that will contribute to some of the emotional feelings that caregivers experienced when she stated the following:

In order to reduce the feelings of being frustrated and overwhelmed I try to be observant of what is going on around my child. Being observant allows me to respond when an event occurs quickly. I feel better when I talk with family and friends because it allows me the time to express how I feel and what I can do to rid myself of feelings of being unhappy or frustrated. I encourage others to make sure they pay attention to the triggers that can cause their child to act out, talk about their problems and do not keep all those emotions bottled up on the inside. (Participant 11)

In this study, I also found that in helping self and others, caregivers found ways to alleviate feelings of withdrawal when Participant 12 stated that:

Because I sometimes feel secluded, I try to keep structure around the house and plan activities that will not take my child by surprise. Being observant is very important because it allows me to know why my child is responding the way he does. Being observant helps me to plan for events outside the home, so I arrange for someone to go with us. I would try to help others by being a part of their

support team. I would tell them to make sure they are taking care of themselves and meeting their own needs so that they will not become worn down and frustrated. Seek as much educational information as possible so that they will have a clear understanding of their child's condition. Most important of all, know when to ask for help. (Participant 12)

It was noted that being observant of the child helped caregivers to adopt coping strategies that would allow for them to respond more appropriately to their child's behavior, thereby improving the outcomes for their child and alleviating feelings of stress and being overwhelmed for themselves as Participant 13 stated the following:

To find ways in resolving my feelings of stress, frustration and being overwhelmed I keep a balance by seeking support from family members so that I can have some time for self. Going through these challenges, I would recommend to others to take time out to become involved in a network of support and seek the help they need to strengthen them. Learn all they can about the disorder and learn different ways in which to help themselves and the child. (Participant 13)

Participant 14 added that:

To keep myself from becoming tired and overwhelmed I try to focus on things that are going on in my child's environment before and after an event occurs so that I will be able to meet the daily challenges of caring for my child. I would advise others to be very observant of their child. Do not feel alone but find someone who will talk with you. Become involved in other activities and develop

a support team. Find ways to take care of self so that they will have the strength to

carry on. (Participant 14)

I further looked at the transcripts and found that keeping daily schedules provided

avenues that aided in the reduction of stressors. I gained a better understanding of how

calendars and routine schedules lent a helping hand to the reduction of stressors and

provided structure as Participant 15 stated the following:

> I keep a daily schedule of things so that I can reduce the anxiety I experience
>
> while caring for my child. Structure during activity time, feeding time, and
>
> bedtime allow me to be more observant so that I will know how to cope with
>
> different outbursts. I would encourage other parents to take time out for
>
> themselves and develop a routine schedule for self and child. Learn more about
>
> autism and the different ways to help their child and also ways to improve self.
>
> (Participant 15)

Participant 15's viewpoints supported the idea that stepping back from the situation

allows for the caregiver to renew self in preparation for caring for a child on the spectrum

when she stated the following:

> When I ask for help from family members and friends, it allows me time to take a
>
> break so that I can take time out for myself. In talking with others, I can release
>
> some of the anxiety and stress by expressing how I feel. In admitting that my
>
> child's condition bothers me emotionally, it helps to prepare me as I try to renew
>
> myself. So as I reach out to other friends and parents who have a child on the
>
> spectrum, I tell them to take care of self as well and increase their understanding

by learning about the diagnosis and the ways to make care better. Learn how to handle the different situations that will develop over time. (Participant 15)

Participant 17 voiced the importance of seeking help when needed. In focusing on the theme regarding seeking help for self, I found that the caregiver was able to release some of the emotions they felt as they sought ways to improve their role in caregiving. The following statement was found to be supportive of seeking help for self and others as the participant stated the following:

Knowing that I experience times of feeling drained and frustrated I reach out to others so that I can find ways to express myself and release some of the aggravation I feel. I would tell anyone who has a child with autism to seek help when needed. Talk to someone about the way you feel and began forming a support system that will work for you and your child. Attend events that provide information on how to deal with different behaviors. Learn your child and know the do's and don'ts of care. (Participant 17)

Participant 18's views on adequate rest and seeking help supported the importance of feeling whole while caregivers found ways to improve self and establish needed support to strengthen them as they provided care for their child.

Getting the proper rest and having a system for support is what helps me to cope with the daily stressors of caring for my child. I encourage others to seek help and resources that are affordable and know when to ask for help. Learn about the disorder and what to expect. Learning ways to cope with the behaviors that come along with a child having autism will help to reduce some of the emotions felt.

Most important of all, take care of self because without caring for self, you will

not be able to provide the necessary care for your child. (Participant 18)

I continued to search the transcripts in an effort to understand the caregiver

perceptions on seeking help and was satisfied with the methods of how these strategies

allowed caregivers to help themselves, build relationships (to be discussed further with

the next theme) and help others to find avenues that would help in regaining a sense of

wholeness. A further look into transcript 19 supported how the expression of emotional

feelings allowed caregivers to renew themselves while learning various ways to cope

with their current situation. Seeking help also allowed caregivers to encourage others to

find ways to improve their situations while connecting with others. The following

statement was supportive of this concept as the participant stated the following:

To help decrease the anxiety and frustration I feel, I have to learn different ways

to cope so that I will be able to meet my child's needs. Taking the time to talk

with others allows me the chance to express how I feel. Prayer and meditation are

also ways that help me relax and release some of my emotional feelings. Because

these are a few things that help me I would encourage others not to feel that they

are alone, but seek support from others so that they can refresh and learn different

ways to cope with the situation. (Participant 19)

Feelings about social support were the fifth theme that emerged from the data.

This category captured the caregiver's feelings about external programs and support that

existed. In addition to expressing feelings about existing supports and resources, the

importance of sharing one's story was also expressed. Examples that described this

category were: *caregiver feelings towards support, seeking more available support, and building relationships.* Statements that fell under these categories were voiced by Participant 1 when she shared her feelings regarding various programs and groups; she commented that "sometimes day programs serve as some "holding pen" for our children and do not provide activities for their age levels."

Participant 2 shared that she had to "Learn patience and take one day at a time. Have time for myself. Get more sleep as I was losing sleep due to caregiving. Seek more available programs for my son to be able to attend when not in school." When asked how she felt about support, she commented that "family members and providers make up a part of your social network, so reach out to individuals and become involved so that you can receive the support needed. You are never alone, and people do not know that you need help unless you speak up."

A more in-depth search into the transcript of participant 2 revealed that social support was perceived as a way of building networks and bonding with the various people that made up those networks. Social support seemed to provide means to adopt strategies that aided in reducing the strain of caregiving. The lack of support impacted the caregiver's perception of existing support resources and caused them to feel a sense of helplessness as it related to available resources and support groups. This perception allowed for the caregivers to seek ways to establish support systems that would promote a positive change. As aforementioned in the previous theme, it also evoked the desire for helping other caregivers in the network as feelings were shared during the caregiving process.

Participant 5 shared her feelings about programs by stating that:

We went through some error with other camps, unfortunately, for two years. We could not find something that was a good fit for him and his diagnosis. Some camps are geared for children on the spectrum, but they are also geared for parents who have deeper pockets about the same amount of some people's mortgage payments every week, so available programs that are friendlier on the pocket would be helpful for families. (Participant 5)

Participant 5 explained the importance of sharing your story with someone else when she stated:

Let people know because you never know who might be able to help you in various capacities to cope with the condition. So now, our family, our immediate family, I would even say our extended family, they know that our boys are on a spectrum, you know. We have talked about it at our panels at the church about the challenges we have even now. Last years was our first year participating in the Autism Speaks walk, and we posted it on Facebook. So now you know everybody knows. That is how you can bring about awareness, and we might be able to help somebody else that's going through the same challenges that we went through and help them deal with coping. (Participant 5)

The second review of Participant 5's transcript showed that caregiver perceptions of talking to others allowed for caregivers to build relationships with someone who understood the challenges that are faced on a daily basis. It provided an avenue by which

help could be gained, and sometimes a listening ear could provide the strength needed to endure the challenges of caregiving.

Other participant responses supported other avenues of support. Participant 6 stated that "more ready access to health care providers & educators that serve autistic individuals is important." Participant 8 stated that:

Receiving the needed support, not just when at work and support agencies send caregivers in, but also support that is provided so that a rest period for leisure would be good. Having more community support that provides programs in the area that would help to sharpen the psychological and social skills of my child as he progresses toward adulthood would be welcomed. (Participant 8)

Participant 9 shared that "more support and understanding from people is needed" and "I would be able to help others by being there for them, listening and helping them out." Participant 10 felt that:

Having someone to talk to so that I can express how I feel helps a lot. Having more support during the challenging times would also help along with more information on what to expect. Because no two people are alike, having the support and more information on the diagnosis would be good. (Participant 10)

Participant 12 stated that:

Better access to resources that provide support for families and programs that are offered outside of a routine work schedule is needed. More resources would allow my child to have activities that will help to engage him in the social environment, such as exposure to other children and play time. (Participant 12)

A further review of the transcripts continued to show how many caregivers felt that more accessible resources were needed that would provide adequate support for families with children of the spectrum. This finding was supported by the following statements when Participant 13 stated that there was a need for "more access to support groups for families. More information on autism disorders, programs for my child that are affordable." Participant 13 also shared that "healthcare professionals should become more aware of the fact that families need support to so that they can meet the needs of the patients and the caregiver."

More education and the involvement of health care providers was also a key factor repeatedly expressed by participants as evidenced by the following statement: "Having more access to support groups and health care providers experienced in dealing with the issues that caregivers experience is needed. Receiving more education on ways to cope with children diagnosed with autism would be beneficial for parents" (Participant 14).

A return to the transcripts showed that more supportive statements were also shared in regard to access to more programs that were affordable. Such statements were evidenced when Participant 16 stated that:

Asking for help, and having access to support groups is important. Having programs that are affordable for your child to become involved. Just having someone to talk to and learning new ways to cope with the challenges of raising a child with autism. (Participant 16)

Participant 17 also shared that "There seem to be a lack of programs and support groups in my area, so better access to various programs and support groups that are not closed memberships are needed."

It became apparent that caregiver perspectives about support caused caregivers to become determined in developing measures that were likely to strengthen themselves and others as they provided care for their child. This theme regarding support also connected to the *desire to help self and others* theme and appeared to be an important issue to the caregivers as this theme was viewed as a means of learning ways to cope with the challenges that were faced on a daily basis. Statements such as the one provided by Participant 18 supported the importance of social groups when she shared that:

> More resources that are affordable, such as after-school programs or summer camps would allow me the opportunity to take time to meet my own needs when he is taking part in other activities. More events for families and their children that will allow families to meet and connect to build groups that will support each other is needed. (Participant 18)

Participant 19 also shared that:

> A lot of times groups are considered as closed groups, and you can only join by invitation, so better access to support groups, a better awareness in the community and adequate access to family programs will help parents to develop better-coping strategies so that they can provide the needed care for their child. (Participant 19)

Based on the process I used for data analysis, the five themes (caregiver perceived stressors, caregiver perceptions of well-being, strategies to cope, desire to help self and

others, and feelings about support) emerged and set the precedence for the merging

theory. In developing the sequential order of each category, the beginning of a theory of

caregiver coping processes was formed. Figure 3 illustrates the subsequent process of the

five main themes that formed this theory of caregiver coping processes.
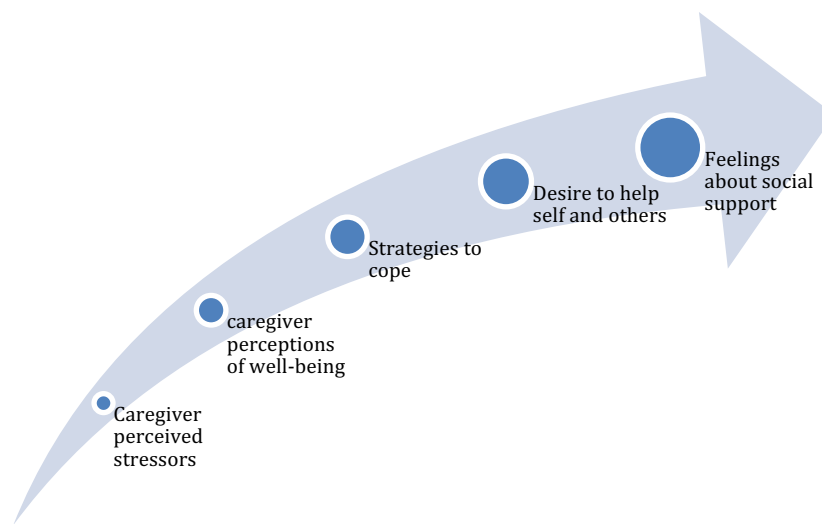
Figure 3. Theory of caregiver coping processes.

In the next section, a summary of the findings will be provided. Additionally, a

discussion of each process within the theory of caregiver coping processes will be

provided in addressing the research questions that aided in grounding this study.

Summary

For this study, three research questions were formulated. Each question was

answered through the emergences of a theory of caregiver coping processes. This theory

was centered on five major themes that emerged from the data analysis. The significant

themes include (a) caregiver perceived stressors; (b) caregiver perceptions of well-being;

(c) strategies to cope; (d) desire to help self & others; and (e) feelings about social

support. The research questions were addressed as follows:

Research Question 1 stated: How do caregivers of individuals with autism perceive their well-being? Significantly, caregivers communicated that in addition to their current health conditions (physically and emotionally), specific factors existed that influenced their current state of well-being. Perceived stressors were a determining factor in the caregiver's ability to maintain their well-being. While providing care for the individual with autism, some caregivers felt that if their needs were not met, they would not be able to provide adequate care for their child. In maintaining well-being, caregivers stated that the physical and psychological stressors became an increasing part of their daily lives that they had to learn to cope with. Understandably, the caregivers expressed the need to seek help at some point to cope with the challenges they faced. Based on caregiver responses, comments of feeling *"overwhelmed" "stressed" "tired"* and *"exhausted"* contributed to a decline in their well-being if avenues were not found to improve their current situations.

Research Question 2 stated: How do caregivers of individuals with autism utilize coping strategies to maintain an optimal level of well-being? As caregivers responded to various challenges across the continuum of providing care for their child, they did not know what to expect along the way and found specific experiences to be overwhelming and stressful. Caregivers expressed an overall need for understanding the importance of adopting effective coping strategies. This understanding was vital to the caregiver's ability to respond to the various challenges that their child presented. Beliefs that influenced the coping skills of the caregivers allowed them to rely on restoration in the form of spirituality which helped the caregivers feel a sense of wholeness. Additionally,

caregivers needed families, friends, communities and healthcare professionals to be open and understanding of the unique needs they had as caregivers. Responses from caregivers revealed that they seek ways to take time out for self in addition to learning ways to reduce stressors when faced with various challenges.

Research Question 3 stated: What beliefs influence caregivers of individuals with autism in adopting effective coping strategies? Caregivers expressed a belief in the need for more knowledge on the diagnosis of autism and the challenges that may be faced. Caregivers indicated that the need for support and multiple resources was not always accessible as many support groups were considered closed groups. Reference was also made to difficulties faced when trying to access resources. Many of the interview responses revealed that caregivers found the need to seek support, and beliefs were that if more resources and support programs were readily accessible, it would allow them to adopt better-coping strategies to face the daily challenges of caring for someone on the spectrum. Some caregivers even indicated having a social network consisting of family members, friends and other caregivers who provide care for an individual on the spectrum. In feeling the need to establish networks, caregivers stated that it enabled them to build relations as an avenue to talk about the situation and share their experiences to help to strengthen themselves and others as they found ways to cope with challenges during caregiving.

In this chapter, the focus was placed on the generation of the *theory of caregiver coping processes*. Steps taken to develop this theory began with the collection of data and the use of methods to build the foundation for this theory. After collecting data, an

overview of the strategies used to analyze the data was presented. Procedures showed how the analysis process moved from the open code phase to the phase of selective coding. Throughout the process of data analysis, five main categories were identified, relationships between each category were found, and significant factors that influenced the movement between each category were presented. During the discussion of results, participant quotes where provided. Each process for caregiver well-being served as evidence for the emergence of the *theory of caregiver coping processes*. Finally, in response to the research questions for this study, a summary of the results concluded this chapter. Chapter 5 will provide an overview of the interpretation of findings, limitations, and recommendations for further research. This chapter will also offer the implications for positive social change to include empirical, theoretical contributions, recommendations for practice, and a conclusion of this research study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this grounded theory study was to explore the social support and processes that caregivers of individuals between the ages of 9-18 diagnosed with autism use to cope with stress in Southeast Georgia. This study was conducted to generate a theory of caregiver coping processes and social support in response to the psychosocial characteristics that influenced caregiver behaviors. A review of the literature showed that many quantitative and few qualitative studies were conducted on the challenges that caregivers of individuals faced as they provided care to a child diagnosed on the autism spectrum. These challenges have been inclusive of noted declines in well-being, events or factors that influence stress levels in the caregivers, and challenges in seeking support. During individual interviews with caregivers who provided care for an individual between the ages of 9-18 on the spectrum, I was able to collect data on the coping processes of caregivers. From this data, I was able to develop a theory that can serve as a framework for families, health care professionals, and communities to implement measures that can meet the needs of the caregiver and enhance well-being so that an optimal level of care can be provided.

This chapter contains a discussion and interpretation of findings and concludes with an explanation that has been drawn from the study. Additionally, all theoretical, practical contributions, limitations, and recommendations for further research are included. Also included in this chapter are implications regarding the need for positive social change in the area of caregiving for individuals diagnosed on the autism spectrum.

Interpretation of Findings

The generation of a theory of caregiver coping processes was developed from this grounded theory study. The theory evolved from the processes that caregivers used for dealing with stress and social support and the factors that influenced the caregivers' processes used in adopting coping strategies. Lazarus & Folkman's (1984) transactional model of stress and coping provided insights for this study by centering on the perceived stressors involved in a person's environment and the influence these stressors have on the person's behavior. For this study, cognitive appraisal phases were used to understand the systems in the caregivers' environment that influenced their coping processes. The caregivers' processes were captured by using semi-structured interviews and surveys.

In regard to the results of this study, I found that the caregivers' feelings about well-being and their perceptions of available support played a significant role in the way they developed coping strategies while providing care for their child. The significant factors in adopting coping strategies were the caregivers' beliefs for coping strategies, situations and events that increased stress levels, understanding of coping strategies, impact on caregiver well-being, and a desire to help self along with recommendations to help others. The influential factors found in this study was confirmed by Ludlow et al. (2012), who explored the challenges and coping mechanisms of 20 parents of children with autism. Findings were further extended by Hodgetts et al. (2013), who explored the experiences of families who lived with autistic individuals.

Lazarus & Folkman's (1984) two stages of the transactional model contained cognitive appraisals that consisted of primary (assess the harm/threat that the situation

may pose) and secondary appraisals (evaluation of what can be done and an individual's

ability to manage and cope with the stressor), which was similar to the five main

categories of the theory of caregiver coping processes that were constructed in this study.

The emerging theory of caregiver coping processes consisted of five main categories: (a)

caregiver perceived stressors, (b) impact on well-being, (c) strategies to cope, (d) desire

to help self and others, and (e) feelings about support.

First, Lazarus and Folkman's (1984) transactional model of stress and coping for

cognitive appraisal is similar to the first two stages in the theory of caregiver coping

processes that developed from this study: *caregiver perceived stressors* and *impact on

well-being*. Cognitive appraisal occurs when the individual considers at least two

significant factors that contribute to response to stress: the threat of the stress to the

individual and the assessment of resources required to minimize, tolerate, or eradicate the

stressor and the stress it produces (Lazarus & Folkman, 1984). The first stage of the

cognitive appraisal consists of a primary evaluation in which the individual asks, "What

does this stressor mean?" and "How can it influence me?" The effect that stress has on a

person is determined by how the person feels about stress, how susceptible the person is

to stress, and the strategies used to cope (Lazarus & Folkman, 1984). In this study, I

found that caregiver perceived stressors focused on the caregivers' awareness of daily

events that seemed to be a contributor that impacted their well-being. The caregivers'

perception of stressors was usually confirmed by situations that increased the level of

stress that the caregiver experienced. This stage dealt with when and how the caregiver

recognized their child's behavioral episodes and other influences that aided in this

recognition. Once the environmental factors were identified, caregivers began to recognize the impact it had on their well-being.

The third stage of the theory of caregiver coping processes, *strategies to cope*, also linked to the first and second phase of cognitive appraisal. In this study, the caregivers' beliefs in regard to what influenced their ability to adopt coping strategies also influenced how caregivers identified problems that increased perceived stressors in their environment and how they responded. The second phase of cognitive appraisal is focused on the individual's available coping options for dealing with stress (Lazarus & Folkman, 1984). Factors that influence the individual's decision to evaluate their competence, social support, and resources to adapt to the circumstances and reestablish a balance between person and environment was similar to the results found in this study. I found that after caregivers evaluated their resources and found ways to balance the daily challenges. These avenues consisted of ways to adopt coping strategies that would help to improve their current conditions and establish a balance between the role of caregiving and life.

The fourth stage of the theory of caregiver coping processes, *desire to help self and others*, also focused on factors that influenced the caregivers' decision to improve their well-being by seeking counsel and address influences on their well-being. A few caregivers expressed the need to seek counsel for themselves in addition to talking to family about the situation. However, some caregivers identified factors that influenced their decision to seek counsel from their pastor or talk with selected peers about how they felt. Other factors included the support that caregivers received from established support

systems. Throughout interviews, the caregivers expressed perceptions and beliefs about their well-being and perceived stressors. These expressions were inclusive of how caregivers felt that additional resources would help them to cope better. One belief was the importance of health care providers becoming more aware of the needs of the caregiver. This finding was confirmed by Weiss and Lunsky (2011), who indicated the importance of health care professionals acquiring the ability to identify when caregivers are at a point of stress so that they can respond promptly.

The fifth process in the theory of caregiver coping processes, *feelings about support*, derived from the caregivers' desire to seek a balance in life as they sought to strengthen self and find avenues to help others who were experiencing this journey in their own lives. In this study, the decision to adopt effective coping strategies and seek a balance in life captured the caregivers' decision to seek help for themselves. Additionally, caregivers believed that becoming involved in events that would strengthen them was the motivating factor that evoked the desire to help others along the way. As they sought to maintain an optimal level of well-being to meet their own needs, caregivers recognized that this would help them also meet the needs of their child. Within this stage, a slight difference of findings was noted in my research because some caregivers expressed the decision to seek help in the third stage of my theory (caregiver coping strategies). As a part of the caregiver decision-making process to seek help, most of the caregivers used informal supports. Either the informal supports were supportive or unsupportive of the caregiver decision, or if they found relief from their informal support

system such as a pastor, friend, or community function, this support was not effective independently in managing the daily challenges they faced.

My findings also indicated that once caregivers recognized a change in their well-being, the decision was made to seek ways to improve their current state of health. The caregivers faced the decision to find solutions to help reduce the stress of daily challenges, which was the fourth stage of my theory of caregiver coping processes. One of the major concerns for the caregivers was being able to meet the needs of their child. During this stage of the desire to help self and others, the caregivers had to filter through their beliefs and perceptions before deciding to adopt different strategies for coping with the challenges they faced.

In this study, caregivers identified situations and events that contributed to stress in their daily lives. Findings reveal that caregivers used problem-focused coping in the identification of stressors that impacted them physically and emotionally. Once factors had been identified, and caregivers felt that they had gained control over the situation, problem-focused coping was used to help manage the source of the problem. Four steps were taken to manage this stress: caregivers (a) defined the problem, (b) generated alternative solutions, (c) learned new skills for dealing with stressors, and (d) re-evaluated and found new standards of behavior. These findings confirmed results in a study conducted by Lovell and Wetherell (2015) in which caregivers who used more problem-focused strategies may have been protected against the psychological conditions that were associated with the caregiving experience.

The final stage of my theory of caregiver coping processes involved feelings about support. Many of the caregivers expressed challenges and motivational factors that influenced their decision to seek ways to strengthen themselves and help others along the way, which was inclusive of forming social networks with known people within their circle. Motivational influences occurred as the caregivers built relationships, found additional support, and gathered more information about their child's disorder. These factors included the way they responded to stressful events and beliefs about access to support and resources. Findings were further confirmed by Ji et al. (2014) with indications of the need for interventions that would enhance the coping strategies of the caregivers as they provide care to an individual diagnosed on the spectrum. In explaining how practice can implement interventions that will aid in improving the identified issues, further research could expound upon the convergence of multiple theoretical models. Convergence would occur by combining the elements of my research with other models to serve as a framework for developing positive interventions that would serve as a theoretically-based hybrid model in which my research could aid in helping to meet caregiver needs.

All the stages of the theory of caregiver coping processes were grounded in rich data collected from caregivers and was informed by a stress-coping model. Based on the findings from this study, I concluded that the caregivers' social environment does play a role in the theory of caregiver coping processes. The conclusion of this research study aligned with Lazarus and Folkman's (1984) transactional model of stress and coping. It is

noted that the process the caregivers in this study went through confirmed the two phases of Lazarus and Folkman's transactional model.

As I conducted my research interviews, I realized that the caregivers felt a deep sense of wanting to regain a feeling of wholeness as they searched for ways to reduce the stressors that impacted their daily lives. A significant factor that contributed to this desire was their beliefs for adopting coping strategies. As data were analyzed, the emergence of themes and categories allowed for the generation of a theory of caregiver coping processes. As aforementioned, additional assistance could be gained by combining my research with another model, such as a Social-cognitive Theory (SCT; Bandura, 1986). A Social-cognitive theory would aid in using a process approach to understanding human cognition, emotion, motivation, and behavior that assumes caregivers are active in shaping their environments as they find ways of regaining a sense of wholeness while providing care for individuals on the autism spectrum.

Further conclusions from the results of my study show that due to inconsistencies found in previous research, the results of the current study have filled the gaps of inconsistency by showing that the development of better frameworks that place focus on promoting positive outcomes for the caregivers of individuals with autism is needed. The development of better frameworks must also focus on the involvement of populations, communities, families, interventions, and outcomes that will improve the emotional and physical well-being of the caregiver.

Comparison to Past Research

Researchers have focused mostly on interventions for the autistic individual and not the caregiver. But the challenges in the literature regarding caregivers were behavioral challenges, decrease in well-being, limited support, isolation, lack of knowledge, and increased stress. Instead of focusing on the barriers, I focused this study on the caregivers' processes for adopting effective coping strategies and explored the influential factors that contributed to their decision making during their caregiver coping processes.

Researchers have demonstrated that limited support and resources are a barrier to caregivers receiving help to cope with challenges while providing care for their child (Cappe et al., 2011; Hodgetts et al., 2013). However, in my study, the caregivers' feelings about support motivated them to become involved in activities, talk to someone about how they felt, and admit when they needed help. By having a support system, the caregivers did not have the stressors associated with isolating themselves or suppressing their feelings because they felt no help was available. The findings of my study emphasized the benefits of having support (whether formal or informal), which influences the ability to form a social network. The findings from my study also confirmed previous studies that indicated having support increased the chance of caregivers reestablishing a balance in life (see Ji et al., 2014).

The literature highlighted that caregivers faced increased stress due to behavioral challenges that depended on the severity of autism (Huang et al., 2014), which was confirmed in my study. Many of the mothers believed that gaining knowledge about

autism and the different challenges that accompany the disorder decreased their stress

when they became more knowledgeable about the disorder. Many of the caregivers

described their child's behavior as unpredictable and tried to address the behaviors using

their methods (i.e., holding the child, keeping the child in eyesight, and giving the child

time to wind down). When their methods were ineffective, the caregivers were motivated

to seek help. This finding from my study was supported by the literature, which

suggested that caregivers who used more problem-focused strategies might develop the

ability to protect themselves against the psychological conditions that are associated with

the caregiving experience (Lovell & Wetherell, 2015), which led them to seek counsel

either formally or informally.

Several coping themes in this study highlighted the use of both problem-focused

coping (reducing stress, seeking information, seeking help) and a few emotion-focused

coping (church attendance, prayer, meditation) strategies in caregivers of children on the

autism spectrum. Some participants revealed existing health conditions (diabetes, high

blood pressure) and expressed that challenging situations such as repetitive behaviors and

concern for child's safety increased their stress in addition to current health conditions.

Others mentioned strategies were eating a balanced diet, exercise, and time for self to

maintain well-being. Most participants stated that other strategies such as meditation and

prayer helped to reduce stress and that such strategies helped to strengthened and prepare

them for providing care for their child. Many participants stated that admitting how they

felt, talking to others, and seeking additional support also helped to strengthen and

encourage them. In adopting coping strategies to maintain health and reduce stress,

caregivers expressed that the everyday choices made shaped their health outcomes. Caregivers who adopted effective coping strategies enhanced their well-being and had support arranged throughout caregiving. Whether the support provided to the caregiver was formal or informal, they experienced less stress. Intervening conditions such as spirituality, assessing the need for help, talking with someone, and actions to improve current health conditions had the most significant impact on the caregiver maintaining their-well-being and outcomes.

Limitations of the Study

Limitations that are inherent in qualitative studies also impacted this study, though many of these are also the positive characteristics that make qualitative research valuable. For example, due to the small sample size and limit to Southeast Georgia, the results are not generalizable in the same way of a quantitative study's results. This means that the results could be viewed as less reliable and not representative of a larger population. The limitation on age range could also limit representation of all individuals on the autism spectrum. However, this study has the advantage of providing a richer, more in-depth understanding of the data. The experiences that caregivers shared in the study could be viewed as essential concepts that give meaning to a deeper understanding of the caregiver perspectives. These concepts can render a better understanding of the psychosocial phenomena under study.

Recommendations

This research study can be extended in future research to include participants from a broader population. A larger response group consisting of participants from

different areas may produce a different response. Including responses from caregivers who provide care to individuals who are at differing levels on the spectrum is also recommended to confirm and expand theoretical contributions. This study can be extended as a phenomenological case study to consider the perceived needs of caregivers or the needs of parents of children with a different disability. Additionally, a case study can be conducted with both caregiver and child as participants. Further, an observational study looking at the needs of caregivers over a specified period who provide care to children diagnosed on the spectrum could make a significant contribution to the field.

Implications

The implications for positive social change entails an improved understanding of the challenges that caregivers face as they provide care for individuals with autism. Other implications include the potential to minimize the negative outcomes of stressors and harness the potential for more positive coping mechanisms that will improve caregiver well-being at the individual, family, community and organizational levels.

Empirical Contributions

This research provides empirical contributions to the field of research by supporting prior research and identifying additional information to close the gap in research about the needs of caregivers of children diagnosed on the autism spectrum. Caregivers in this study agreed that the most considerable amount of stress they endured was due to challenging events or situations that occurred. A discussion during the interview sessions revealed that caregivers were in their greatest time of need when they used negative coping strategies such as frustration and feelings of being alone. Findings

on stress and coping strategies of these caregivers are a contribution to the field of research.

In this study, I focused on the processes caregivers use to cope with stress and social support. I found a gap in the literature regarding information to help parents cope more effectively while providing care for individuals on the opposite end of the spectrum (Hoefman et al., 2012). The responses of the caregivers indicate that they share many commonalities and have a group of similar needs. The common need indicated by caregivers was the need to be understood. Caregivers communicated that they need people to be aware of and understand their unique struggles.

Likewise, caregivers of children diagnosed on the autism spectrum need others to understand that along with their children; there exist unique needs and expectations. Additionally, caregivers felt it was important for healthcare professionals to understand their prior experiences and possible struggles that have been experienced in the realm of caregiving. Caregivers stressed the need to be informed and have quality information on their child's condition and progress. These findings help support previous research in which the collaborated efforts of healthcare professionals can make a significant contribution that will increase the well-being of caregivers and autistic individuals (Sullivan et al., 2011).

Theoretical Contributions

Theoretical implications identified in this study confirms Lazarus & Folkman (1984) Stress, Appraisal and Coping by addressing how the theory applies to parents of children with autism. According to Lazarus & Folkman (1984), stress is a condition or

feeling experienced when a person perceives that the *"demands exceed the personal and social resources the individual can mobilize."* this is called the 'transactional model of stress and coping'. Lazarus (1984) stated that the individual's perception of the psychological situation is a critical factor, and the effect that stress has on a person is based on their perceived thoughts and their ability to cope more than on the stressful event itself.

In addition to theoretical and empirical contributions, practical implications can also be drawn from the findings in this study. Findings from this study provide insight for parents in similar situations. The following practical implications were identified through participants' responses and can help foster working relationships between families, organizations, communities and healthcare professionals.

Recommendation for Practice

Regarding coping strategies, problem-focused coping has been found to be the ultimate method of reducing caregiver stress; while professional support has been identified as the most influential form of support in reducing caregiver stress. However, family and partner support is also found to be important buffers in reducing stress as caregivers provide care. As a need exist to understand better the problems that caregivers face (Hoefman et al., 2014), based on the findings as mentioned earlier, health professionals might look into promoting the importance of professional support to caregivers of individuals on the autism spectrum; and to also provide subsidies for professional interventions to aid these caregivers. Additionally, it is also essential to ensure that these professionals are well trained in the area of autism spectrum disorders,

and would be able to give useful information on managing the challenges faced. Such strategies may aid in the facilitation and support of the caregiver's role. Families and communities should also be encouraged to support and help these caregivers to adopt problem-focused coping strategies to enable them to cope with their caregiving stress actively and healthily.

Conclusions

This study has identified and discusses valuable findings related to the processes caregivers use to cope with stress and social support in Southeast Georgia. For one, the present findings inferred that the severity levels of the child's autism diagnosis have a detrimental impact on the caregiver's perception of stress and well-being and that the caregivers' cognitive appraisals do not have a physiological effect on their perceived stress. However, the stress and decline in well-being inflicted upon the caregivers can be lessened through seeking good support from their spouses, family members, friends, and professionals, as these support systems are postulated to help decrease their stress levels, disrupted schedules, perceptions of support, and declines in well-being. Furthermore, another effective method of lessening the aspects of their stress levels is through the use of problem-focused coping strategies. In conclusion, caregivers who provide care for individuals on the autism spectrum are strongly encouraged to utilize problem-focused coping strategies to decrease the stress felt from the challenges that are faced as they provide care to the individual.

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Appendix A: Severity of Autism

Severity Level	Social Communication	Restricted/Repetitive Behaviors
Level 1: Requires support	With no supports there are noticeable deficits in this area. Difficulty occurs in: a. initiation of social interactions b. clear examples of atypical or unsuccessful responses to social overtures of others. c. May appear to have decreased interest in social interactions	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.
Level 2: Require substantial support	Marked deficits in: a. Verbal/nonverbal social communication skills b. Social impairments even with supports in place c. Limited initiation of social interactions d. Reduced or abnormal responses to social overtures from others	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 3: Require very substantial support	Severe deficits in: a. Verbal/nonverbal social communication skills b. Severe impairments in functioning c. Very limited initiation of social interactions d. Minimal response to social overtures from others	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Note. From Autism Speaks DSM-5 Diagnostic Criteria Autism Spectrum Disorder Guideline. Copyright 2017 by Autism Speaks

Appendix B: Caregiver Survey

Please complete questions including questions on second and third page.

1. I am a parent/guardian of a child who is currently diagnosed with Autism Spectrum Disorder.
   _____ Yes

   _____No

2. My children who are diagnosed with Autism Spectrum Disorder are _____ years of age.

3. Please identify your gender
   _____ Male
   _____ Female
   _____ Other

4. Please identify your marital status
   _____Single

   _____Married

   _____Divorced

   _____Widowed

   _____Other

5. Please identify your age range
   _____Under 20
   _____20-29
   _____30-39
   _____40-49
   _____50-59
   _____60-69
   _____70-79
   _____80 or older
   _____Other

6. Are you currently employed?
   _____Yes
   _____No

7. Please identify your employment
    _____full-time
    _____part-time
    _____student
    _____other

8. Please identify how many children who are 18 years of age or younger live with you.

9. Are you currently using outside caregiver support?
    _____Yes
    _____No

10. How many hours per week do you use outside caregiver support?

11. How do you describe well-being in terms of your own health (physical health, mental health)?

12. What are the coping strategies used to maintain your own well-being? (such as talking to people, time by yourself, hobbies)

13. What do you believe would help you use more effective coping strategies in caring for an individual with Autism?

Appendix C: Demographic Chart

Participants M/F	Age Range of Participant	Severity level of Child's Autism	Age of Child	Primary challenge (behavior, financial, support, etc.)	Outside supports utilized
P1 (F)	40 - 49	Level 2	18	Behavior/Support	Yes
P2 (F)	40 - 49	Level 2	17	Behavior/Financial	Yes
P3 (M)	20 -29	Level 3	16	Behavioral/Support	Yes
P4 (F)	40 - 49	Level 3	10	Behavioral/Support	Yes
P5 (F)	30 - 39	Level 2	9	Behavioral/Support	Yes
P6 (M)	30 -39	Level 2	9	Behavioral/Support	Yes
P7 (M)	20 - 29	Level 3	16	Behavioral	Yes
P8 (M)	50 -59	Level 3	16	Behavioral	Yes
P9 (F)	30 -39	Level 2	11	Behavioral/Support	Yes
P10 (F)	30 -39	Level 2	14	Behavioral	Yes
P11 (F)	20 - 29	Level 2	12	Support/Behavioral	No
P12 (F)	30 -39	Level 2	15	Behavioral	Yes
P13 (F)	40 - 49	Level 2	17	Support	Yes
P14 (F)	30 -39	Level 1	15	Behavioral/Support	Yes
P15 (F)	30-39	Level 2	11	Behavioral/Support	Yes
P16 (F)	20 - 29	Level 3	9	Behavioral/Support	Yes
P17 (F)	30 - 39	Level 2	13	Behavioral/Support	Yes
P18 (F)	30 - 39	Level 2	9	Behavioral/Financial	Yes
P19 (F)	20 -29	Level 1	12	Behavioral/Support	Yes
P20 (F)	40- 49	Level 3	14	Behavioral/Support	Yes

Appendix D: Research and Interview Questions

Research Question 1: How do caregivers of individuals with autism perceive their well-being?
1. What situations or events bring about stress while taking care of persons with autism?
2. How do you respond to your child's behavioral episodes?
3. How might these stressors impact your health?

Research Question 2: How do caregivers utilize coping strategies to maintain an optimal level of well-being?
1. How do you describe well-being in terms of your own health?
1. 2.What are the coping strategies used to maintain your own well-being?
2. 3.Do you experience difficulties during the provision of care to the individual
3. with autism?"

Research Question 3: What beliefs influence caregiver behaviors in adopting effective coping strategies?
1. How do you understand strategies for coping with different situations that arise while providing care for the autistic individual?
2. What do you think leads to factors that will increase stress levels in caregiving?
3. Do you think these factors can influence whether you are able to cope?