Examining Chronic Sorrow Among Parents of a Child With Autism Spectrum Disorder (ASD)

Tiffany M. Bordonada
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EXAMINING CHRONIC SORROW AMONG PARENTS OF A CHILD WITH AUTISM SPECTRUM DISORDER (ASD)

by

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DEDICATION

This dissertation is dedicated in loving memory of my dad, Dr. Jose Bordonada, Jr., who taught me compassion towards others and encouraged me to be persistent.
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ABSTRACT

The purpose of this quantitative study was to examine the directional relationship between chronic sorrow and each of the following (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with autism spectrum disorder (ASD). Specifically, this examination tested the hypothesized directional relationship that parents of a child with ASD scoring higher levels of family understanding, social support, coping behaviors, and competence indicate lower levels of chronic sorrow. A descriptive, correlational research design was employed to examine the research hypothesis. The data was analyzed using structural equation modeling (SEM). The results indicated parents of a child with ASD experience chronic sorrow. Moreover, these findings provide counselors with the knowledge and awareness to support parents of a child with ASD. A discussion of results, implications for counselors, and study limitations are provided.
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LIST OF SYMBOLS

\( x^2 \)  
Chi Square

\( df \)  
Degree of freedom

\( p \)  
Probability value; the probability of rejecting the null hypothesis

\( r \)  
Spearman Rho correlation

\( n \)  
Sample size

\( N \)  
Population size

\( M \)  
Mean

\( SD \)  
Standard Deviation

\( \text{CMIN/df} \)  
The ratio of chi square to degrees of freedom
# LIST OF ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABQ</td>
<td>Adapted Burke Questionnaire</td>
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<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<tr>
<td>CFA</td>
<td>Confirmatory Factor Analysis</td>
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<td>CFI</td>
<td>Comparative Fit Index</td>
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<tr>
<td>CHIP</td>
<td>Coping Health Inventory for Parents</td>
</tr>
<tr>
<td>CPIR</td>
<td>The Center for Parent and Information Resources</td>
</tr>
<tr>
<td>CPRC</td>
<td>Community Parent Resources Center</td>
</tr>
<tr>
<td>FICD</td>
<td>Family Impact of Childhood Disability Scale</td>
</tr>
<tr>
<td>GFI</td>
<td>Goodness of Fit Index</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>MSPSS</td>
<td>Multidimensional Scale of Perceived Social Support</td>
</tr>
<tr>
<td>MTurk</td>
<td>Amazon Mechanical Turk</td>
</tr>
<tr>
<td>PSOC</td>
<td>Parenting Sense of Competence Scale</td>
</tr>
<tr>
<td>PTI</td>
<td>Parent Training Information Centers</td>
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<tr>
<td>RMSEA</td>
<td>Root Mean Square Error of Approximation</td>
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<td>SEM</td>
<td>Structural Equation Modeling</td>
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<td>TLI</td>
<td>Tucker-Lewis Index</td>
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CHAPTER 1
INTRODUCTION

The purpose of this research study was to examine the relationship between chronic sorrow and each of the following: family understanding, social support, coping behaviors, and competence, specifically among parents of a child with autism spectrum disorder (ASD). This examination assessed family understanding [as measured by the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983)], and competence [as measured by the *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989)] with chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)]. More specifically, this examination tested the hypothesized directional relationship that parents of a child with ASD will have lower levels of chronic sorrow due to high levels of family understanding, social support, coping behaviors, and competence.

The parenting role is multifaceted and may present challenges based on particular circumstances. Moreover, parents of a child with a disability experience higher levels of stress due to specific demands and lower levels of well-being than parents of a child without a disability (Oelofsen & Richardson, 2006; Cheshire, Barlow, & Powell, 2010).
A few main predictors of parenting stress include psychological well-being, emotions, coping style, and the child’s behavior (Norizan & Shamsuddin, 2010). More specifically, these authors found parents of a child with ASD reported significant levels of distress and unique family experiences.

Hock, Timm, and Ramisch (2012) found that couples experienced conflict and distance throughout their relationships while providing care for their child with ASD. A range of factors, including physical and emotional exhaustion, financial strain, and social isolation contributed to stressful marital relationships (Hock, Timm, & Ramisch, 2012). However, parents reported a sense of renewed resiliency and confidence in their relationship as they learned to appropriately address their child’s needs (Hock, Timm, & Ramisch, 2012). Moreover, planning family events can be difficult and maintaining sibling communication is often a concern for parents of a child with ASD (Alli, Abdoola, & Mupawose, 2015). Parents also reported a concern for their child’s future due to the lack of specialized service providers and high rates of caregiver burnout (White, McMorris, Weiss, & Lunsky, 2012). Furthermore, one of the greatest stressors among parents is observing their child’s delay in achievement of physical and emotional development milestones in comparison to typically developing peers, as well as anxiety from the uncertainty of when the child will reach key milestones (Pillay et al., 2012).

Despite current understanding of stress and emotions among parents of a child with ASD, little is known about chronic sorrow among mothers and fathers of a child with ASD. More specifically, little is known about the relationships in which chronic sorrow is associated with family understanding, social support, coping behaviors, and competence among parents of a child with ASD. Therefore, an examination between
chronic sorrow and these factors was conducted. Moreover, counselors need to be informed of chronic sorrow and the ways in which it impacts parents throughout the lifespan of raising a child with ASD.

**Problem Statement**

Parents who provide care for a child with a disability reported intense emotional experiences throughout the lifespan (Cameron, Snowdon, & Orr, 1992; Dabrowska & Pisula, 2010; Pillay et al., 2012; Shobana & Saravanan, 2014). These emotional experiences may include shock, disbelief, feelings of isolation, anger, frustration and a profound sense of sadness and loss (Cameron, Snowdon, & Orr, 1992). Although periods of emotions will occur, these intense emotions may not be experienced on a consistent basis. Therefore, it is suggested that parents of a child with a disability are more likely to report feelings of chronic sorrow (Olshansky, 1962).

According to Olshansky (1962), chronic sorrow is described as a parental response to a child with a disability characterized by recurrent grief and sadness due to coping with the loss of a ‘perfect child.’ Parents not only grieve the loss of their own dreams for their child, but also the loss of opportunities for their child (Olshansky, 1962). The sadness is profound and varies in intensity during key transitional points across the lifespan (Olshansky, 1962; Lichtenstein, Laska, & Clair, 2002). Moreover, both child and parent report feeling sadness due to the child’s inability or delay to experience special milestones such as saying first words, taking first steps, and attending social outings (Olshansky, 1962). Additionally, as parents realized the reality of their child’s disability, they often reported feelings of hopelessness, uncertainty, fear and anxiety pertaining to their child’s day to day to routine and future in general (Olshansky, 1962). Thus, chronic
sorrow is a living loss that cannot be removed and is cyclical, pervasive, and progressive
in nature (Roos, 2002).

Olshansky (1962) suggested four basic ideas when working with families who
have children with a disability in order to address chronic sorrow. First, parents must be
given time to accept the diagnosis of the disability for their child and be allowed to adapt
to the loss of dreams and hopes for their child as they seek understanding of their child’s
quality of life. Second, the counselor must allow the family to process their emotions and
frustrations in hopes to better understand what the diagnosis means for the family
dynamic. Third, family members will need to be reminded to seek counseling, or multiple
social networks, throughout their child’s life due to losses at critical points in
development, death of a caregiver, and a loss of hope in general. And finally, the fourth
component suggests if implications one through three are accomplished, then the fourth
component will be achieved. The fourth component is to increase the parents’ comfort
level and self-efficacy when dealing with and managing life with a child with a disability.
Therefore, this examination will assess chronic sorrow as indicated by each of the
following: family understanding, social support, coping behaviors, and competence,
among parents of a child with ASD.

**Significance of the Study**

The contribution of the current study provided the following to the counseling
literature (a) increased attentiveness of chronic sorrow within the counseling profession
(b) further understanding of the directional relationship between chronic sorrow and each
of the following: family understanding, social support, coping behaviors, and
competence, and (c) increased knowledge for counselors when fostering guidance and
support for parents of a child with ASD. A gap in the literature pertaining to chronic sorrow among parents of a child with ASD is addressed. Additionally, the importance of examining family understanding, social support, coping behaviors, and competence as each influences chronic sorrow among parents of a child with ASD is discussed.

Additionally, counselors appear to be unprepared to assist individuals in dealing with their unique experience of chronic sorrow and may mistakenly treat these symptoms as grief, depression, and anxiety (Rossheim & McAdams, 2012). Therefore, counselors are cautioned against equating chronic sorrow with one of its features independently (Rossheim & McAdams, 2012). Rossheim and McAdams (2012) suggest that counselors avoid applying familiar counseling approaches to grief that rely on bringing the loss to a sense of closure. Instead, the role of the counselor requires being comfortable with uncertain direction and structure in the counseling process, as well as willing to listen tirelessly and actively to personal stories of anticipated joy and objective tragedy (Rossheim & McAdams, 2012).

Given the lack of research and awareness regarding chronic sorrow as it pertains to parents of a child with a disability, both counselors and parents are unsure of how to appropriately address chronic sorrow as indicated by family understanding, social support, coping behaviors, and competence, specifically among parents of a child with ASD. Thus, identifying the relationships between chronic sorrow and these factors in this examination is significant to the counseling field, as well as those working closely with parents of a child with ASD.
Theoretical Framework

Chronic Sorrow

Olshansky (1962) first introduced chronic sorrow as characterized by the reoccurring waves of grief observed in parents, specifically among parents of mentally impaired children, as they struggled to cope with the loss of a “perfect child” in which the pervasive, recurrent sadness was viewed as a normal response to disruptions of normalcy. Subsequent research validated chronic sorrow among parents of a child with mental or physical disabilities and expanded on the emotions commonly experienced among parents to include feelings of fear, anger, helplessness, anger, frustration, and other characteristics of grief (Burke, 1989; Damrosch & Perry, 1989; Hummel & Eastman, 1991; Phillips, 1991; Wikler, Waslow, & Hatfield, 1981). Moreover, these studies concluded that the never-ending nature of the loss of the perfect child prevented resolution of grief and precipitated periodic episodes of re-grief or chronic sorrow during the lifespan (Eakes, Burke, & Hainsworth, 1998).

Eakes, Burke, and Hainsworth (1998) developed the Middle-Range Theory of Chronic Sorrow derived from ten qualitative studies conducted by members at the Nursing Consortium for Research on Chronic Sorrow (NCRCS) in which the foundation of the theoretical model is based upon analyses of chronic sorrow documented by Lindgren, Burke, Hainsworth, and Eakes (1992) and Teel (1991). Lindgren and colleagues (1992, p. 31) define characteristics of chronic sorrow to include: (a) the perception of sadness or sorrow over time in a situation with no predictable end, (b) sadness or sorrow that is cyclic or recurrent, (c) sadness or sorrow that is triggered internally or externally and brings to mind a person’s losses, disappointments, or fears,
and (d) sadness or sorrow that is progressive and can intensify. Additionally, a description of events and circumstances are antecedent to the occurrence of chronic sorrow and include involvement in the trajectory of a chronic illness or disability, either as the one affected or as a caregiver; a recognized negative disparity between the past and present; and the occurrence of events that bring the disparity into focus (Lindgren et al., 1993; Teel, 1991).

Chronic sorrow is differentiated from time bound models of grief and depression (Burke et al., 1992; Lindgren et al., 1992; Teel, 1991). Traditional grief theorists (Bowlby, 1988; Lindemann, 1944) suggest that resolution is the necessary and normal outcome of grief reactions associated with loss. Whereas the theoretical premise of chronic sorrow allows that people may periodically re-experience the pervasive sadness or grief-related feelings when the individual is confronted with the disparity created by the loss (Eakes, Burke, & Hainsworth, 1998). Furthermore, due to the cyclical nature of chronic sorrow, periods of happiness and satisfaction are interspersed with episodes of re-grief, preventing the re-grief from becoming incapacitating (Burke et al., 1992; Copley & Bodensteiner, 1987; Lindgren et al., 1992; Teel, 1991). Thus, chronic sorrow is defined as “the periodic recurrence of permanent, pervasive sadness of grief-related feelings associated with ongoing disparity resulting from a loss experience” (Eakes, Burke, & Hainsworth, 1998, p. 180).

**Family Understanding**

For the purposes of this research study, family understanding refers to “cognitive appraisal which is the process of categorizing an encounter, and its various facets, with its respect to significance for well-being” (Lazarus & Folkman, 1984, p. 31). Moreover,
cognitive appraisal is largely evaluative, focused on meaning or significance, and occurs on a continuum during life (Lazarus & Folkman, 1984, p. 31). Lazarus and Folkman (1984) make a distinction between primary and secondary appraisal by identifying two main evaluative issues of appraisal. Primary appraisal involves assessing for trouble and in what way, whereas secondary appraisal entails identifying what can be done about it, if anything (Lazarus & Folkman, 1984). In essence, Lazarus and Folkman (1984) suggest that the process of subjective evaluation, or cognitive appraisal, may determine the ways in which individuals respond to situations. For instance, when an individual perceives an encounter as having no implication on his or her well-being, then the individual has no interest in a possible outcome (Lazarus & Folkman, 1984). However, if an individual does perceive an encounter as having an impact on his or her well-being, the individual is likely to invest commitment in appraising the situation in hopes for a good outcome (Lazarus & Folkman, 1984). Thus, the process of cognitive appraisal influences the ways in which individuals behave in various contexts.

Social Support

The initial foundations of the concept of social support were first introduced by Caplan (1974), Cassel (1974), and Cobb (1976) in which they viewed social support in the context of health, illness, and mortality. Since then, several operational definitions of social support have been described. Tilden (1985) notes social support as caring friendship and community cohesion. Some theoretical definitions include the act of providing a resource (Antonucci, 1985; Hilbert, 1990; Shumaker & Brownell, 1984). Other definitions describe support in relation to the recipient having the belief that someone is there for them, loves them, and cares for their well-being (Cobb, 1976;
Jacobson, 1986; Pilisuk, 1982). Furthermore, social support has been described as an interaction between the provider and the recipient of support (Antonucci & Jackson, 1990; Thoits, 1985). Although these descriptions attempt to define social support, Hupcey (1998) suggests these definitions are vague and neglect specific aspects of the process of social support. Therefore, Hupcey (1998) proposes structural features of social support to include preconditions, characteristics, outcomes, and boundaries.

Preconditions entail the provider perceives a need in the participant and is motivated to take appropriate action (Hupcey, 1998). Characteristics of social support focus on the action and include the following: (a) action toward a particular person as defined as having a personal relationship, (b) action must be well intentioned, and (c) action must be willingly/freely given (Hupcey, 1998). Furthermore, the outcomes of social support involve a positive response or change in the recipient and this response may be subjective, objective, or delayed (Hupcey, 1998). Lastly, boundaries as a structural feature of social support help delineate the concept from other concepts such as social networks. According to Hupcey (1998), social networks include a number of supporters which in turn influences what actions are being taken. Therefore, social networks consist of the number of people that influence actions, or social support. Moreover, an action is not social support if it has a negative intent or known to result in a negative outcome; is given grudgingly; or given to or from an organization (Hupcey, 1998). Thus, social support is defined as “a well-intentioned action that is giving willingly to a person with whom there is a personal relationship and that produces an immediate or delayed positive response in the recipient” (Hupcey, 1998, p. 313).
Coping Behaviors

An individual’s coping resources are a crucial aspect of the coping process (Beresford, 1994). For example, these resources may include morale, physical health, beliefs, parenting skills, intelligence, marital relationship, social networks, and economic circumstances (Beresford, 1994). Additionally, the family environment can either be a resource for coping or additional sources of stress (Beresford, 1994).

Richard Lazarus and colleagues (1966) first developed the process model of stress and coping. This model has since received considerable attention in research applied to families of children with disabilities. The model is primarily concerned with how individuals cope with stress and views the individual as actively and creatively seeking ways to manage stresses as they are encountered (Beresford, 1994). Moreover, the central tenet of this model states that process of coping mediates the effects of stress on an individual’s well-being (Beresford, 1994, p. 174). The four fundamental concepts of this model include: (a) process, (b) management, (c) appraisal, and (d) mobilization of effort.

The model recognized that not every problem can be resolved. Therefore, coping is a process or ongoing complex interaction between an individual and the environment in which coping is viewed in terms of management as opposed to mastery (Beresford, 1994, p. 174). Moreover, the notion of appraisal is mediated by situational and personal factors. Appraisal is concerned with the individual’s perception or interpretation of how the stressor or particular phenomena is cognitively represented (Beresford, 1994). Additionally, appraisal is influenced by internal factors based on previous experiences and attitudes towards people (Beresford, 1994). Lastly, coping is a mobilization of effort which includes both “cognitive and behavioral efforts to manage (reduce, minimize,
master or tolerate) the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person’s resources” (Folkman, Lazarus, Gruen, & DeLongis, 1986, p. 572).

Bergman (1980) found that parents of children with disabilities felt successful when they focused on the present and aimed to maintain a lifestyle as normal as possible. Moreover, parents also benefited from educating others about their child’s condition (Bergman, 1980). Although coping behaviors will vary among individuals and influence different outcomes, the process of model and coping states that any attempt to manage a stressor is coping whether or not it is successful and coping is therefore independent of its outcome (Folkman, 1984; Beresford, 1994). Thus, coping is an ongoing process and involves the utilization of resources.

**Competence**

The concept of competence has been discussed in various contexts such as motivation (e.g., White, 1959, 1965), intellect (e.g., McClelland, 1973), behavioral adjustment (e.g., Goldfried & D’Zurilla, 1969), and work performance (e.g., Hager & Gonczi, 1996). Additionally, the term competence has referred to different domains of behavior (Waters & Sroufe, 1983). Waters and Sroufe (1983) view competence as an integrative concept which involves (a) an individual’s own contribution to a situation or opportunity for response, (b) recognition of opportunity or demand for response, (c) motivation to respond, and (d) selection from among response alternatives. Moreover, an individual who demonstrates the ability to use resources in certain circumstances is deemed competent. Furthermore, Waters and Sroufe (1983) suggest these resources are within both the individual and the environment.
Resources within the environment refers to those things that can support or help develop one’s ability to coordinate affect, cognition, and behavior in order to make necessary adaptations or maintain long-term progress (Waters & Sroufe, 1983). Furthermore, the quality of the environment is not as important as is one’s ability to manage those resources that exist in the environment. Therefore, this notion of resources within the environment focuses on one’s ability to coordinate, engage in, and make contact with resources in such a way that he or she can profit from a particular environment (Waters & Sroufe, 1983).

Resources within the individual refers to specific skills, motivation, or self-esteem in which one has the ability to capitalize on resources within the environment (Waters & Sroufe, 1983). Additionally, one’s development at a particular point of time in the context of a particular set of demands will determine indicators of success or failure (Waters & Sroufe, 1983). For instance, if an individual can alter his or her view from negative to positive then he or she has successfully utilized resources within oneself. Moreover, the individual has successfully demonstrated competence by coordinating a new way of thinking about the situation. Therefore, competence is based on one’s ability to mobilize and coordinate resources in such a way that opportunities are created and resources are recognized (Waters & Sroufe, 1983). Thus, “a competent individual is one who is able to make use of environmental and personal resources to achieve a good developmental outcome” (Waters & Sroufe, 1983, p. 80).
Operational Definition of Terms

For the purposes of this study, the following definitions are provided: parent, autism spectrum disorder (ASD), child with autism spectrum disorder (ASD), chronic sorrow, family understanding, social support, coping behaviors, and competence.

Parent

A father or mother, or individual who identifies as a guardian, at least 18 or older, and currently provides care for a child (ages 3 – 17) with ASD.

Autism Spectrum Disorder (ASD)

A neurological disorder that affects brain functioning pertaining to problems with thinking, feeling, language and the ability to relate to others, in which symptoms vary in severity per person (American Psychiatric Association, 2016).

Child with Autism Spectrum Disorder (ASD)

An individual, between the ages of 3 and 17, who currently resides with his or her parent(s)/guardian(s) and has a diagnosis of ASD.

Chronic Sorrow

Chronic sorrow is defined as “the periodic recurrence of permanent, pervasive sadness of grief-related feelings associated with ongoing disparity resulting from a loss experience” (Eakes, Burke, & Hainsworth, 1998, p. 180).

Family Understanding

Family understanding refers to “cognitive appraisal which is the process of categorizing an encounter, and its various facets, with its respect to significance for well-being” (Lazarus & Folkman, 1984, p. 31).
Social Support

Hupcey (1998) defines social support as “a well-intentioned action that is giving willingly to a person with whom there is a personal relationship and that produces an immediate or delayed positive response in the recipient” (p. 313).

Coping Behaviors

Lazarus and Folkman (1984) define coping as “… the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person” (p. 283); actions, behaviors, and thoughts used to deal with a stressor (Folkman et al., 1986a).

Competence

Waters and Sroufe (1983) define competence as “an individual who is able to make use of environmental and personal resources to achieve a good developmental outcome” (p. 80).

Research Hypothesis

The purpose of this research study was to examine the directional relationships between the level of chronic sorrow among parents of a child with ASD as indicated by each of the following: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence. The following research hypothesis was further explored:

Primary Research Question

Do family understanding [as measured by the Family Impact of Childhood Disability Scale (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the Coping Health Inventory for
Parents (CHIP; McCubben et al., 1983), and competence [as measured by the Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989)] among parents of a child with ASD influence their level of chronic sorrow [as measured by the Adapted Burke Questionnaire (ABQ; Hobdell, 2004)]? (see Figure 1.1)

![Figure 1.1 Hypothesized Path Model](image)

**Research Hypothesis**

I hypothesized that: Family understanding [as measured by the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the *Coping Health*...
Inventory for Parents (CHIP; McCubben et al., 1983), and competence [as measured by the Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989)] among parents of a child with ASD will influence their level of chronic sorrow [as measured by the Adapted Burke Questionnaire (ABQ; Hobdell, 2004)]. Specifically, this examination explored the hypothesized directional relationship that higher levels of family understanding, social support, coping behaviors, and competence among parents of a child with ASD will have lower levels of chronic sorrow (see Figure 1.2).

Figure 1.2 Hypothesis

Research Design

The aim of this study was best met utilizing a quantitative, correlational research design. Quantitative research can be defined as a type of empirical research into a social
phenomenon or human problem, testing a theory consisting of variables which are measured with numbers, and analyzed with statistics in order to determine if the theory explains or predicts a phenomenon of interest (Creswell 1994; Gay & Airasian, 2000; Yilmaz, 2013). A correlational research design involves collecting data to determine the degree to which a relationship exists between two or more variables (Fraenkal, Wallen, Hyun, 1993). Moreover, the purpose of a correlational study is to use these relationships to make predictions and can only be used to examine the possible existence of causation (Gay & Airasian, 2000; Charles, 1998).

The purpose of the current study was to examine the directional relationships between multiple variables pertaining to parents of a child with ASD. The study is non-experimental and aims to examine the extent of the directional relationships in which chronic sorrow is indicated by each of the following: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with ASD. Therefore, a quantitative approach using a correlational design is appropriate based on the purpose of this study. Additionally, structural equation modeling (SEM) analyses will be used due to its ability to deal with several equations simultaneously which allows the researcher to gain a more precise understanding of the complex relationships between multiple variables within a causal framework (Crockett, 2012; Nachtigall, Kroehne, Funke, & Steyer, 2003).

**Research Method**

**Population and Sampling Procedures**

The target population for this study were individuals who identified as a parent (e.g. mother, father, aunt, uncle, etc.) of a child (ages 3 – 17) with ASD. I selected
parents for this study as parental well-being has only recently become an area of investigation. Moreover, there is a lack of research pertaining to chronic sorrow among parents of a child with ASD. Specifically, research regarding the relationship between chronic sorrow and other factors such as family understanding, social support, coping behaviors, and competence among parents of a child with ASD is limited (Pillay et al., 2012; Dabrowska & Pisula, 2010; Siklos & Kerns, 2006).

According to the Centers for Disease Control and Prevention (CDC, 2016), about 1 in 68 children are diagnosed with ASD. Boys (1 in 42) are about 4.5 times more likely to be diagnosed with ASD than girls (1 in 189) (CDC, 2016). Older parents are at a higher risk of having a child with ASD and parents who have a child with ASD have a 2% - 18% chance of having a second child with ASD (CDC, 2016). Moreover, the societal cost to care for a child with ASD is over 11 billion per year (CDC, 2016). Therefore, parents are in need of support. Furthermore, research is needed to gain an understanding of parents of a child with ASD to better inform counselors who provide support for this particular population.

I recruited potential participants from state organizations located on the East coast of the United States via The Center for Parent and Information Resources (CPIR) website. Specifically, I contacted parent centers within each of the following states on the East coast: New York, Pennsylvania, West Virginia, Maryland, Virginia, North Carolina, South Carolina, Georgia, and Florida. Additionally, the I contacted local organizations in Columbia, South Carolina such as The Therapy Place, South Carolina Autism Society, Family Connection of South Carolina, and Special Olympics South Carolina. Due to using SEM to test the hypothesized directional relationship that higher levels of family
understanding, social support, coping behaviors, and competence indicate lower levels of chronic sorrow, a minimum sample size of 200 participants is recommended (Kline, 2011).

**Data Collection Procedures**

Prior to data collection, I obtained IRB approval from the University of South Carolina. I did not seek permission to use any instrumentation because all of the assessment materials were public domain. All instrumentation was combined into one survey using Qualtrics Survey Software. Qualtrics Survey Software is a web based software that allows users to create secure online surveys.

Data collection began November 2016 and concluded February 2017. I invited participants via email from state organizations located on the East coast of the United States (New York, Pennsylvania, West Virginia, Maryland, Virginia, North Carolina, South Carolina, Georgia, and Florida) via the CPIR website. The CPIR is a nationally, government funded organization that serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRC) within each state nationwide that focus their efforts on serving families with children with disabilities. Additionally, I contacted local organizations in Columbia, South Carolina such as The Therapy Place, South Carolina Autism Society, Family Connection of South Carolina, and Special Olympics South Carolina. Additionally, the incentive for this study included a $1.00 donation to CPIR for every completed survey.

Furthermore, I utilized Amazon Mechanical Turk (MTurk) to increase response rate. Mechanical Turk is a crowdsourcing web service that coordinates the supply and the
demand of tasks that require human intelligence to complete (Paolacci, Chandler, & Ipeirotis, 2010). MTurk is an online labor market where requesters post jobs (e.g. surveys) and workers choose which jobs to complete for a small wage. Due to a vast number of people online, MTurk serves as an ideal platform for recruiting and compensating subjects in online experiments (Mason & Suri, 2012). The benefits of using MTurk for online experiments include: (1) large subject pool access, (2) subject pool diversity, and (3) low cost (Mason & Suri, 2012). Although there were concerns when using MTurk in research, I implemented appropriate guidelines to successfully and appropriately collect data via this platform.

Instrumentation

**General Demographic Survey**

The *General Demographic Survey* (Appendix C) is a 13-item questionnaire created by the researcher, which is a self-report of participants’ demographic information such as age, gender, ethnicity, marital status, employment status, current age of child with ASD, etc. I chose these demographics because they are the most common demographics in similar research studies and they also provided relevant background information for each participant.

**Adapted Burke Questionnaire**

The 8-item *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004; Appendix D) was used to measure chronic sorrow. The ABQ is an adaptation of Burke’s Chronic Sorrow Questionnaire (CSQ; Burke, 1989). Parents rate their current experiences of the intensity of eight mood states including ‘grief’, ‘shock’, ‘anger’, ‘disbelief’, ‘sadness’, ‘hopelessness’, ‘fear’, and ‘guilt’ on a 4 point Likert scale ranging from (0) Absent, (1)
Not Intense, (2) Somewhat Intense, to (3) Very Intense. An intensity score is calculated by summing the eight item scores for a possible range of 0 – 24. A higher cumulative score indicates increased chronic sorrow symptoms. The assessment takes approximately two minutes to complete.

The ABQ has good reliability (α = 0.90 for parents, α = 0.89 for fathers, α = 0.91 for mothers; Hobdell, 2004). Various research has contributed to the development of the ABQ and the instrument has been used across diverse populations to assess chronic sorrow (Damrosch & Perry, 1989; Teel, 1993; Fraley, 1986; Hainsworth, 1994; Kearney & Griffin, 2001; Hobdell, 2004; Lowes & Lyne, 2000; Melnyk et al. 2001). Moreover, the instrument has been cited in at least thirty research articles assessing chronic sorrow among parents of a child with a disability.

**Family Impact of Childhood Disability Scale**

The 15-item *Family Impact of Childhood Disability Scale* (FICD; Trute & Hiebert-Murphy, 2002; Appendix E) was used to measure family understanding. More specifically, the FICD assesses parent perception of the impact of developmental disability on the family (Trute & Hiebert-Murphy, 2002). The scale is comprised of two subscales: Positive (5 items) and Negative (10 items) appraisals. Participants are asked to identify what consequences have resulted from having a child with a disability in their family on a 4 point Likert scale: (1) Not at all, (2) To a mild degree, (3) To a moderate degree, or (4) To a substantial degree. Example questions include: ‘There has been unwelcome disruption to “normal” family routines’ and ‘The experience has made us come to terms with what should be valued in life’. The reliability demonstrates good internal consistency with coefficient alphas of .88 for the Negative subscale and .71 for
the Positive subscale, with a total discrepancy score that predicts long-term parenting stress which can impact the family dynamic. The assessment takes approximately five minutes to complete.

The measure has been used in numerous research studies to assess the family impact of a child with a developmental disability (Trute et al. 2007; Warfield et al. 1999; Kersh et al. 2006; Herring et al. 2006; Oelofsen & Richardson, 2006; Hauser-Cram et al. 2001; Benzies et al. 2011). Moreover, the FICD is consistent with previous research pertaining to primary parental appraisal of the impact of childhood disability on the family (Lazarus & Folkman, 1984; Stein, Folkman, Trabasso, & Richards, 1997). Furthermore, positive and negative affect have been found to be independent of one another, yet co-occur, and predict caregiver psychological well-being (Trute & Hiebert-Murphy, 2002). Additionally, the use of the FICD is consistent with previous research that confirms the importance of the marital relationship in family adjustment to childhood developmental disabilities (Nihira, Meyers, & Mink, 1980; Trute, 1990; Trute & Hiebert-Murphy, 2002).

**Multidimensional Scale of Perceived Social Support**

The 12-item *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988; Appendix F) was used to measure social support. The MSPSS is designed to measure the perceived adequacy of support from others on three subscales: Family (4 items), Friends (4 items), and Significant Other (4 items). Participants are asked to indicate how they feel about each statement using a 7 point Likert scale: (1) Very Strongly Disagree, (2) Strongly Disagree, (3) Mildly Disagree, (4) Neutral, (5) Mildly Agree, (6) Strongly Agree, or (7) Very Strongly Agree. Example
questions include: ‘There is a special person who is around when I am in need’, ‘My family really tries to help me’, and ‘I can count on my friends when things go wrong’. The assessment takes approximately five minutes to complete.

The MSPSS indicated adequate internal consistency with coefficient alpha scores ranging from .81 to .90 for the Family subscale, from .90 to .94 for the Friends subscale, from .83 to .98 on the Significant Other subscale, and from .84 to .92 on the scale as a whole (Zimet, Powell, Farley, Werkman, & Berkoff, 1990). Additionally, test-retest values range from .72 to .85, indicating good stability (Zimet et al., 1990). According to Zimet et al (1988), the MSPSS is psychometrically sound across several different subject groups based on the original study using the MSPSS and other additional studies (Zimet et al., 1988; Zimet et al., 1990; Blumenthal et al., 1987; Hsiao, 2014).

**Coping Health Inventory for Parents**

The 45-item *Coping Health Inventory for Parents* (CHIP; McCubbin, McCubbin, & Cauble, 1979; Appendix G) was used to measure coping behaviors. The CHIP was used to assess positive coping behaviors that parents use in response to their child’s illness. The CHIP consists of three subscales: (1) Coping Pattern I - Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation (19 items, maximum score of 57), (2) Coping Pattern II - Maintaining Social Support, Self-esteem, and Psychological Stability (18 items, maximum score of 54), and (3) Coping Pattern III - Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff (8 items, maximum score of 24). Participants are asked to rate the level of “helpfulness” for each coping behavior on a 4 point Likert scale: (3) Extremely Helpful, (2) Moderately Helpful, (1) Minimally Helpful, or (0) Not
Helpful. Example questions include: ‘Doing things with my children’, ‘Entertaining friends in our home’, and ‘Reading about how other persons in my situation handle things’. Higher scores indicated greater usefulness of that particular coping pattern.

Due to subscale scoring only, Cavallo, Feldman, Swaine, and Meshefedijian (2009) suggested determining the percentage of the maximum score per pattern to allow for comparison between the three coping patterns. This percentage is calculated by dividing the total score for each coping pattern by the maximum possible score of that specific pattern (Cavallo et al., 2009). The CHIP indicated adequate internal consistency with coefficient alpha scores of .79 for Coping Pattern I and II subscales and .71 for Coping Pattern III subscale (McCubbin et al., 1983) and fair concurrent validity (McCubbin, 1993). The assessment takes approximately ten minutes to complete. The CHIP has been found to be psychometrically sound for assessing coping patterns among diverse groups of parents managing a child with various chronic illnesses and disabilities (Aguilar-Vafaie, 2008; Cavallo et al., 2009; Sira, 2014).

**Parenting Sense of Competence Scale**

The 16-item *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989; Appendix H) was used to measure competence. The PSOC consists of two subscales: Satisfaction (9 items) and Efficacy (7 items). Participants are asked to rate the extent to which they agree or disagree with statements on a 6 point Likert scale ranging from (1) Strongly Disagree, (2) Somewhat Disagree, (3) Disagree, (4) Agree, (5) Somewhat Agree, to (6) Strongly Agree. Example questions include: ‘If anyone can find the answer to what is troubling my child, I am the one’, ‘Sometimes I feel like I’m not getting anything done’, and ‘Being a parent makes me tense and anxious’. A higher total
score indicates a higher parenting sense of competency. The Satisfaction subscale reflects parenting anxiety, frustration and motivation with a coefficient alpha score of .79 (Johnston & Mash, 1989). The Efficacy subscale reflects perceived competence and problem-solving ability in the parenting role with a coefficient alpha score of .76 (Johnston & Mash, 1989).

Although the original development of the PSOC (Johnston & Mash, 1989) was used primarily for infants, Ohan, Leung, and Johnston (2000) found that factor structure was highly similar to that obtained by Johnston and Mash (1989) in a combined sample of parents and across children with a wider age range. Therefore, the assessment is suggested for use among parents of children who are older than infants. The assessment takes approximately five minutes to complete.

**Data Analysis**

I utilized SEM to examine the directional relationships between chronic sorrow as indicated by each of the following: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with ASD. SEM is a combination of regression, path, and confirmatory factor models used to test complex relationships between multiple variables (Schumacker & Lomax, 2010; Crockett, 2012). Moreover, it is proposed that “structural equation modeling can perhaps best be defined as class methodologies that seeks to represent hypotheses about the means, variances and covariances of observed data in terms of a smaller number of ‘structural’ parameters defined by a hypothesized underlying model” (Kaplan, 2008, p. 1). SEM represents a multitude of techniques ‘under one umbrella’ and has the ability to consider several
equations simultaneously in which such a system of equations is called a model (Nachtigall, Kroehne, Funke, & Steyer, 2003).

The basic application of SEM involves observed and latent variables. The observed variables, or manifest variables, represent the data collected from surveys and used as an indirect measure of a construct is referred to as an indicator (Kline, 2011). Latent variables correspond to hypothetical constructs or factors, which are explanatory variables on a continuum that are not directly observable (Kline, 2011). Furthermore, the structural equation model consists of a structural model representing the relationship between the latent variables of interest, and measurement models representing the relationships between the latent variable and their manifest or observable indicators (Figure 2). Additionally, a special characteristic of SEM is the explicit representation of measurement error which represents variance unexplained by the factor that the corresponding indicator is supposed to measure (Kline, 2011).

The hypothesized model for this particular study examined family understanding, social support, coping behaviors, and competence as indicators of chronic sorrow among parents of a child with ASD. The hypothesized model includes circles that represent latent variables and squares that represent observed variables (see Figure 2). Each of the latent variables are measured by a number of observed variables. Chronic sorrow is a latent variable measured by eight observed variables: (1) Grief, (2) Shock, (3) Disbelief, (4) Anger, (5) Guilt, (6) Sadness, (7) Helplessness, and (8) Fear. Family understanding is a latent variable measured by two observed variables: (1) Positive appraisal and (2) Negative appraisal. Social support is a latent variable measured by three observed variables: (1) Significant other, (2) Family, and (3) Friend. Coping behaviors is a latent
variable measured by three observed variables: (1) Family integration, (2) Social support, and (3) Communication. Competence is a latent variable measured by two observed variables: (1) Satisfaction and (2) Efficacy. The arrows from the latent variables (family understanding, social support, coping behaviors, and competence) pointing towards chronic sorrow demonstrates the hypothesized relationship that higher levels of family understanding, social support, coping behaviors, and competence directly influence lower levels of chronic sorrow.

The implementation of SEM is advantageous when analyzing the relationships between variables. SEM permits the researcher to analyze constructs without measurement error, handle multiple equations simultaneously, and integrate numerous statistical methods at once (Kline, 2011). In essence, SEM improves understanding of the complex relationships between observed variables and latent constructs (Crockett, 2012). Therefore, as the counseling field continues to explore increasingly complex phenomenon, the theoretical models used to explain such phenomenon warrants the use of SEM (Crockett, 2012). Furthermore, the use of SEM allows a researcher to examine a wide range of multiple variables and their interrelations by collecting information from participants. More importantly, a thorough understanding of the associations between latent constructs and their observable indicators in this particular study better informs counselors working with parents of a child with ASD.

Ethical Considerations

Ethical considerations include, but are not limited to the following:

1. I obtained permission of all dissertation committee members and IRB approval at the University of South Carolina prior to data collection.
2. All data was collected anonymously and reported in aggregate form to ensure confidentiality of participants.

3. The participants were provided with a statement of the purpose of the study, informed consent, and IRB approval documentation.

4. The participants were also made aware their participation was voluntary and participants were given the opportunity to withdraw at any time without consequences.

5. I did not need seek permission to use instrumentation in this study because each were identified as public domain.

**Assumptions and Potential Limitations of the Study**

**Assumptions**

My primary assumption included all participants had a child between the ages of 3 and 17 with ASD and currently resided with their child. In addition, it was assumed that all participants have a fifth-grade reading level and understood how to correctly complete the survey.

Another assumption was my role as the researcher. I did not have a personal or professional relationship with the participants. Thus, I remained objective and solely analyzed the data.

Furthermore, there were assumptions when employing SEM. It was assumed that I had theoretical knowledge of each variable being measured and the goal was to better understand the directional relationships rather than identify such relationships among variables (Crockett, 2012; Stage, Carter, & Nora, 2004; Kelloway, 1998).
Limitations

One limitation of the study was the truthfulness of the participants. Although I assumed each participant had a child between the ages of 3 and 17 with ASD in which they currently resided with, I did not require participants to provide proof as such. Furthermore, the participants may not have been honest when completing the questionnaires due to responses being socially undesirable or they may have felt inclined to respond in a certain way.

The scope may have limited generalizability of the findings. Although the scope of this study examined parents of a child between the ages of 3 and 17 with ASD, the findings of the study may provide insight to all parents of a child beyond the age of 18 with ASD and with other types of developmental disabilities, as well as insight for other professionals such as social workers, medical professionals, etc., who provide parents support in various capacities.

Another limitation may be the survey instruments. Each instrument utilized a Likert-type scale for participant responses and participants may have needed clarification on questions and/or wanted to provide more information to their responses. However, a Likert-type scale does not permit room for additional responses. Thus, participant responses are limited. In addition, my choice of instruments may have been a limitation. The poorer the reliability of its measures, the greater the degree to which a study’s observed correlation is expected to underestimate the true correlation between constructs of interest (Hoyt, Leierer, & Millington, 2006). Although I thoroughly reviewed the reliability and validity of each instrument, other instruments may have provided additional results for this particular study.
Lastly, SEM could be considered a limitation of the study. Although SEM examines correlations among variables, it cannot establish causal effects (Crockett, 2011). Moreover, SEM is a confirmatory technique used to test an a priori theoretical model and is not an exploratory technique for simply identifying relationships among variables (Crockett, 2012; Kelloway, 1998). Therefore, successful application of the SEM techniques relies on the researchers’ theoretical knowledge of each variable (Crockett, 2012; Stage, Carter, & Nora, 2004). Additionally, SEM requires a large sample size of at least 200 to ensure trustworthiness of the results (Kline, 2011).

**Chapter Summary**

In chapter one, the main aspects of the study were identified. This was a descriptive, correlational examination of parents of a child (ages 3 – 17) with ASD. In particular, the examination tested the directional relationship of chronic sorrow as indicated by each of the following: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with ASD.

In chapter two, the literature review will include more detailed reference to the variables being measured in the study and discuss previous empirical research.

In chapter three, the quantitative theoretical methodology, research design, sample, instrumentation, data collection, and data analysis will be provided.

In chapter four, the results of the data analyses will be presented.

In chapter five, findings, limitations, implications, and suggestions for future research will be discussed.
CHAPTER 2

LITERATURE REVIEW

The purpose of this chapter is to provide the theoretical framework for the constructs in this examination: (a) chronic sorrow, (b) family understanding, (c) social support, (d) coping behaviors, and (e) competence, among parents of a child with autism spectrum disorder (ASD). A thorough review of the literature and supporting empirical research is presented for each construct.

**Strategy Used for Searching the Literature**

In conducting a literature review for the topic of chronic sorrow and each construct (family understanding, social support, coping behaviors, and competence) among parents of a child with ASD, the literature review consisted of searching online resources particularly through the search engine EBSCOhost. The key terms used in the search included: chronic sorrow, parents of a child with ASD, family understanding among parents of a child with ASD, social support among parents of a child with ASD, coping behaviors among parents of a child with ASD, and competence among parents of a child with ASD.

I first performed a general search using the constructs as key terms and only included peer-reviewed journal articles. The key terms, number of articles, and date ranges included: chronic sorrow among parents of a child with ASD, 1 article, 2016; family understanding among parents of a child with ASD, 26 articles, 2000 - 2017; social support among parents of a child with ASD, 135 articles, 2010 - 2017; coping behaviors
among parents of a child with ASD, 11 articles, 2002 - 2017; and competence among parents of a child with ASD, 202 articles, 2010 – 2017. Additionally, the search resulted in no articles for chronic sorrow and each of the following key terms: family understanding and competence, with the exception of social support, 3 articles, 2002 – 2015; and coping behaviors, 1 article, 2013. Furthermore, the search resulted in no articles for chronic sorrow and each construct (family understanding, social support, coping behaviors, and competence), specifically among parents of a child with ASD.

**Theoretical and Previous Empirical Research**

The following section presents an overview of the theoretical base and empirical research for each variable under investigation in this study: (a) chronic sorrow, (b) family understanding, (c) social support, (d) coping behaviors, and (e) competence, specifically among parents of a child with ASD.

**Chronic Sorrow**

Olshansky (1962) first introduced chronic sorrow as characterized by the reoccurring waves of grief observed in parents as they struggled to cope with the loss of a ‘perfect child’ in which the pervasive, recurrent sadness was viewed as a normal response to disruptions of normalcy. Subsequent research validated chronic sorrow among parents of a child with mental or physical disabilities and expanded on the emotions commonly experienced among parents to include feelings of fear, helplessness, anger, frustration, and other characteristics of grief (Burke, 1989; Damrosch & Perry, 1989; Hummel & Eastman, 1991; Phillips, 1991; Wikler, Waslow, & Hatfield, 1981). Moreover, these studies concluded that the never-ending nature of the loss of the perfect child prevented resolution of grief and precipitated periodic episodes of re-grief or chronic sorrow during
the lifespan (Eakes, Burke, & Hainsworth, 1998). Therefore, research has shown that the
never-ending loss of a ‘perfect’ child experienced among parents of a child with mental
or physical disabilities places them at high risk for chronic sorrow (Burke, 1989;
Damrosch & Perry, 1989; Olshansky, 1962; Phillips, 1991; Seideman & Kleine, 1995;
Shumaker, 1995; Wikler et al., 1981; Kearney & Griffin, 2001; Lowes & Lynn, 2000;
Hobdell et al., 2007; Whittingham, Sanders, & Boyd, 2013).

According to Teel (1991), the experience of loss that follows the onset of a
permanent disability in a loved one is extreme and differs from bereavement loss
following the death of a loved one. Although the person with a disability remains in the
physical environment, family members experience constant reminders of the loss that
preclude mourning (Warden, 1982). Essentially, the components of loss relate to altered
present and future roles, as well as altered expectations (Lezak, 1978; Romano, 1974).
Family members may adjust to changes associated with the altered life situations and the
disability of their loved one, but continue to experience recurrent, periodic sadness due to
having a family member with a disability (Worthington, 1989). Moreover, for
circumstances in which death does not occur, yet there is a disruption in the relationship,
an individual may experience an emotional pain due to ongoing loss in their lifetime
(Teel, 1991). Furthermore, parents not only grieve the loss of their own dreams for their
child, but also the loss of opportunities for their child (Olshansky, 1962). The sadness
varies in intensity during different situations and times over the parenting journey
(Olshansky, 1962). Thus, a critical attribute of chronic sorrow is the waxing and waning
nature of these emotions, often surging during key points in the child’s development
(Teel, 1991; Olshansky, 1962).
Eakes, Burke, and Hainsworth (1998) developed the Middle-Range Theory of Chronic Sorrow derived from ten qualitative studies conducted by members at the Nursing Consortium for Research on Chronic Sorrow (NCRCS) in which the foundation of the theoretical model is based upon analyses of chronic sorrow documented by Lindgren, Burke, Hainsworth, and Eakes (1992) and Teel (1991). Lindgren and colleagues (1992, p. 31) define characteristics of chronic sorrow to include: (a) the perception of sadness or sorrow over time in a situation with no predictable end, (b) sadness or sorrow that is cyclic or recurrent, (c) sadness or sorrow that is triggered internally or externally and brings to mind a person’s losses, disappointments, or fears, and (d) sadness or sorrow that is progressive and can intensify. Additionally, a description of events and circumstances are antecedent to the occurrence of chronic sorrow (Lindgren et al., 1993; Teel, 1991). Moreover, these experiences include involvement in the trajectory of a chronic illness or disability, either as the one affected or as a caregiver; a recognized negative disparity between the past and present; and the occurrence of events that bring the disparity into focus (Lindgren et al., 1993; Teel, 1991). Therefore, the characteristics of chronic sorrow are different from grief symptoms.

Chronic sorrow is differentiated from time bound models of grief and depression (Burke et al., 1992; Lindgren et al., 1992; Teel, 1991). Traditional grief theorists (Bowlby, 1988; Lindemann, 1944) suggest that resolution is the necessary and normal outcome of grief reactions associated with loss. Whereas the theoretical premise of chronic sorrow allows that people may periodically re-experience the pervasive sadness or grief-related feelings when the individual is confronted with the disparity created by the loss (Eakes, Burke, & Hainsworth, 1998). Furthermore, due to the cyclical nature of
chronic sorrow, periods of happiness and satisfaction are interspersed with episodes of re-
grief, preventing the re-grief from becoming incapacitating (Burke et al., 1992; Copley &
Bodensteiner, 1987; Lindgren et al., 1992; Teel, 1991). Thus, chronic sorrow is defined
as “the periodic recurrence of permanent, pervasive sadness of grief-related feelings
associated with ongoing disparity resulting from a loss experience” (Eakes, Burke, &

Overview of the Chronic Sorrow Model

Eakes, Burke, and Hainsworth (1998), view chronic sorrow as a normal response
to an abnormal situation and continues as long as disparity created by the loss exists.
Chronic sorrow is characterized as pervasive, periodic, permanent, and potentially
progressive in nature, especially for those who anticipate life being disrupted throughout
one’s lifespan (Eakes, Burke, & Hainsworth, 1998). According to Eakes, Burke, and
Hainsworth (1998), their theory of chronic sorrow offers an alternative view of
explaining how people respond in a cyclical manner to both single and ongoing loss
situations. Thus, the chronic sorrow model addresses the following: (a) Loss Situations,
(b) Disparity, (c) Trigger Events, (d) Affected Individuals, (e) Family Caregivers, and (f)
Bereaved Individuals (see Figure 2.1).

Loss Situations

The initial onset of chronic sorrow is preceded by a significant loss (Eakes et al.,
1998). The significant loss is an experience that is highly individualistic and may be
ongoing with no predictable end (Eakes et al., 1998). The actual and symbolic losses
associated with chronic illness or disability during one’s lifespan are ongoing (Eakes et
al., 1998). Moreover, the presence of uncertainty and unpredictability pertaining to the
chronic illness or disability can lead to the development of chronic sorrow (Eakes et al., 1998; Loveys, 1990; Mishel, 1990).

Figure 2.1: Theoretical Model of Chronic Sorrow (Eakes et al., 1998, p. 180)

Disparity

Another aspect prior to the onset of chronic sorrow is unresolved disparity resulting from the loss (Eakes et al., 1998; Lindgren et al, 1993; Teel, 1991; Burke et al., 1997; Hainsworth et al., 1995). Disparity occurs once the individual recognizes that his or her reality differs from his or her idealized way of being (Eakes et al., 1998). In essence, the lack of unresolved disparity creates a gap between reality and the ideal which sets the stage for chronic sorrow symptoms to be experienced in bits and pieces, periodically over
time (Eakes et al., 1998). Thus, it’s a continual, adaptive process (Eakes et al., 1998; Burke, 1994).

**Trigger Events**

Trigger events are closely related to disparity (Eakes et al., 1998). “Triggers, also referred to as milestones, are defined as those circumstances, situations, and conditions that bring the negative disparity resulting from the loss experience clearly into focus or that exacerbate the experience of disparity” (Burke et al., 1997; Eakes, 1995; Teel, 1991; Eakes et al., 1980, p. 181). Furthermore, various types of events that trigger the ongoing disparity are subjective (Eakes et al., 1998).

**Affected Individuals**

Chronic sorrow is most often triggered in individuals with chronic or life threatening conditions when they experience disparity with accepted norms (Eakes et al., 1998). Therefore, the individual realizes he or she as different compared to others, or the norm (Eakes et al., 1998). These norms may be developmental, social, or personal (Burke et al., 1997; Eakes, 1993; Eakes et al., 1998). Furthermore, as anticipated milestones are confronted by disparity, both individuals with the chronic illness or family caregivers are likely to experience chronic sorrow (Eakes et al., 1998).

**Family Caregivers**

As family caregivers provide care for children with disabilities or a loved one with a chronic illness, they become more aware of their normalcy regarding situations as compared to those who are not caregivers (Eakes et al., 1998). The situations and circumstances that precipitate awareness of disparities between the self and others brings the disparity clearly into focus (Eakes et al., 1998). Moreover, chronic sorrow is most
often triggered as family caregivers recognize their unending responsibilities as a caregiver (Burke et al., 1995; Eakes et al., 1998; Lindgren, 1996).

**Bereaved Individuals**

For bereaved individuals, the disparity that triggers chronic sorrow is not the presence of the person with the chronic condition, but instead is the absence of the person who was once central in the life of the bereaved (Eakes et al., 1998). Moreover, the disparity between the past and present may lead to chronic sorrow as the bereaved individual is confronted with memories of the past (Eakes et al., 1998).

**Chronic Sorrow Among Parents of a Child with a Disability**

Copley and Bodensteiner (1987) suggest that chronic sorrow is descriptive of the bereavement process experienced by parents of a child with disability. Most parents of a child with a disability maintain a circular movement among the stages of impact, denial, and grief (Copley & Bodensteiner, 1987). However, denial has been suggested as a coping mechanism following the initial diagnosis of the disability and is not considered as a long-term factor in parental response to having a child with a disability (Hollingsworth & Pasnau, 1977; Jackson, 1974; Murphy, 1982; Pueschel, 1986; Willner & Crane, 1979). Chronic sorrow is unique because the feelings of loss and disappointment are revisited throughout the child’s lifespan and these intense emotions may not end until the death of the parent or of the child (Patrick-Ott & Ladd, 2012). According to Boss (1999), family roles need to be redefined and the parent’s experience of chronic sorrow may interfere with one’s ability to move forward and make new meanings within their family system due to having a child with a disability. Furthermore, chronic sorrow asserts that transitions within families occurs more frequently and can
entail a greater magnitude of adjustment on the part of all family members (Patrick-Ott & Ladd, 2012). Thus, the relentless stress and consequently ongoing distress and dysfunction in families is implicit (Beckman, 1991).

It is common for parents of a child with a disability to feel chronic sorrow because the expectations each parent has for the child are no longer being met and the hope for a ‘normal’ child is no longer present (Damrosch & Perry, 1989; Griffin & Kearney, 2001). In a phenomenological study completed by Griffin and Kearney (2001), six parents of a child with a significant developmental disability reported having experiences of anguish, sorrow, hope, joy, strength, and love. The interpretations of the parents’ experiences revealed themes between joy and sorrow, hope and no hope, and defiance and despair. In addition, the authors found that the parents reported an initial overwhelming reaction of having no hope, in which healthcare professionals were identified as contributors to this feeling of hopelessness. Furthermore, parents related to the concept of chronic or periodic sorrow as part of their everyday lives and the notion of acceptance was confusing. Due to the nature of this qualitative study, the lack of generalizability is recognized. The interpretation of the stories from only six parents were included in the study. Although the authors suggested chronic sorrow symptoms among parents of a child with a disability, there was a sense of qualitative difference in their stories in which the authors chose to ignore. Therefore, predictors to chronic sorrow appear to be unclear. Thus, this current quantitative study will offer insight to multiple variables that may predict chronic sorrow among a larger population which can be representative of the sample.
Cameron, Snowdon, and Orr (1992) completed an exploratory investigation to examine 36 mothers’ emotional perceptions of their experiences caring for a child with a developmental disability and explored how these emotions changed throughout the lifespan. The authors conducted semi-structured interviews and included questions that elicited the participants’ perceptions of their emotional experiences while caring for a child with a developmental disability. Each interview was audiotaped and transcribed verbatim. The authors utilized grounded theory methods to analyze the data from the interviews. The mothers reported feelings of sadness, loss, and guilt for many years after the diagnosis of the developmental disability and feelings of anger and frustration that extended over time. Despite feelings of sadness and anger, some mothers reported feeling satisfied in their ability to parent their child, as well as a sense of acceptance was described over a period of time. However, not all mothers reported a sense of acceptance and described their experiences as life-long stresses. Additionally, the mothers reported that the impact of the child with special needs on the family was difficult. Although, this study was a qualitative approach, it provides some insight to the emotions parents may experience while providing care for a child with a developmental disability.

Whittingham, Wee, Sanders, and Boyd (2013) explored parental experiences of grief, coping and resilience in parents of children with cerebral palsy (CP) and investigated whether chronic sorrow theory provided an appropriate framework to understand these experiences. The authors conducted focus groups pertaining to grief, coping and resiliency and these discussions were transcribed verbatim. In addition, parents also completed the Adapted Burke Questionnaire online, which measures chronic sorrow symptoms in eight different mood states. Thematic analysis was used to analyze
the data collected from focus groups and content analysis using descriptive statistics was used to analyze the data from the online survey. The results indicated an ongoing sense of loss and feelings of sadness, frustration and guilt, which are consistent with that of chronic sorrow symptoms. Parents also reported that symptoms worsened with triggering events such as their child’s inability to reach a developmental milestone. Therefore, the lack of developmental progress over time was distressing. The authors in this study primarily took a qualitative approach to gather rich data about chronic sorrow among parents. Whereas, this current study will use a quantitative approach to measure multiple variables to predict chronic sorrow among parents of a child with ASD.

In a cross-sectional, correlational study, Whittingham, Wee, Sanders and Boyd (2013) investigated the role of child behavior, parental coping, and experiential avoidance in predicting outcomes of psychological symptoms, chronic sorrow symptoms, and parenting burden in parents of children with cerebral palsy (CP). Ninety-four parents of children with CP participated in the study and completed six questionnaires online. The statistical analysis consisted of a series of three multiple regressions with psychological symptoms, chronic sorrow symptoms and experienced parenting burden as the criterion variables. The results indicated that together, the three predictors of child behavior, parental coping and experiential avoidance explained 36.8% of the variance in psychological symptoms with child behavioral problems and experiential avoidance as significant unique predictors. In addition, 15.8% of the variance in chronic sorrow symptoms was explained by the three predictors with experiential avoidance alone as a significant unique predictor. Lastly, the predictors together explained 24.3% of the variance in experienced parenting burden with child behavioral problems and experiential
avoidance as significant unique predictors. Thus, child behavioral problems and parental experiential avoidance predict psychological outcomes in parents of CP. Although the authors attempted to measure variables that predicted chronic sorrow symptoms, the study cannot be a representative sample of parents due to the low response rate and the majority of participants were mothers. Thus, in this current study, participants will include both mothers and fathers.

Bowes, Lowes, Warner and Gregory (2008) completed in-depth interviews with 17 parents to explore longer-term experiences of having a child with Type 1 diabetes. The data collected were explored within a theoretical framework of grief, loss, adaptation, and change. More specifically, the authors explored parental emotion to adaptation to childhood diabetes 7-10 year post diagnosis, determined whether parents experience the periodic resurgence of grief that characterizes chronic sorrow, and examined whether emotional adjustment differs among fathers and mothers. Furthermore, the authors continually reviewed, discussed, and challenged analysis of the data by examining similarities and differences between cases. The findings indicated that parents of children with Type 1 diabetes experience intermittent grief, which is consistent with the concept of chronic sorrow. Although parents reported having adapted to the demands of a child with diabetes, the data strongly suggested that parents had not resolved their feelings of sadness since receiving the diagnosis 7-10 years previously. Both mothers and fathers experienced continuous feelings associated with grief, such as anger and guilt, but mothers demonstrated the ability to talk more about their emotions than fathers. In addition, the authors found that emotional support for parents should be ongoing and reassessed periodically. Although healthcare professionals have an awareness of grief
among parents of a child with a disability, it is possible that chronic sorrow is being left unrecognized, and not addressed. Moreover, the awareness of chronic sorrow could assist healthcare professionals to provide appropriate emotional supports for parents.

Canbulat, Demirgoz, and Coplu (2014) used a qualitative descriptive approach to explore the experiences of Turkish mothers living with/diagnosed with a child with Down Syndrome (DS). The researchers completed semi-structured, audio recorded, face-to-face, 25-35 minute interviews to explore a deeper insight into the experiences of Turkish mothers living with/diagnosed with a child with DS. The selected sample was based on the following criteria: agreed to participate in the study, had no difficulty in communication, and a presence of diagnosis of DS after amniocentesis. Twelve women were selected to undergo an in-depth interview, but one rejected to participate. Thus, 11 women participated in the study. The data analysis consisted of a thematic analysis approach by Yildirim and Simsek (2011).

The researchers completed two rounds of data coding processes to identify and interpret descriptive categories and to further analyze meaningful categories. Furthermore, each interview was verbally summarized for the participants to validate the researchers’ interpretation and to guarantee the rigor of the data analysis. The results section of the study provided two tables of the overall results and the discussion of the findings which included the mothers’ emotional reaction after diagnosed with DS and a subtheme of fear, anxiety, and guilt. The second main theme was mother and healthcare professional interactions with a subtheme of lack of nursing support and not giving enough information. The third and final theme was mother’s coping with diagnosed DS and a subtheme of fatalism and submission. Overall, all participants emphasized more
demand for nursing care before, during, and after amniocentesis, as well as complained about not getting enough time with their doctor to better understand DS. The results of this study cannot be generalized due to only 12 participants in which they were mothers. For this current study, I collected data from a large sample of both mothers and fathers.

**Chronic Sorrow Among Parents of a Child with ASD**

Based on an extensive search, there is only one conceptual article that examines chronic sorrow specifically among mothers of children with ASD. Coughlin and Sethares (2016) completed a literature review to describe how the model of chronic sorrow, which is described above, and can guide family-centered interventions when caring for a child with ASD. Thus, there is a gap in the literature regarding chronic sorrow.

**Empirical Research on Each Indicator Variable**

The following section provides an overview of empirical research on each indicator variable being measured in this examination. The indicator variables include: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence, specifically among parents of a child with ASD.

**Family Understanding**

Freda, Dice, Auricchio, Salerno, and Valerios (2015) completed a qualitative study investigating the understanding of the diagnosis for mothers of children with a disorder of sex development (DSD). The authors completed semi-structured interviews with 10 mothers to investigate the representation modality of the condition, the process of making sense about the diagnosis, and the ability of the participants to contend with the diagnosis, both within the doctor–patient relationship and while talking with their child. The mothers were asked open-ended questions aimed at investigating their relationship
with the medical team and their experience with learning about their child’s condition.

The mothers were asked to recount the manner in which the diagnosis was communicated and their family’s feelings about it. The second part of the interview was aimed at investigating the dialogue within the family about the received information, the extent of the child’s knowledge of the syndrome and its therapy, the child’s questions, and the most difficult topics for the mother to address. All interviews were audio-recorded and transcribed verbatim. The authors used Interpretive Phenomenological Analysis (IPA; Smith & Osborn, 2003) to analyze narratives from interviews. The results indicated that mothers revealed an inclination to remain rigidly impervious to dialogue about DSD related issues, along with a tendency to independently deal with their emotional subjective experiences. According to the mothers, this tendency is facilitated by the family, who maintains silence and concealment. They can experience these feelings as the lack of communication and understanding, feelings of inadequacy, the need for secrecy and feelings of confusion and helplessness within the family system. Moreover, this tendency for secrecy affects a significant part of the emotional life of the family and drains and impoverishes other aspects of the family’s social life. Additionally, the mothers have described that the fathers of their children participate through silence in these behaviors. Based on the results of this study, it is apparent that understanding what the diagnosis means for the family needs to be addressed. However, this study only addressed mothers’ perspective. Hence, the purposes of this current study will address perspectives from both mothers and fathers of children with ASD.

Hsiao (2014) completed a cross-sectional, correlational study to examine how family demographics, family demands and social support relate to family functioning as
well as the potential mediating effect of social support on the relationship between family demands and family functioning in Taiwanese families of children with DS. Participants included 155 parents (80 mothers and 75 fathers) from 83 families that independently completed mailed questionnaires. Data was analyzed using a principal component analysis and mixed linear modelling. The results indicated that families having older children with DS, greater parental education, higher family income, fewer family demands and greater social support contributed to healthier family functioning. Social support partially mediated the effects of family demands on family functioning. Although this study addresses factors contributing to functioning in Taiwanese families living with DS, the current study will address similar factors among parents of a child with ASD.

Milshtein, Yirmiya, Oppenheim, Koren-Karie, and Levi (2010) investigated parental resolution with the child’s diagnosis among 61 mothers and 60 fathers of 61 children with autism spectrum disorders (ASD) aged 2 – 17 years. The authors administered various measures for the assessment of the child’s diagnosis and functioning level and specific measures pertaining to the parents’ perspective at various intervals. Moreover, the authors used ANOVAs and Chi-square analyses to analyze the data. The results indicated that only about one-third of the mothers in the sample and half of the fathers were resolved to their children’s ASD diagnosis. Furthermore, in only one-fifth of the families (20%) both parents were resolved, whereas in 33% of the families both parents were unresolved, and in close to half (47%) only one parent was resolved. The results indicated that parental resolution with respect to the child’s diagnosis appears to be an attribute of parents among children with ASD and should be further addressed in larger and diverse populations.
**Social Support**

Siklos and Kerns (2006) completed a between-subject’s comparison of two groups of participants, parents of children with ASD and parents of children with DS to examine the needs that parents feel are most important and whether these needs are being met. Therefore, in order to determine how the experiences and needs of parents of children with ASD are unique when compared to parents of children with other developmental disorders, parents of children with DS were used as a comparison group. The authors used a modified version of the Family Needs Questionnaire (FNQ; Waaland et al., 1993) to address needs for children with developmental disorders. A sample of 56 parents of children with autism and a comparison group of 32 parents of children with Down syndrome completed the FNQ. The results indicated that parent reports on the FNQ revealed that the two groups of participants did not differ in the number of important needs reported. However, closer examination of the supports rated as most important provides evidence that the two groups differed with respect to the specific needs rated as most important. Parents of children with ASD more consistently endorsed needs relating to professionals working with their child and family, whereas the parents of children with DS endorsed items related to school supports, community programming, and friendship opportunities for their child. Although this study addressed support needs pertaining to parents of a child with DS, it did not address whether or not these supports increase or decrease chronic sorrow among parents. Hence, justification for measuring social support as an indicator of chronic sorrow among parents of a child with ASD for this current study.
Cuzzocrea, Murdaca, Costa, Filipello, and Larcan (2016) compared parental stress, coping strategies and social support perceived in families of children with low functioning autism (n = 8), high functioning autism (n = 10), Down syndrome (n = 12) and parents of typically developing children (n = 20). Specifically, the objective was to investigate which variables (coping strategies and perception of social support available) might better predict different stress outcomes in the four groups. Parents were asked to complete three questionnaires: Parent Stress Index, Coping Orientation to Problems Experienced and Social Support Questionnaire. The results indicated that the perception of social support has different effects on parental stress in the four groups considered. For parents of children with Down syndrome in particular, family support is highly functional. Therefore, it seems that by increasing support, all aspects of stress are reduced (related to parental role, children difficulties, parent–child interactions and total stress).

For parents of children with autism, the support received is not as functional. It seems to have negative effects, especially for parents of children with low functioning autism. In this group, in fact, perception of social support received from all sources is very low, and therefore satisfaction with this support is probably lower than the other groups. These findings support the evidence that it is the quality of such support, rather than the quantity available, which is important. These results suggest the advisability of fostering functional coping strategies and social supports received in families of children with disabilities, and especially in those with children with low functioning autism. Although the authors addressed social supports among parents of children with DS, it did not address social supports as an indicator of chronic sorrow among parents. Thus, for the
purposes of this current study, social support will be measured to indicate chronic sorrow among parents of a child with ASD.

Bruns and Foerster (2011) examined the support needs of parents with a child or adult with a rare trisomy condition (n = 20). Participants were recruited from the Tracking Rare Incidence Syndromes (TRIS) project. The TRIS Family, Friends and Finances Protocol was the data collection instrument. The authors conducted qualitative analyses to identify themes from the protocol and follow-up phone contacts. The results indicated that support from immediate and extended family members varied from very positive to participants describing very negative interactions with specific individuals. Many in the sample reported affirming experiences with spouses and difficulties with grandparents and other extended family members. Thus, the authors suggested it is critical to raise awareness of the similar and disparate support needs of this unique population, as the affected children are living longer and their families require continuing support to meet their needs as well as their children’s needs. Based on these results, it is evident that various support needs should be considered for parents of a child with a developmental disability. Thus, for the purposes of this current study, support needs should be addressed as an indicator of chronic sorrow in closer examination among parents of a child ASD.

**Coping Behaviors**

Cavallo, Feldman, Swaine, and Meshefedjian (2009) conducted a study to examine coping in parents living with a child with a physical disability. Therefore, the aim of the study was to (a) describe parental coping behaviors in a cohort of children with physical disabilities, (b) to determine whether the child’s level of function is associated
with parental coping, and (c) to explore what socio-demographic factors are associated with parental coping. One hundred and fifty parents were interviewed and completed the following: (1) the Coping Health Inventory for Parents (CHIP); the Functional Independence Measure for Children (WeeFIM); and (3) a demographic questionnaire that included socio-demographic information. The results indicated that parents reported seeking social support from community resources as useful. Additionally, coping behaviors related to communicating with healthcare professionals regarding their child’s condition was useful. Moreover, lower maternal education, working parents, and two-parent families, was associated with greater perceived usefulness of maintaining social support through community resources. Although this study addresses coping behaviors among parents of a child with a physical disability, it does not address coping behaviors and chronic sorrow. Thus, the current study will address coping behaviors by using the CHIP scale among parents of a child with ASD.

Van Der Veek, Kraaij, and Garnefski (2009) investigated how parents praised their ability to attain life goals in the face of having a child with a disability and how this affected their coping efforts and emotional well-being. Five hundred and fifty-three parents completed questionnaires containing measures of goal disturbance, cognitive coping, social support, partner bonding and coping self-efficacy. The statistical analysis first consisted of regressing all coping strategies which included: goal hindrance, coping resources of social support, partner bonding, coping self-efficacy, and cognitive coping strategies on depressive symptoms and positive affect. In the second step, goal hindrance and the three coping resources were regressed on cognitive coping strategies. In the third step, correlations between goal hindrance and the three coping resources were calculated.
To be as complete as possible, the authors decided to investigate these relationships by checking the goodness of fit of the total using structural equation modeling. The results indicated that rumination, self-blame, experiencing more goal disturbance, and having a less caring partner were positively related to depressive symptoms. Whereas, coping self-efficacy and social supports were related to positive affect. Although the results of this study indicated factors related to depressive symptoms, chronic sorrow differs from depression. Therefore, in this current study, social support, coping behaviors, and competence will be examined using SEM among parents of a child with ASD.

Competence

Schultz et al (2012) examined the effectiveness of the Social Competence Intervention for Parents (SCI-P), a parent education program, facilitated in conjunction with a social competence intervention that targeted youth with ASD ages 11–14. Sixteen parents participated in the study. The authors used a quasi-experimental pre-post design. Data was analyzed using Analyses of covariance (ANCOVAs). The findings revealed that participants experienced significantly greater reductions in levels of stress and increase in parenting sense of competence from pre- to post-intervention. Moreover, parents reported high satisfaction with the program. Therefore, these findings suggest that parent education can result in positive outcomes for parents’ well-being (Schultz et al, 2012).

Gilmore and Cuskelly (2012) investigated parenting sense of competence for mothers of children with Down syndrome (DS) from early childhood to adolescence. The sample comprised of 25 mothers whose child with DS was aged 4–6 years in the first
phase of the study, and 11–15 years at the second phase of the study. The results indicated that maternal satisfaction with parenting increased over time, but there were no changes in parenting self-efficacy. Moreover, scores on these measures were no different from those reported in a normative sample of mothers of typically developing children. Thus, suggesting that the challenges of parenting a child with DS do not impact significantly on parenting sense of competence during the early childhood and adolescent periods. Furthermore, there were some significant relationships of maternal sense of competence with child characteristics and self-reported parenting style. The authors did not include whether self-efficacy predicts chronic sorrow. Thus, for the purposes of this current study, both mothers’ and fathers’ perspectives will be included. Moreover, competence is identified as one of the indicator variables for chronic sorrow among parents of a child with ASD for the purposes of this study.

**Chapter Summary**

For the purposes of the current study, I attempted to provide theoretical and empirical research for the following: (a) chronic sorrow, (b) family understanding, (c) social support, (d) coping behaviors, and (e) competence among parents of a child with a DD. While a review of the existing literature demonstrated the need for further consideration of various factors among parents of a child with a ASD, the literature failed to inform the reader of factors that specifically predict chronic sorrow among parents of a child with DD. Moreover, the lack of empirical literature pertaining to chronic sorrow as it pertains to each indicator variable (family understanding, social support, coping behaviors, and competence) among parents of a child with a ASD, justified the significance of this study. Thus, a study indicating the directional relationship between
chronic sorrow and each of the following: family understanding, social support, coping behaviors, and competence, among parents of a child with ASD offers further insight and guidance in the counseling field.

The following chapter will discuss the methodology of the current study with specification to a quantitative correlational design and approach, instrumentation and materials used to collect data, the data analysis process, and protective measures used for the participants. In chapter four, the results obtained from the research instruments will be presented. In the final chapter, an in-depth discussion of the data and professional and future implications for research is provided.
CHAPTER 3

METHODOLOGY

The purpose of this chapter is to explain how I examined the directional relationship between chronic sorrow and each of the following: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with autism spectrum disorder (ASD). Specifically, this investigation tested the hypothesized directional relationship that parents of a child with ASD having higher levels of family understanding [as measured by the 15-item Family Impact of Childhood Disability Scale (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the 12-item Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the 45-item Coping Health Inventory for Parents (CHIP; McCubben et al., 1983)], and competence [as measured by the 16-item Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989)] indicated lower levels of chronic sorrow [as measured by the 8-item Adapted Burke Questionnaire (ABQ; Hobdell, 2004)].

The following sections of the methodology chapter include (a) research design and approach, (b) population and sampling procedures, (c) data collection procedures, (d) instrumentation, (e) research hypothesis, (f) data analysis process, (g) protective measures used for participants, (h) ethical considerations, and (i) potential limitations of the study.
Research Design and Approach

For the present study, the I utilized a quantitative approach. Quantitative research can be defined as a type of empirical research into a social phenomenon or human problem, testing a theory consisting of variables which are measured with numbers, and analyzed with statistics in order to determine if the theory explains or predicts a phenomenon of interest (Creswell 1994; Gay & Airasian, 2000; Yilmaz, 2013). Due to the nature of the study, which will test a phenomenon of interest, a quantitative approach is justified. Furthermore, the study is non-experimental and will aim to examine the relationships in which chronic sorrow is indicated by each of the following (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with ASD. More specifically, a correlational research design and structural equation modeling (SEM) analysis was employed to further examine the hypothesis.

A descriptive, correlational research design is appropriate because it allows the researcher to determine the degree in which a relationship exists between two or more variables as described in numerical form (Fraenkal & Wallen, 1993). The purpose of a correlational study is to determine relationships between variables or to use these relationships to make predictions (Gay & Airasian, 2000). Additionally, correlational research design can only be used to examine the possible existence of causation (Charles, 1998). Due to the present study being non-experimental which lacks manipulation of the independent variable under control (Johnson, 2001) and seeks to examine relationships between variables in order to make inferences (Gay & Airasian, 2000), the use of correlational design is appropriate. Thus, I selected a correlational research design
because the purpose of the study was to determine the directional relationships between chronic sorrow as indicated by each of the following (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with ASD.

To gain a precise understanding of the directional relationships between multiple variables within a causal framework, I used structural equation modeling (SEM) to analyze the data. SEM deals with a multitude of statistical procedures and has the ability to consider several equations simultaneously (Nachtigall, Kroehne, Funke, & Steyer, 2003). SEM allows the researcher to gain a better understanding of the complex relationships that occur among observed variables and latent constructs (Crockett, 2011). Therefore, its most prominent feature is the capability to deal with latent variables (i.e., nonobservable quantities or factors) underlying observed variables (Nachtigall et al., 2003). Observed variables (i.e., indicator variables) can be directly measured using a survey to define a latent construct, whereas latent constructs cannot be directly observed or measured, and as a result must be inferred from a set of observed variables (Crockett, 2012). Moreover, SEM tests models that specify how groups of variables define a construct, as well as the relationships among constructs (Crockett, 2012).

The present study could also be considered using a qualitative approach. Qualitative research is an emergent, inductive, interpretive, and naturalistic approach to the study of people, cases, phenomena, social situations, and processes in their natural settings to reveal in descriptive terms the meanings that people attach to their experiences (Yilmaz, 2013). I could have opted to interview a small number of parents of a child with ASD to describe subjective experiences and gain new insights to establish unifying theories that are not causal (Trafimow, 2014). Moreover, I could have conducted focus
groups with the participants to further explore perspectives regarding this group and to describe aspects of a phenomenon with a specific view to explain the subject of interest (Glesne, 2016). Therefore, data collection and data analysis could involve thematic analysis to better understand the processes that tend to involve the phenomena of interest as well as the perceptions, values, and beliefs of people toward it (Glesne, 2016).

However, the scope of a qualitative study is limited due to the nature of this study which includes examining multiple variables among one particular group. Moreover, a qualitative approach would limit the sample size causing lack of generalizability (Bryman et al., 1988) and a large number of participants may cause an overwhelming amount of data for coding processes for the researcher (Carr, 1994). Therefore, a quantitative approach makes it feasible to collect data from many participants to enable findings to be more generalizable. Additionally, I accounted for extraneous variables (Duffy, 1985) and presented data in numbers in an orderly and organized fashion (Carr, 1994) to thoroughly present the findings of this study. Thus, a quantitative approach employing a correlational research design using SEM analysis was appropriate for this particular study. The following section describes the instrumentation used to collect data in this study.

**Population and Sampling Procedures**

The target population for this study were individuals who identified as a parent (e.g. mother, father, aunt, uncle, etc.) of a child (ages 3 – 17) with ASD. I selected parents for this study as parental well-being has only recently become an area of investigation. Moreover, there is a lack of research pertaining to chronic sorrow among parents of a child with ASD. Specifically, research regarding the relationship between chronic sorrow and other factors such as family understanding, social support, coping
behaviors, and competence among parents of a child with ASD is limited (Pillay et al., 2012; Dabrowska & Pisula, 2010; Siklos & Kerns, 2006).

According to the Centers for Disease Control and Prevention (CDC, 2016), about 1 in 68 children are diagnosed with ASD. Boys (1 in 42) are about 4.5 times more likely to be diagnosed with ASD than girls (1 in 189) (CDC, 2016). Older parents are at a higher risk of having a child with ASD and parents who have a child with ASD have a 2% - 18% chance of having a second child with ASD (CDC, 2016). Moreover, the societal cost to care for a child with ASD is over 11 billion dollars per year (CDC, 2016). Therefore, parents are in need of support. Furthermore, research is needed to gain an understanding of parents of a child with ASD to better inform counselors who provide support for this particular population.

I recruited potential participants from state organizations located on the East coast of the United States via The Center for Parent and Information Resources (CPIR) website. The CPIR is a nationally, government funded organization that serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRC) within each state nationwide that focus their efforts on serving families of children with disabilities. I contacted parent centers within each of the following states on the East coast: New York, Pennsylvania, West Virginia, Maryland, Virginia, North Carolina, South Carolina, Georgia, and Florida. Additionally, I contacted local organizations in Columbia, South Carolina such as The Therapy Place, South Carolina Autism Society, Family Connection of South Carolina, and Special Olympics South Carolina. Due to the using SEM to test the hypothesized directional relationship between chronic sorrow and
each of the following: family understanding, social support, coping behaviors, and competence; a minimum sample size of 200 participants was required. SEM requires a large sample size of at least 200 participants in order to provide accurate estimates of the constructs being measured among a particular population (Kline, 2011).

According to Dillman, Smyth, and Christian (2009), a 70% response rate is possible if using a paper survey administered using the tailored design method. However, I expected a lower response rate due to collecting data electronically and recruiting participants via a study flyer posted in their organization or monthly newsletter, as opposed to emailing a certain number of potential participants directly in order to maintain an accurate response rate. Unfortunately, the organizations that agreed to distribute my study flyer were unable to provide an accurate number of individuals who potentially viewed the study flyer. Therefore, my overall response rate for this study was incomplete.

**Data Collection Procedures**

Prior to data collection, I sought IRB approval from the University of South Carolina and the dissertation committee. I did not have to seek permission from the authors to use the instruments because all of the assessment materials were public domain. All instrumentation was combined into one survey using Qualtrics Survey Software which is a web based software that allows users to create secure online surveys. The survey included a total of 106-items comprised of the following instruments: (a) 15-item *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002), (b) 12-item *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988), (c) 45-item *Coping Health Inventory for Parents*
(CHIP; McCubben et al., 1983), (d) 16-item *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989), (e) 8-item *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004), and (f) 10-item *General Demographic Questionnaire* created by the researcher. Additionally, the informed consent form and a statement of the purpose of the study was also included at the beginning of the survey.

The dissertation committee and ten of my colleagues reviewed the survey to check for any errors and to ensure instructions and questions were clear (Dillman et al., 2009). Moreover, an introduction was included at the beginning of the survey which included the purpose of the study, informed consent, incentive, and overall significance of the study in order to increase participant motivation to complete the survey (Smyth, Dillman, Christian, & McBride, 2009). Furthermore, I also considered the look and feel of the survey by choosing soft color choices and providing a percentage completion bar at the top of the survey to inform participants of the remaining items as they completed the survey (Dillman et al., 2009). I was receptive to all feedback from the dissertation committee and colleagues and implemented all feedback into the survey before dissemination to participants.

Data collection began in November 2016 and concluded in February 2017. I invited participants via email from a listserv provided by The Center for Parent and Information Resources (CPIR) website from the following states: New York, Pennsylvania, West Virginia, Maryland, Virginia, North Carolina, South Carolina, Georgia, and Florida. Additionally, I contacted local organizations in Columbia, South Carolina such as The Therapy Place, South Carolina Autism Society, Family Connection of South Carolina, and Special Olympics South Carolina to recruit participants. As a
result, five organizations responded and agreed to assist with recruiting potential participants in their organizations. Due to confidentiality, these organizations did not share contact information for potential participants with the researcher. However, they agreed to distribute the study flyer via in the lobby of their organization or via monthly newsletter. The organizations that agreed to distribute the study flyer included: PRO Parents, The Therapy Place, North Carolina Autism Society, South Carolina Autism Society, and South Carolina Commission for the Blind. Additionally, I attended a local Autism Conference to recruit potential participants.

I also recruited potential participants via online discussion groups that included the target population for this study. These online groups were found on Yahoo as most active discussion forums. I initially contacted five Yahoo discussion groups based on the most recent activity in the group. Three group moderators responded to my request to share the study flyer in the discussion forum which included: The Autism Research Institute (1500 members), Autism Society Connecticut Yahoo Group (150 members), and Autism Society Central Texas (950 members). Thus, a total of 31 surveys were completed by participants from these organizations between November 2016 - January 2017. Therefore, I decided to utilize Amazon Mechanical Turk (MTurk) during February 2017 to increase data collection.

MTurk is a crowdsourcing web service that coordinates the supply and the demand of tasks that require human intelligence to complete (Paolacci, Chandler, & Ipeirotis, 2010). MTurk is an online labor market where requesters post jobs (e.g. surveys) and workers choose which jobs to complete for a small wage. Due to a vast number of people online, MTurk serves as an ideal platform for recruiting and
compensating subjects in online experiments (Mason & Suri, 2012). The benefits of using MTurk for online experiments include: (1) large subject pool access, (2) subject pool diversity, and (3) low cost (Mason & Suri, 2012). Moreover, Buhrmester, Kwang, and Gosling (2011) found that the quality of data provided by MTurk met or exceeded the psychometric standards associated with published research. Additionally, there are limitations when utilizing MTurk such as it may not be representative of the desired population and concerns about the overall quality of the data exist (Paolacci, Chandler, & Ipeirotis, 2012). However, due to the open market design and large, diverse participant pool, MTurk has the necessary elements to complete a research project from start to finish (Buhrmester, Kwang, & Gosling, 2011).

Fortunately, my decision to pursue MTurk resulted in a successful outcome. During February 2017, I conducted a total of eight batches (50 surveys per batch; 400 total available) on MTurk in which 368 out of 400 surveys were completed in its entirety, resulting in a 78.6% response rate. Therefore, I met the recommended sample size of at least 200 participants (Kline, 2011) via MTurk in one month.

All participants received notification inviting them to participate including an informed consent, a link to access the survey, the IRB approval documentation, and an explanation of the incentive for this study. The incentive for this study included a $1.00 donation to CPIR for every completed survey. I chose to donate to CPIR because it is a nationally, government funded organization that serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRC) within each state nationwide that
focus their efforts on serving families with children with disabilities. Therefore, I made an anonymous donation of $394.00 to CPIR.

**Instrumentation**

The following instruments were used to measure the constructs identified in this study. The constructs and instruments included: (a) chronic sorrow (*Adapted Burke Questionnaire* [ABQ]; Hobdell, 2004), (b) family understanding (*Family Impact of Childhood Disability Scale* [FICD]; Trute & Hiebert-Murphy, 2002), (c) social support (*Multidimensional Scale of Perceived Social Support* [MSPSS]; Zimet, Dahlem, Zimet, & Farley, 1988), (d) coping behaviors (*Coping Health Inventory for Parents* [CHIP]; McCubbin, McCubbin, & Cauble, 1979), and (e) competence (*Parenting Sense of Competence* scale [PSOC]; Johnston & Mash, 1989). Additionally, a *General Demographic Survey*, created by the researcher, included ten questions to obtain general background information of each participant. I combined all instrumentation into one electronic survey and administered the survey to each participant once via online. The following provides information pertaining to each instrument used to collect data.

**General Demographic Questionnaire**

The 10-item *General Demographic Questionnaire* (Appendix C) is a questionnaire created by the researcher, which is a self-report of participants’ demographic information such as age, gender, ethnicity, age of child with a ASD, marital status, employment status, etc. These demographics were chosen because they are the most common demographics in other similar research studies.
Adapted Burke Questionnaire

The 8-item Adapted Burke Questionnaire (ABQ; Hobdell, 2004; Appendix D) was used to measure chronic sorrow. The ABQ is an adaptation of Burke’s Chronic Sorrow Questionnaire (CSQ; Burke, 1989). Parents rate their current experiences of the intensity of eight mood states including ‘grief’, ‘shock’, ‘anger’, ‘disbelief’, ‘sadness’, ‘hopelessness’, ‘fear’, and ‘guilt’ on a 4 point Likert scale ranging from (0) Absent, (1) Not Intense, (2) Somewhat Intense, to (3) Very Intense. An intensity score is calculated by summing the eight item scores for a possible range of 0 – 24. A higher cumulative score indicated increased chronic sorrow symptoms. The assessment takes approximately two minutes to complete.

The ABQ has good reliability (α = 0.90 for parents, α = 0.89 for fathers, α = 0.91 for mothers; Hobdell, 2004). Various research has contributed to the development of the ABQ and the instrument has been used across diverse populations to assess chronic sorrow (Damrosch & Perry, 1989; Teel, 1993; Fraley, 1986; Hainsworth, 1994; Griffin & Kearney, 2001; Hobdell, 2004; Lowes & Lyne, 2000; Melnyk et al. 2001). Moreover, the instrument has been cited in at least thirty research articles assessing chronic sorrow among parents of a child with a disability.

Family Impact of Childhood Disability Scale

The 15-item Family Impact of Childhood Disability Scale (FICD; Trute & Hiebert-Murphy, 2002; Appendix E) was used to measure family understanding. More specifically, the FICD assessed parent perception of the impact of developmental disability on the family (Trute & Hiebert-Murphy, 2002). The scale is comprised of two subscales: Positive (5 items) and Negative (10 items) appraisals. Participants are asked to
identify what consequences have resulted from having a child with a disability in their family on a 4 point Likert scale: (1) Not at all, (2) To a mild degree, (3) To a moderate degree, or (4) To a substantial degree. Example questions include: ‘There has been unwelcome disruption to “normal” family routines’ and ‘The experience has made us come to terms with what should be valued in life’. The reliability demonstrates good internal consistency with coefficient alphas of .88 for the Negative subscale and .71 for the Positive subscale, with a total discrepancy score that predicts long-term parenting stress which can impact the family dynamic. The assessment takes approximately five minutes to complete.

The measure has been used in numerous research studies to assess the family impact of a child with a developmental disability (Trute et al. 2007; Raina et al. 2005; Warfield et al. 1999; Kersh et al. 2006; Herring et al. 2006; Oelofsen & Richardson, 2006; Hauser-Cram et al. 2001; Benzies et al. 2011). Moreover, the FICD is consistent with previous research pertaining to primary parental appraisal of the impact of childhood disability on the family (Lazarus & Folkman, 1984; Baker, 1993; Stein, Folkman, Trabasso, & Richards, 1997). Furthermore, positive and negative affect have been found to be independent of one another, yet co-occur, and predict caregiver psychological well-being (Bradburn & Caplovitz, 1965; Watson & Clark, 1984; Stein et al., 1997; Trute & Hiebert-Murphy, 2002). Additionally, the use of the FICD is consistent with previous research that confirms the importance of the marital relationship in family adjustment to childhood developmental disabilities (Abbott & Meredith 1986; Friedrich, 1979; Nihira, Meyers, & Mink, 1980; Trute, 1990; Trute & Hiebert-Murphy, 2002).
Multidimensional Scale of Perceived Social Support

The 12-item *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988; Appendix F) was used to measure social support. The MSPSS is designed to measure the perceived adequacy of support from others on three subscales: Family (4 items), Friends (4 items), and Significant Other (4 items). Participants are asked to indicate how they feel about each statement using a 7 point Likert scale: (1) Very Strongly Disagree, (2) Strongly Disagree, (3) Mildly Disagree, (4) Neutral, (5) Mildly Agree, (6) Strongly Agree, or (7) Very Strongly Agree. Example questions include: ‘There is a special person who is around when I am in need’, ‘My family really tries to help me’, and ‘I can count on my friends when things go wrong’. The assessment takes approximately five minutes to complete.

The MSPSS indicated adequate internal consistency with coefficient alpha scores ranging from .81 to .90 for the Family subscale, from .90 to .94 for the Friends subscale, from .83 to .98 on the Significant Other subscale, and from .84 to .92 on the scale as a whole (Zimet et al., 1990). Additionally, test-retest values range from .72 to .85, indicating good stability (Zimet et al., 1990). According to Zimet et al (1988), the MSPSS is psychometrically sound across several different subject groups based on the original study using the MSPSS and other additional studies (Zimet et al., 1988; Zimet et al., 1990; Blumenthal, 1987; Hsiao, 2014).

Coping Health Inventory for Parents

The 45-item *Coping Health Inventory for Parents* (CHIP; McCubbin, McCubbin, & Cauble, 1979; Appendix G) was used to measure coping behaviors. The CHIP was used to assess positive coping behaviors that parents use in response to their child’s
illness. The CHIP consists of three subscales: (1) Coping Pattern I - Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation (19 items, maximum score of 57), (2) Coping Pattern II - Maintaining Social Support, Self-esteem, and Psychological Stability (18 items, maximum score of 54), and (3) Coping Pattern III - Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff (8 items, maximum score of 24). Participants are asked to rate the level of “helpfulness” for each coping behavior on a 4 point Likert scale: (3) Extremely Helpful, (2) Moderately Helpful, (1) Minimally Helpful, or (0) Not Helpful. Example questions include: ‘Doing things with my children’, ‘Entertaining friends in our home’, and ‘Reading about how other persons in my situation handle things’. Higher scores indicate greater usefulness of that particular coping pattern.

Due to subscale scoring only, Cavallo, Feldman, Swaine, and Meshefedijian (2009) suggested determining the percentage of the maximum score per pattern to allow for comparison between the three coping patterns. This percentage is calculated by dividing the total score for each coping pattern by the maximum possible score of that specific pattern (Cavallo et al., 2009). The CHIP indicated adequate internal consistency with coefficient alpha scores of .79 for Coping Pattern I and II subscales and .71 for Coping Pattern III subscale (McCubbin et al., 1983) and fair concurrent validity (McCubbin, 1993). The assessment takes approximately ten minutes to complete. The CHIP has been found to be psychometrically sound for assessing coping patterns among diverse groups of parents managing a child with various chronic illnesses and disabilities (Aguilar-Vafaie, 2008; Bhattacharya et al., 2016; Cavallo et al., 2009; Myers et al., 2014; Lakkis et al., 2016; Sira, 2014)
Parenting Sense of Competence Scale

The 16-item Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989; Appendix H) was used to measure competence. The PSOC consists of two subscales: Satisfaction (9 items) and Efficacy (7 items). Participants were asked to rate the extent to which they agree or disagree with statements on a 6 point Likert scale ranging from (1) Strongly Disagree, (2) Somewhat Disagree, (3) Disagree, (4) Agree, (5) Somewhat Agree, to (6) Strongly Agree. Example questions include: ‘If anyone can find the answer to what is troubling my child, I am the one’, ‘Sometimes I feel like I’m not getting anything done’, and ‘Being a parent makes me tense and anxious’. A higher total score indicates a higher parenting sense of competency. The Satisfaction subscale reflected parenting anxiety, frustration and motivation with a coefficient alpha score of .79 (Johnston & Mash, 1989). The Efficacy subscale reflected perceived competence and problem-solving ability in the parenting role with a coefficient alpha score of .76 (Johnston & Mash, 1989).

Although the original development of the PSOC (Johnston & Mash, 1989) was used primarily for infants, Ohan, Leung, and Johnston (2000) found that factor structure was highly similar to that obtained by Johnston and Mash (1989) in a combined sample of parents and across children with a wider age range. Therefore, the assessment is suggested for use among parents of children who are older than infants. The assessment takes approximately five minutes to complete. The following section identifies the research hypothesis and follow-up questions.
Research Hypothesis

The purpose of this research study was to examine the directional relationships between the level of chronic sorrow among parents of a child with ASD as indicated by each of the following: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence. The following research hypothesis was further explored:

Primary Research Question

Do family understanding [as measured by the Family Impact of Childhood Disability Scale (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the Coping Health Inventory for Parents (CHIP; McCubben et al., 1983)], and competence [as measured by the Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989)] among parents of a child with ASD influence their level of chronic sorrow [as measured by the Adapted Burke Questionnaire (ABQ; Hobdell, 2004)]?

Research Hypothesis

I hypothesized that: Family understanding [as measured by the Family Impact of Childhood Disability Scale (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the Coping Health Inventory for Parents (CHIP; McCubben et al., 1983)], and competence [as measured by the Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989)] among parents of a child with ASD will influence their level of chronic sorrow [as measured by the Adapted Burke Questionnaire (ABQ; Hobdell, 2004)]. Specifically, this examination
explored the hypothesized directional relationship that higher levels of family understanding, social support, coping behaviors, and competence among parents of a child with ASD will indicate lower levels of chronic sorrow.

**Data Analysis**

The data analysis was conducted based on the information collected from the electronic survey including a total of five instruments: (a) the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004), (b) the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002), (c) the *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988), (d) the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983), and (e) the *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989). The data from these instruments was downloaded from Qualtrics Software System to Statistical Programs Statistical Software 24th edition (SPSS, Version 24, 2016) and analyzed using IBM SPSS Analysis of Moment Structures (AMOS, Version 24, 2016). AMOS is a statistical software used to compute SEM which allows the researcher to closely examine multiple models fit in a single analysis and compare particular parameters of each model (Arbuckle, 2013). Additionally, AMOS completes statistical tests for each observed variable, attempts to detect outliers, and provides researchers with path diagrams for clear representations of models (Arbuckle, 2013). To ensure that the data collected for the study was appropriate for the data analysis (SEM), statistical assumptions were met (normality, homogeneity, and multicollinearity). The next section discusses the data analyses used to test the research hypothesis in this study.
**Research Hypothesis**

SEM was used to test the proposed research hypothesis for this study. SEM is a combination of regression, path, and confirmatory factor models used to test complex relationships between multiple variables (Schumacker & Lomax, 2010; Crockett, 2012). SEM was chosen because it permits the researcher to analyze constructs without measurement error, handle multiple equations simultaneously, and integrate numerous statistical methods at once, as opposed to ordinary regression analysis (Kline, 2011). Moreover, SEM improves understanding of the complex relationships between observed variables and latent constructs (Crockett, 2012). Therefore, as the counseling field continues to explore increasingly complex phenomenon, the theoretical models used to explain such phenomenon warrants the use of SEM (Crockett, 2012).

The basic application of SEM involves observed and latent variables. The observed variables, or manifest variables, represent the data collected from surveys and used as an indirect measure of a construct is referred to as an indicator (Kline, 2011). Latent variables correspond to hypothetical constructs or factors, which are explanatory variables on a continuum that are not directly observable (Kline, 2011). Furthermore, the structural equation model consists of a structural model representing the relationship between the latent variables of interest, and measurement models representing the relationships between the latent variable and their manifest or observable indicators (Figure 2). Additionally, a special characteristic of SEM is the explicit representation of measurement error which represents variance unexplained by the factor that the corresponding indicator is supposed to measure (Kline, 2011).
The hypothesized model for this particular study is included circles that represent latent variables and squares that represent observed variables. The hypothesized model examined family understanding, social support, coping behaviors, and competence as indicators of chronic sorrow among parents of a child with ASD. Chronic sorrow was a latent variable measured by eight observed variables: (1) Grief, (2) Shock, (3) Disbelief, (4) Anger, (5) Guilt, (6) Sadness, (7) Helplessness, and (8) Fear. Family understanding was a latent variable measured by two observed variables: (1) Positive appraisal and (2) Negative appraisal. Social support was a latent variable measured by three observed variables: (1) Significant other, (2) Family, and (3) Friend. Coping behaviors were a latent variable measured by three observed variables: (1) Coping Patterns I, (2) Coping Patterns II, and (3) Coping Patterns III. Competence was a latent variable measured by two observed variables: (1) Satisfaction and (2) Efficacy. Thus, I hypothesized that higher levels of family understanding, social support, coping behaviors, and competence directly influenced lower levels of chronic sorrow among parents of a child with ASD.

There are six basic steps and two additional optional steps to conduct SEM analysis (Kline, 2011, p. 91 - 94): (1) Specify the model; (2) Evaluate model identification (if not identified, go back to step 1; (3) Select the measures (operationalize the constructs) and collect, prepare, and screen the data; (4) Estimate the model: a. Evaluate model fit (if poor, skip to step 5, b. Interpret parameter estimates, c. Consider equivalent or near-equivalent models (skip to step 6; (5) Respecify the model (return to step 4); and (6) Report the results. Two additional steps could be added to the basic steps and include: (7) Replicate the results and (8) Apply the results.
Dependent and Independent Variables

For this particular study, the dependent and independent variables were identified as the following:

**Dependent/Endogenous Variable**

Chronic sorrow was chosen as the dependent variable as it represents the criterion that may be impacted by the independent variables (family understanding, social support, coping behaviors, and competence).

**Independent/Exogenous Variables**

The independent variables were based on a review of the literature that indicated chronic sorrow. The independent variables included: (1) family understanding, (2) social support, (3) coping behaviors, and (4) competence.

Participants’ Rights

**Protective Measures**

Prospective participants for the present study were invited via email to participate in an electronic survey which included a total of five questionnaires and a demographic form. In addition, the electronic survey included a letter of consent and participants had the option to accept or decline participation without consequences. Therefore, any non-responses were considered as those who declined participation. In an effort to maintain confidentiality, the General Demographic Questionnaire did not request identifiable information from any participant. Furthermore, I did not have any knowledge of which prospective participants who completed the electronic survey. Thus, there was no possibility for me to link any participants’ identity with the completed survey due to only reporting aggregate data.
Risks and Benefits/IRB

The nature of the survey did not pose any major risks to participants due to the method of data collection via online survey. Although participants used their time and energy to complete a 30-minute electronic survey, possible discomforts to participants were minimal. Moreover, as an effort to minimize risk, participants did not provide any identifiable information. Prior to the study, I applied to the IRB committee at the University of South Carolina requesting approval to complete the present study. Therefore, the statement of approval from the IRB was included in the invitation to participate in the study and the IRB approval number was listed on the informed consent form. Additionally, the incentive for this study included a $1.00 donation to CPIR for every completed survey. Furthermore, the information obtained from this study aimed to increase awareness of chronic sorrow and served as a basis to demonstrate the need for additional training and education when working with parents of a child with ASD.

Ethical Considerations

Ethical considerations were included, but are not limited to the following:

1. I obtained permission of all dissertation committee members and IRB approval at the University of South Carolina prior to data collection.
2. All data was collected anonymously and reported in aggregate form to ensure confidentiality of participants.
3. The participants were provided with a statement of the purpose of the study, informed consent, and IRB approval documentation.
4. The participants were also made aware their participation was voluntary and participants were given the opportunity to withdraw at any time without consequences.
5. I did not need seek permission to use instrumentation in this study because each were identified as public domain.

**Limitations**

1. The correlational research design may pose threats to validity.
2. I not request participants to show proof of eligibility for the study; therefore, the truthfulness of participants could be questionable.
3. The participants may not have been honest when completing the survey due to responses being socially undesirable or they may have felt inclined to respond in a certain way.
4. The scope of this study may limit generalizability of the findings.
5. The choice of instruments may be a limitation because the poorer the reliability of its measures, the greater the degree to which a study’s observed correlation is expected to underestimate the true correlation between constructs of interest (Hoyt, Leierer, & Millington, 2006). However, I thoroughly reviewed the reliability and validity of each instrument for this study.
6. The use of MTurk may not be representative of the desired population and concerns about the overall quality of the data exist (Paolacci, Chandler, & Ipeirotis, 2012).
7. Successful application of the SEM techniques relies on the researchers’ theoretical knowledge of each variable (Crockett, 2012; Stage, Carter, & Nora, 2004).

**Chapter Summary**

The purpose of the present study was to examine the directional relationships in which chronic sorrow was indicated by each of the following: family understanding, social support, coping behaviors, and competence among parents of a child with a ASD.
A quantitative approach using a correlational research design was utilized to measure variables to predict a phenomenon of interest (Creswell 1994; Gay & Airasian, 2000; Yilmaz, 2013) and to determine the degree to which a relationship exists between two or more variables (Fraenkel & Wallen, 1993). I recruited potential participants to include parents of a child with ASD via a listserv provided by The Center for Parent and Information Resources (CPIR) website from the following states: New York, Pennsylvania, West Virginia, Maryland, Virginia, North Carolina, South Carolina, Georgia, and Florida. Additionally, I contacted local organizations in Columbia, South Carolina such as The Therapy Place, South Carolina Autism Society, Family Connection of South Carolina, and Special Olympics South Carolina to recruit potential participants. Furthermore, I utilized MTurk to collect data. The data collected in the study was analyzed using SEM analysis to determine directional relationships among multiple variables.

The following chapter will present the results of the study. The final chapter will provide an in-depth discussion of the data and professional and future implications for research.
CHAPTER 4

RESULTS

The purpose of chapter four is to present the results of the researcher hypothesis and follow-up analyses under examination in this study. The purpose of this study was to examine the directional relationship between chronic sorrow and each of the following (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with autism spectrum disorder (ASD). Specifically, this investigation tested the hypothesized directional relationship that parents of a child with ASD scoring higher levels of family understanding [as measured by the 15-item Family Impact of Childhood Disability Scale (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the 12-item Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the 45-item Coping Health Inventory for Parents (CHIP; McCubben et al., 1983)], and competence [as measured by the 16-item Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989)] will indicate lower levels of chronic sorrow [as measured by the 8-item Adapted Burke Questionnaire (ABQ; Hobdell, 2004)].

The research hypothesis was analyzed using structural equation modeling (SEM). More specifically, path analysis and confirmatory factor analysis was conducted. The results are presented in the following order: (a) sampling and data collection procedures, (b) descriptive statistics, and (c) data analyses per the research hypothesis and follow-up analyses.
Sampling and Data Collection Procedures

The target population for this study were individuals who identified as a parent (e.g. mother, father, aunt, uncle, etc.) of a child (ages 3 – 17) with ASD. I selected parents for this study as parental well-being has only recently become an area of investigation. Moreover, there is a lack of research pertaining to chronic sorrow among parents of a child with ASD. Specifically, research regarding the relationship between chronic sorrow and other factors such as family understanding, social support, coping behaviors, and competence among parents of a child with ASD is limited (Pillay et al., 2012; Dabrowska & Pisula, 2010; Siklos & Kerns, 2006).

According to the Centers for Disease Control and Prevention (CDC, 2016), about 1 in 68 children are diagnosed with ASD. Boys (1 in 42) are about 4.5 times more likely to be diagnosed with ASD than girls (1 in 189) (CDC, 2016). Per a community report completed by the CDC (2016), there is not a full count of all individuals in the United States living with ASD. However, it is estimated there are currently between 500,000 to 1 million children aged 6-17 years living in the United States with ASD (CDC, 2016). Therefore, due to this extremely large number of children estimated to be living with ASD, it can be assumed that for each child with ASD, he or she has at least one parent or caregiver. Thus, to ensure a 95% confidence level of generalizability for a population of 500,000, a minimum sample size of 200 participants is needed (MacCallum, Browne, and Sugawara, 1996). The sample size for this study concluded a total of 394 participants.

I implemented purposive sampling to invite participants via email from state organizations located on the East coast of the United States (New York, Pennsylvania, West Virginia, Maryland, Virginia, North Carolina, South Carolina, Georgia, and
Florida) via The Center for Parent and Information Resources (CPIR) website. The CPIR is a nationally, government funded organization that serves as a central resource of information and products to the community of Parent Training Information (PTI) Centers and the Community Parent Resource Centers (CPRC) within each state nationwide that focus their efforts on serving families with children with disabilities. Additionally, I contacted local organizations in Columbia, South Carolina such as The Therapy Place, South Carolina Autism Society, Family Connection of South Carolina, PRO Parents, South Carolina Commission for the Blind, and Special Olympics South Carolina. Furthermore, I contacted North Carolina Autism Society and West Virginia University Center for Excellence in Disabilities. I also invited participants via three online discussion forums and an online labor market, Amazon Mechanical Turk (MTurk). In addition, I presented at an Autism Conference in Lexington, South Carolina and used snowball sampling to contact participants through personal and professional contacts.

A survey was designed to collect data. The survey began with an informed consent and all instrumentation was combined into one survey using Qualtrics Survey Software. The survey concluded with the general demographic questionnaire. I implemented the Dillman (2000) Tailored Design Method to support sound data collection and response rates. Moreover, to prevent missing data from the survey, I designed the survey with force response completion per each question to prevent participants from skipping questions. Additionally, upon completion of the entire survey, the survey generated a random numeric code for the participant to submit their survey responses. This random numeric code ensured that an actual participant completed the survey. Furthermore, to decrease measurement error, the survey link was reviewed by the
researcher’s major professor and ten of her colleagues to ensure that the survey instructions were clear and instrumentation was legible (Dillman et al., 2000). All feedback from the dissertation committee and colleagues was implemented into the survey design.

All participants received an email invitation that included the informed consent, secure link to the survey, and an explanation of the incentive to participate in the study. The incentive for this study included a $1.00 donation to autism research for each survey completed. Five email reminders within three months (November 2016, December 2016, and January 2017) were sent to all participants and state organizations encouraging participation. In regards to MTurk, I ran a total of eight batches (50 surveys per batch) during February 2017, which concluded data collection.

**Descriptive Data Results**

**Response Rate**

I initially contacted ten local organizations via email in the state of South Carolina to recruit participants. Five organizations responded and agreed to assist with recruiting potential participants in their organizations. Due to confidentiality, these organizations did not share contact information for potential participants with the researcher. However, they agreed to distribute the study flyer via in the lobby of their organization or via monthly newsletter. The organizations that agreed to distribute the study flyer included: PRO Parents, The Therapy Place, North Carolina Autism Society, South Carolina Autism Society, and South Carolina Commission for the Blind. Additionally, I attended a local Autism Conference to recruit potential participants. Unfortunately, these organizations that agreed to distribute my study flyer were unable to provide an accurate number of
individuals who potentially viewed the study flyer. Therefore, my response rate regarding these organizations was incomplete.

I also recruited potential participants via online discussion groups. These online groups were found on Yahoo as most active discussion forums. I initially contacted five Yahoo discussion groups based on the most recent activity in the group. Three group moderators responded to my request to share the study flyer in the discussion forum which included: The Autism Research Institute (1500 members), Autism Society Connecticut Yahoo Group (150 members), and Autism Society Central Texas (950 members).

Additionally, I decided to utilize Amazon Mechanical Turk (MTurk) to increase data collection. Mechanical Turk is a crowdsourcing web service that coordinates the supply and the demand of tasks that require human intelligence to complete (Paolacci, Chandler, & Ipeirotis, 2010). MTurk is an online labor market where requesters post jobs (e.g. surveys) and workers choose which jobs to complete for a small wage. Due to a vast number of people online, MTurk serves as an ideal platform for recruiting and compensating subjects in online experiments (Mason & Suri, 2012). The benefits of using MTurk for online experiments include: (1) large subject pool access, (2) subject pool diversity, and (3) low cost (Mason & Suri, 2012).

To determine how many surveys were completed via MTurk as compared to other recruitment strategies, I created an additional secure survey link for MTurk users. As per MTurk, the researcher conducted a total of eight batches (50 surveys per batch; 400 total available) during February 2017. Out of the 400 surveys, 368 were completed in its entirety, resulting in a 92% response rate. As per the other recruitment strategies via
organizations and monthly newsletters, 46 surveys were attempted, but only 31 were completed. Out of the 31 surveys completed: 12 were completed by participants from the Autism Society Central Texas online discussion forum, resulting in a 38.7% response rate; 2 were completed by participants from the Autism Society Connecticut online discussion forum, resulting in a 6.5% response rate; and the response rate for the remaining surveys is unknown due to participants not choosing to report. Therefore, a total of 399 participants completed the survey. However, I screened the data, 5 surveys were omitted due to participants only completing one out of five instruments, which concluded a total sample size of $N = 394$.

**Participant Demographics**

Descriptive data are presented for all participants in the study. However, five participants did not complete the demographic form in the survey. Therefore, demographic variables are presented on 389 participants, as opposed to 394 participants analyzed in the overall study. The following demographic variables are reported on the sample ($N = 389$; see Table 4.1)

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</tr>
<tr>
<td>Caucasian</td>
<td>288</td>
<td>74.0%</td>
</tr>
<tr>
<td>Black/African American</td>
<td>45</td>
<td>11.5%</td>
</tr>
<tr>
<td>Asian</td>
<td>29</td>
<td>7.5%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>26</td>
<td>6.7%</td>
</tr>
<tr>
<td>Hawaiian/Pacific Islander</td>
<td>1</td>
<td>0.3%</td>
</tr>
</tbody>
</table>

(*This table is representative of $n = 389$)
Most of the participants were female \((n = 227, 58.4\%)\) as opposed to those who identified as male \((n = 162, 41.6\%)\). The participants’ ages ranged from 20 to 65 and the most common age among participants was 35 (see Figure 4.1). Ethnicity among participants was 288 (74.0%) Caucasian, 45 (11.5%) Black/African American, 29 (7.5%) Asian, 26 (6.7%) Hispanic, and 1 (0.3%) Hawaiian/Pacific Islander. The current relationship status for participants was 251 (64.5%) married, 78 (20.1%) single, 32 (8.2%) partner, 15 (3.9%) divorced, and 13 (3.3%) separated. The current employment status was 242

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>251</td>
<td>63.7%</td>
</tr>
<tr>
<td>Single</td>
<td>78</td>
<td>19.8%</td>
</tr>
<tr>
<td>Partner</td>
<td>32</td>
<td>8.1%</td>
</tr>
<tr>
<td>Divorced</td>
<td>15</td>
<td>3.8%</td>
</tr>
<tr>
<td>Separated</td>
<td>13</td>
<td>3.3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment Status</th>
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<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time</td>
<td>242</td>
<td>62.2%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>84</td>
<td>21.6%</td>
</tr>
<tr>
<td>Part-time</td>
<td>63</td>
<td>16.2%</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Relationship to the Child</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>200</td>
<td>51.4%</td>
</tr>
<tr>
<td>Father</td>
<td>126</td>
<td>32.4%</td>
</tr>
<tr>
<td>Stepmother</td>
<td>11</td>
<td>2.8%</td>
</tr>
<tr>
<td>Grandmother</td>
<td>3</td>
<td>0.77%</td>
</tr>
<tr>
<td>Aunt</td>
<td>3</td>
<td>0.77%</td>
</tr>
<tr>
<td>Uncle</td>
<td>3</td>
<td>0.77%</td>
</tr>
<tr>
<td>Foster Parent</td>
<td>2</td>
<td>0.5%</td>
</tr>
<tr>
<td>Stepfather</td>
<td>3</td>
<td>0.77%</td>
</tr>
<tr>
<td>Unknown</td>
<td>38</td>
<td>9.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Others in the Home</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
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<td>No</td>
<td>195</td>
<td>50.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>194</td>
<td>49.9%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Previous Counseling</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>311</td>
<td>79.9%</td>
</tr>
<tr>
<td>Yes</td>
<td>78</td>
<td>20.1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participate in Support Group</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>343</td>
<td>88.1%</td>
</tr>
<tr>
<td>Yes</td>
<td>46</td>
<td>11.8%</td>
</tr>
</tbody>
</table>
(62.2%) full-time, 84 (21.6%) unemployed, and 63 (16.2%) part-time. Each participant identified his or her relationship to the child with ASD which was 200 (51.4%) mother, 126 (31.6%) father, 11 (2.8%) stepmother, 3 (0.77%) grandmother, 3 (0.77%) aunt, 3 (0.77%) uncle, 3 (0.77%) stepfather, 2 (0.5%) foster parent, and 38 (9.8%) unknown because the participant chose not to answer. Moreover, 194 (49.9%) participants reported other family members living in the home with him or her and his or her child with ASD, as opposed to 195 (50.1%) participants reported no one else living in the home. Additionally, 311 (79.9%) participants reported not having received previous counseling and 78 (20.1%) participants reported receiving previous counseling. Furthermore, 343 (88.2%) participants reported no active participation in a support group and 46 (11.8%) participants reported active participation in a support group.

**Instrumentation for Each Variable**

**Chronic Sorrow**

The 8-item *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004; Appendix D) was used to measure chronic sorrow. The ABQ is an adaptation of Burke’s Chronic Sorrow Questionnaire (CSQ; Burke, 1989). Parents rate their current experiences of the intensity of eight mood states including ‘grief’, ‘shock’, ‘anger’, ‘disbelief’, ‘sadness’, ‘hopelessness’, ‘fear’, and ‘guilt’ on a 4 point Likert scale ranging from (0) Absent, (1) Not Intense, (2) Somewhat Intense, to (3) Very Intense. An intensity score is calculated by summing the eight item scores for a possible range of 0 – 24. A higher cumulative score indicates increased chronic sorrow symptoms. Cronbach’s $\alpha$ assessing the internal consistency of the ABQ was .844, indicating an acceptable internal consistency of the scale measuring 8 factors of chronic sorrow among parents (Pallant, 2013).
Family Understanding

The 15-item *Family Impact of Childhood Disability Scale* (FICD; Trute & Hiebert-Murphy, 2002; Appendix E) was used to measure family understanding. More specifically, the FICD assesses parent perception of the impact of developmental disability on the family (Trute & Hiebert-Murphy, 2002). The scale is comprised of two subscales: Positive Appraisal (PA; 5 items) and Negative Appraisal (NA; 10 items). However, due to researcher error, participants only completed a total of 12 items: PA (3 items) and NA (9 items); resulting in items 3 (PA subscale), 14 (NA subscale), and 15 (PA subscale) not being included in the survey. Again, this was due to researcher error and was not done intentionally. Therefore, the reliability should be interpreted with caution. Participants are asked to identify what consequences have resulted from having a child with a disability in their family on a 4 point Likert scale: (1) Not at all, (2) To a mild degree, (3) To a moderate degree, or (4) To a substantial degree. Example questions include: ‘There has been unwelcome disruption to “normal” family routines’ and ‘The experience has made us come to terms with what should be valued in life’. Cronbach’s α assessing the internal consistency was .550 for the PA subscale, indicating low internal consistency, and .849 for the NA subscale, indicating acceptable internal consistency of the subscale. Additionally, Cronbach’s α assessing the internal consistency of the total FICD without items 3, 14, and 15 was .793, indicating a good internal consistency measuring family understanding.

Social Support

The 12-item *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988; Appendix F) was used to measure social support. The
MSPSS includes three subscales: Family (4 items), Friends (4 items), and Significant Other (4 items). Participants are asked to indicate how they feel about each statement using a 7 point Likert scale: (1) Very Strongly Disagree, (2) Strongly Disagree, (3) Mildly Disagree, (4) Neutral, (5) Mildly Agree, (6) Strongly Agree, or (7) Very Strongly Agree. Example questions include: ‘There is a special person who is around when I am in need’, ‘My family really tries to help me’, and ‘I can count on my friends when things go wrong’. Cronbach’s α assessing the internal consistency for each subscale was .895 for Family, .872 for Friends, and .897 for Significant Other, indicating acceptable internal consistency. Additionally, Cronbach’s α assessing the internal consistency of the total MSPSS was .935, indicating a good internal consistency for measuring social support.

Coping Behaviors

The 45-item Coping Health Inventory for Parents (CHIP; McCubbin, McCubbin, & Cauble, 1979; Appendix G) was used to measure coping behaviors. The CHIP consists of three subscales: (1) Coping Pattern I - Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation (19 items, maximum score of 57), (2) Coping Pattern II - Maintaining Social Support, Self-esteem, and Psychological Stability (18 items, maximum score of 54), and (3) Coping Pattern III - Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff (8 items, maximum score of 24). Participants are asked to rate the level of “helpfulness” for each coping behavior on a 4 point Likert scale: (3) Extremely Helpful, (2) Moderately Helpful, (1) Minimally Helpful, or (0) Not Helpful. Example questions include: ‘Doing things with my children’, ‘Entertaining friends in our home’, and ‘Reading about how other persons in my situation handle things’. Higher scores indicate
greater usefulness of that particular coping pattern. Due to subscale scoring only, Cavallo, Feldman, Swaine, and Meshefedijian (2009) suggest determining the percentage of the maximum score per pattern to allow for comparison between the three coping patterns. This percentage is calculated by dividing the total score for each coping pattern by the maximum possible score of that specific pattern (Cavallo et al., 2009).

Cronbach’s α assessing the internal consistency for each subscale was .863 for Coping Pattern I, .862 for Coping Pattern II, and .785 for Coping Pattern III, indicating acceptable internal consistency.

**Competence**

The 16-item *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989; Appendix H) was used to measure competence. The PSOC consists of two subscales: Satisfaction (9 items) and Efficacy (7 items). Participants are asked to rate the extent to which they agree or disagree with statements on a 6 point Likert scale ranging from (1) Strongly Disagree, (2) Somewhat Disagree, (3) Disagree, (4) Agree, (5) Somewhat Agree, to (6) Strongly Agree. Example questions include: ‘If anyone can find the answer to what is troubling my child, I am the one’, ‘Sometimes I feel like I’m not getting anything done’, and ‘Being a parent makes me tense and anxious’. A higher total score indicates a higher parenting sense of competency. Cronbach’s α assessing the internal consistency for each subscale was .790 for Satisfaction and .787 for Efficacy, indicating acceptable internal consistency. Additionally, Cronbach’s α assessing the internal consistency of the total PSOC was .725, indicating a good internal consistency for measuring social support.
Data Analyses for the Research Hypothesis

The following section reviews the results of the analyses for the primary research question, the hypothesis, and all follow-up questions. All of the data was analyzed using the Statistical Package for the Social Sciences (SPSS, Version 24, 2016) and the IBM SPSS Analysis of Moment Structures (AMOS, Version 24, 2016) for SEM. An alpha level of .05 was set to confirm that 95% of the variance of the relationship between the variables was due to an actual relationship and not sampling error (Frankel & Wallen, 2009).

Statistical Assumptions and Data Screening

Preliminary analyses of the data were conducted to ensure the sample size was appropriate for SEM. Byrne (2016) suggests that the following assumptions are met: (a) appropriate sample size, (b) address missing data, (c) limited multicollinearity and singularity, (d) account for outliers, (e) multivariate normality, and (f) linearity between the variables. The suggested sample size for SEM is 200 (Kline, 2011). The dataset did not have any data that was missing other than the five participants that chose not to complete the General Demographic Questionnaire in the survey. However, due to researcher error, items 3, 14, and 15 on the FICD scale were not included in the survey, but this was completely unintentional. Additionally, to prevent missing data from occurring, I implemented a force completion feature per each question in the survey to prevent participants from skipping questions.

To address these assumptions, I used a standard multiple regression. To assess for multicollinearity and singularity, the correlation matrix and the Tolerance and VIF (Variance inflation factor) were evaluated. Pallant (2013) suggests that correlations
between the independent variables should be less than .7 to retain all variables.

Addtionally, the Tolerance value should be less than .10 and the VIF value should be above 10 to determine the presence of multicollinearity (Pallant, 2013). The data met the assumption of multicollinearity because the correlations between the independent variables was below .7 and none of the values for the Tolerance and the VIF suggested non-multicollinearity. Moreover, I examined the Normal Probability Plot (P-P) of the Regression Standardised Residual and the Scatterplot. The Normal Probability P-P Plot had points in a reasonably straight diagonal line which suggested no major deviations from normality (Pallant, 2013). Furthermore, the Scatterplot illustrated residuals roughly rectangularly distributed with most of the scores concentrated in the center (Pallant, 2013). Therefore, the data met the assumptions for outliers, normality, and linearity between variables.

The purpose of this study was to examine the directional relationship between chronic sorrow and each of the following (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence among parents of a child with ASD. The following section describes the results for the research hypothesis based on SEM analyses. The five steps of SEM (Crockett, 2012; Kline, 2011) include: (a) model specification, (b) model identification, (c) model estimation, (d) model evaluation, and (e) model modification. All five steps were used and repeated to analyze the primary hypothesis. To determine overall goodness of fit, the following fit indices and their recommended values were used (Hu & Bentler, 1999; Kline, 2011; Byrne, 2016; Brown, 2015): (a) Chi Square ($\chi^2$) is the extent to which the overall model predicts the observed covariance, the ratio of $\chi^2$ to $df$ should be $\leq 2$ or 3; (b) Tucker-Lewis Index (TLI) describes the extent to which the
specified model performs better than a baseline model, the TLI should be ≥ .95, however .90 is considered acceptable; (c) Comparative Fit Index (CFI), is similar to the TLI but accounts for sample size, CFI should be ≥ .95; (d) Root Mean Square Error of Approximation (RMSEA), compares the fit of an independent model (a model which indicates no relationships between variables) to the fit of the estimated model, RMSEA should be < .06; (e) Goodness of Fit Index (GFI) is the proportion of variance that is determined by the estimated population covariance, GFI should be ≥ .95; and (f) Hoelter’s Critical N addresses the adequacy of the sample size to provide a good model fit for Chi square and should be > 200.

**Primary Research Question**

Do family understanding [as measured by the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983)], and competence [as measured by the *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989)] among parents of a child with ASD contribute to their level of chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)]?

**Research Hypothesis**

The research hypothesis tested in this examination was: Family understanding [as measured by the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as
measured by the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983)], and competence [as measured by the *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989)] among parents of a child with ASD contribute to their level of chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)]. Specifically, this examination tested the hypothesized directional relationship that higher levels of family understanding, social support, coping behaviors, and competence among parents of a child with ASD will have lower levels of chronic sorrow (see Figure 1.1).

**Model Specification and Identification**

To appropriately test the hypothesized model, the measurement models were specified and identified. Byrne (2016) suggests that measurement models are psychometrically sound for the dataset and the validity of the measurements should be evaluated before assessing the structural model. Therefore, to assess the validity of each measurement model, confirmatory factor analysis (CFA) was conducted to assess the fit of the indicators measuring each latent variable. A CFA was conducted on each instrument used in this study to ensure that items were loading independently and correctly on the factors under examination. The recommended factor loading cutoff used in this study was .70 (Schumacker & Lomax, 2004). However, Kline (2011) states that indicators fail to have substantial standardized loadings when they are < .20. The CFA of each instrument provided rationale for specification of each measurement model.

**Confirmatory Factor Analysis for Chronic Sorrow**

Chronic sorrow was measured using the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004). Chronic sorrow was specified using eight indicators (1) Grief, (2) Shock,
(3) Disbelief, (4) Anger, (5) Guilt, (6) Sadness, (7) Helplessness, and (8) Fear. The Cronbach’s α assessing the internal consistency of the ABQ was .844. Although the factor loadings met the recommended cutoff of .50, the overall goodness of fit indices did not meet the recommended values. Therefore, I freed errors 2 and 3 based on the modification indices, resulting in a good fit for the measurement model of the ABQ (see Table 4.2 and Figure 4.1). Due to freeing errors 2 (Shock) and 3 (Disbelief) this may suggest that both shock and disbelief somewhat overlap and/or suggest there is another multidimensional layer to consider when addressing these emotions pertaining to chronic
sorrow (Byrne, 2016). Moreover, it can be considered that shock and disbelief may not account for emotions attributing to chronic sorrow long-term. Additionally, I chose to

Table 4.2 Model Fit Indices for the ABQ

<table>
<thead>
<tr>
<th></th>
<th>x^2</th>
<th>df</th>
<th>p</th>
<th>CMIN/df</th>
<th>GFI</th>
<th>CFI</th>
<th>TLI</th>
<th>RMSEA</th>
<th>Hoelter</th>
</tr>
</thead>
<tbody>
<tr>
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<td>115.526</td>
<td>20</td>
<td>.000</td>
<td>5.626</td>
<td>.926</td>
<td>.909</td>
<td>.872</td>
<td>.108</td>
<td>&lt; 200</td>
</tr>
<tr>
<td>∆Figure 4.1</td>
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<td>19</td>
<td>.000</td>
<td>2.739</td>
<td>.965</td>
<td>.967</td>
<td>.952</td>
<td>.067</td>
<td>&gt; 200</td>
</tr>
</tbody>
</table>

Figure 4.1 Measurement Model of the ABQ

examine each indicator more closely. Therefore, the descriptive data and frequencies are provided in Table 4.3 and 4.4.

Table 4.3 Descriptive Statistics for ABQ

<table>
<thead>
<tr>
<th>Emotion</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grief</td>
<td>2.55</td>
<td>.908</td>
</tr>
<tr>
<td>Shock</td>
<td>2.31</td>
<td>.931</td>
</tr>
<tr>
<td>Emotion</td>
<td>Scale</td>
<td>Total (n)</td>
</tr>
<tr>
<td>---------</td>
<td>---------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Grief</td>
<td>Absent</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td>Not Intense</td>
<td>127</td>
</tr>
<tr>
<td></td>
<td>Somewhat Intense</td>
<td>154</td>
</tr>
<tr>
<td></td>
<td>Very Intense</td>
<td>58</td>
</tr>
<tr>
<td>Shock</td>
<td>Absent</td>
<td>83</td>
</tr>
<tr>
<td></td>
<td>Not Intense</td>
<td>150</td>
</tr>
<tr>
<td></td>
<td>Somewhat Intense</td>
<td>116</td>
</tr>
<tr>
<td></td>
<td>Very Intense</td>
<td>45</td>
</tr>
<tr>
<td>Disbelief</td>
<td>Absent</td>
<td>88</td>
</tr>
<tr>
<td></td>
<td>Not Intense</td>
<td>137</td>
</tr>
<tr>
<td></td>
<td>Somewhat Intense</td>
<td>114</td>
</tr>
<tr>
<td></td>
<td>Very Intense</td>
<td>55</td>
</tr>
<tr>
<td>Anger</td>
<td>Absent</td>
<td>79</td>
</tr>
<tr>
<td></td>
<td>Not Intense</td>
<td>118</td>
</tr>
<tr>
<td></td>
<td>Somewhat Intense</td>
<td>138</td>
</tr>
<tr>
<td></td>
<td>Very Intense</td>
<td>59</td>
</tr>
<tr>
<td>Guilt</td>
<td>Absent</td>
<td>74</td>
</tr>
<tr>
<td></td>
<td>Not Intense</td>
<td>121</td>
</tr>
<tr>
<td></td>
<td>Somewhat Intense</td>
<td>139</td>
</tr>
<tr>
<td></td>
<td>Very Intense</td>
<td>60</td>
</tr>
<tr>
<td>Sadness</td>
<td>Absent</td>
<td>48</td>
</tr>
</tbody>
</table>
Confirmatory Factor Analysis for Family Understanding

Family Understanding was measured using the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002). The factor loadings were examined using .20 as a cutoff. Initially, the overall goodness of fit indices did not meet the recommended values. Therefore, the model was respecified by deleting item 1 (“There have been extraordinary time demands created in looking after the needs of the disabled child”) due to a very large covariance value. Additionally, the I freed error 10 on item 3 (“It has led to additional financial costs”) and freed 4 on item 12 (“The situation has led to tension with spouse”) based on the modification indices, resulting in a good fit for the measurement model of the FICD (see Table 4.5 and Figure 4.2). Furthermore, the indicator values were calculated using the results of the respecified models of the instrument. The indicator values were calculated using the results of the CFA for respecified measurement model for Family Understanding: (a) Positive Appraisal (PA) subscale score items 4, 6, and 10 (Cronbach’s α = .550) and (b) Negative Appraisal (NA) subscale score items 2, 3, 5, 7, 8, 9, 11, and 12 (Cronbach’s α = .840). The total of the
items (4, 6, 10, 2, 3, 5, 7, 8, 9, 11, and 12) that were included in the final measurement model were used to measure Family Understanding (Cronbach’s α = .772).

These respecified indices suggest that the freed and deleted items may not necessarily influence family understanding among this target population. Thus, parents may not experience positive appraisal due to an improved spousal relationship. Moreover, financial costs and tensions with one’s spouse may not necessarily lead to negative appraisal when assessing family understanding. Therefore, the subjective evaluation of events based on one’s particular circumstances may not be what one might expect when assessing family understanding among parents of a child with ASD.

Table 4.5 Model Fit Indices for the FICD

<table>
<thead>
<tr>
<th></th>
<th>x²</th>
<th>df</th>
<th>p</th>
<th>CMIN/df</th>
<th>GFI</th>
<th>CFI</th>
<th>TLI</th>
<th>RMSEA</th>
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</tr>
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<tbody>
<tr>
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<td>179.998</td>
<td>53</td>
<td>.000</td>
<td>3.396</td>
<td>.925</td>
<td>.897</td>
<td>.871</td>
<td>.078</td>
<td>&lt; 200</td>
</tr>
<tr>
<td>ΔFigure 4.2</td>
<td>98.067</td>
<td>42</td>
<td>.000</td>
<td>2.335</td>
<td>.956</td>
<td>.947</td>
<td>.930</td>
<td>.058</td>
<td>&gt; 200</td>
</tr>
</tbody>
</table>

Confirmatory Factor Analysis for Social Support

Social Support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988). The overall goodness of fit indices met the recommended cutoff of .70. Therefore, the final measurement model for MSPSS resulted in a good fit for these data with this sample (see Table 4.4 and Figure 4.3). The indicator values were calculated using the results of the CFA for social support. The measurement model for Social Support includes three subscales: (a) Significant Other (F1) subscale score includes items 1, 2, 5, and 10 (Cronbach’s α = .897), (b) Family (F2) subscale score includes items 3, 4, 8, and 11 (Cronbach’s α = .895) and (c)
Friends (F3) subscale score includes items 6, 7, 9, and 12 (Cronbach’s $\alpha = .872$). The total score is determined by summing all total subscale scores (Cronbach’s $\alpha = .935$).

These findings suggest that these subscales (significant others, friends, and family) appropriately measured social support for this target population. Moreover, it suggests that parents need social support from family and friends which involves
discussing problems, sharing emotions, and engaging in collaborative decision making with others.

Table 4.6 Model Fit Indices for the MSPSS

<table>
<thead>
<tr>
<th></th>
<th>$x^2$</th>
<th>df</th>
<th>p</th>
<th>CMIN/df</th>
<th>GFI</th>
<th>CFI</th>
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<th>RMSEA</th>
<th>Hoelter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 4.3</td>
<td>131.072</td>
<td>51</td>
<td>.000</td>
<td>2.570</td>
<td>.947</td>
<td>.975</td>
<td>.968</td>
<td>.063</td>
<td>&lt; 200</td>
</tr>
</tbody>
</table>

Confirmatory Factor Analysis for Coping Behaviors

Coping Behaviors were measured using the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983). The factor loadings were examined using .40 as a cutoff. Initially, the overall goodness of fit indices did not meet the recommended values. Therefore, the model was respecified by deleting items (1, 3, 6, 8, 16, 21, 23, 26, 28, 31, 36, 38, 41, 44) on the Coping Pattern I subscale (F1), deleting items (4, 9, 17, 22, 27, 29, 32, 33, 34, 39, and 42) on the Coping Pattern II subscale (F2), and deleting items (10, 25, 30, and 35) on the Coping Pattern III subscale (F3) based on the modification indices, resulting in a good fit for the measurement model of the FICD (see Table 4.7 and Figure 4.4). Additionally, the indicator values were calculated using the results of the respecified models for coping behaviors. The final measurement model includes the following: (a) Coping Pattern I (F1) subscale score items 11, 13, 18, 43, and 45 (Cronbach’s $\alpha = .791$), (b) Coping Pattern II (F2) subscale score items 2, 7, 12, 14, 19, 24, and 37 (Cronbach’s $\alpha = .804$), and (c) Coping Pattern III (F3) subscale score items 5, 15, 20, and 40 (Cronbach’s $\alpha = .667$). The CHIP does not have a total scale score.
Although the instrument used to measure coping behaviors involved an extensive list of coping strategies, these findings suggest that many of these coping strategies may not appropriately measure coping behaviors for this population due to deleting 29 out of 45 items on the instrument to meet the recommended indices. Therefore, the remaining coping strategies appear to be appropriate for these parents. These specific coping strategies include involvement in social activities with friends and family, encouraging
the child to be more independent, trusting one’s spouse, and reminding oneself of the things he or she has to be thankful for.

Table 4.7 Model Fit Indices for the CHIP

<table>
<thead>
<tr>
<th>Model</th>
<th>$x^2$</th>
<th>df</th>
<th>p</th>
<th>CMIN/df</th>
<th>GFI</th>
<th>CFI</th>
<th>TLI</th>
<th>RMSEA</th>
<th>Hoelter</th>
</tr>
</thead>
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<tr>
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<td>3246.005</td>
<td>942</td>
<td>.000</td>
<td>3.446</td>
<td>.672</td>
<td>.690</td>
<td>.674</td>
<td>.079</td>
<td>&lt; 200</td>
</tr>
<tr>
<td>ΔFigure 4.4</td>
<td>233.933</td>
<td>101</td>
<td>.000</td>
<td>2.316</td>
<td>.931</td>
<td>.939</td>
<td>.928</td>
<td>.058</td>
<td>&gt; 200</td>
</tr>
</tbody>
</table>

Confirmatory Factor Analysis for Competence

Competence was measured using the Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989). The factor loadings were examined using .50 as a cutoff. Therefore, the model was respecified by deleting item 11 (“If anyone can find the answer to what is troubling my child, I am the one.”) on the Efficacy subscale (F1), and deleting item 5 (“My mother was better prepared to be a good mother than I am.”), deleting item 8 (“A difficult problem in being a parent is not knowing whether you’re doing a good job or a bad one.”), and deleting item 14 (“If being a mother of a child were only more interesting, I would be motivated to do a better job as a parent.”) on the Satisfaction subscale (F2) that did not meet the suggested cutoff. Additionally, error 10 on item 12 (“My talents and interests are in other areas, not being a parent.”) and error 11 on item 9 (“Sometimes I feel like I’m not getting anything done.”) were freed based on the modification indices. The respecification provided a good fit for the measurement model of the PSOC (see Table 4.8 and Figure 4.5). Additionally, the indicator values were calculated using the results of the respecified model which includes the following: (a) Efficacy (F1) subscale score items 1, 6, 7, 10, 13, and 15 (Cronbach’s $\alpha = .791$) and
Figure 4.4 Measurement Model for the CHIP

(b) Satisfaction (F2) subscale score items 2, 3, 4, 9, 12, and 16 (Cronbach’s α = .804).

These findings from the measurement model suggest that efficacy and satisfaction among parents of a child with ASD appropriately measured competence, with the exception of the 3 out of 16 deleted items mentioned above. Moreover, the results suggest that although one may experience an absence of satisfaction and efficacy in one self, her or she may not necessarily lack competence in the parenting role.
Table 4.8 *Model Fit Indices for the PSOC*

<table>
<thead>
<tr>
<th></th>
<th>$x^2$</th>
<th>df</th>
<th>p</th>
<th>CMIN/df</th>
<th>GFI</th>
<th>CFI</th>
<th>TLI</th>
<th>RMSEA</th>
<th>Hoelter</th>
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<td>103</td>
<td>.000</td>
<td>4.521</td>
<td>.845</td>
<td>.778</td>
<td>.741</td>
<td>.095</td>
<td>&lt; 200</td>
</tr>
<tr>
<td>ΔFigure 4.5</td>
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<td>52</td>
<td>.000</td>
<td>2.642</td>
<td>.943</td>
<td>.926</td>
<td>.906</td>
<td>.065</td>
<td>&gt; 200</td>
</tr>
</tbody>
</table>

Complete Measurement Model

The complete measurement model included all measurement models of each construct. Modification indices were reviewed and due to moderate fit, the complete measurement model was not respecified (see Table 4.9 and Figure 4.6).
Table 4.9 Model Fit Indices for the Complete Measurement Model

<table>
<thead>
<tr>
<th></th>
<th>$x^2$</th>
<th>df</th>
<th>p</th>
<th>CMIN/df</th>
<th>GFI</th>
<th>CFI</th>
<th>TLI</th>
<th>RMSEA</th>
<th>Hoelter</th>
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</thead>
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<td>Figure 4.6</td>
<td>418.617</td>
<td>124</td>
<td>.000</td>
<td>3.376</td>
<td>.890</td>
<td>.896</td>
<td>.871</td>
<td>.078</td>
<td>&lt; 200</td>
</tr>
</tbody>
</table>

Figure 4.6: Complete Measurement Model

**Hypothesized Structural Model**

The hypothesized structural model was specified based on the complete measurement model. Chronic sorrow (F5) was defined as the endogenous latent variable (dependent variable) and the following were defined as the exogenous latent variables (independent variables): Family Understanding (F1), Social Support (F2), Coping Behaviors (F3) and Competence (F4). Maximum Likelihood (ML) was used to estimate the hypothesized model. Based on examination of the fit indices, it indicated a poor model fit for these data. However, due to several attempts to respecify the model by
deleting and/or freeing indicators, I accepted the model was a poor fit for these data with this sample (see Table 4.10 and Figure 4.8).

Table 4.10 *Model Fit Indices for the Hypothesized Structural Model*

<table>
<thead>
<tr>
<th></th>
<th>$\chi^2$</th>
<th>df</th>
<th>p</th>
<th>CMIN/df</th>
<th>GFI</th>
<th>CFI</th>
<th>TLI</th>
<th>RMSEA</th>
<th>Hoelter</th>
</tr>
</thead>
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<td>4.567</td>
<td>.846</td>
<td>.836</td>
<td>.807</td>
<td>.095</td>
<td>&lt; 200</td>
</tr>
</tbody>
</table>

Figure 4.7: Hypothesized Structural Model

**Follow-up Analyses**

Additionally, the I conducted follow-up analyses by conducting Spearman’s Rho correlations to further support the results of the SEM for the research hypothesis.

According to Pallant (2013), a Spearman rho is particularly useful when data does not meet criteria for Pearson correlations. Moreover, preliminary analyses were performed to examine if the data met the assumptions (normality, linearity, and homoscedasticity) for Pearson product-moment correlation and the data violated these assumptions. Moreover,
correlational research does not provide a researcher the ability to determine causal relationships, but the correlation coefficient does determine the strength, direction, and significance of the relationship (Cohen, 1988). A correlation coefficient is between -1.00 and +1.00. The – or + determine the direction of the relationship and the closer the coefficient is to -1.00 or +1.00, the stronger the relationship. The relationships were evaluated based on suggested guidelines according to Cohen (1988) including: small r = .10 to .29, medium r = .30 to .49, and large r = .50 to 1.0. The analyses were conducted including all the items in each instrument. Therefore, any items that were removed for SEM analyses were put back into the total scores to ensure that all items were accounted for.

Follow-up Question 1: Is there a statistically significant relationship between family understanding [as measured by the Family Impact of Childhood Disability Scale (FICD; Trute, & Hiebert-Murphy, 2002)] and chronic sorrow [as measured by the Adapted Burke Questionnaire (ABQ; Hobdell, 2004)] among parents of a child with ASD?

The relationship between family understanding and chronic sorrow was examined using a Spearman rho correlation. There was a strong, positive correlation between the two variables \( r = .524, p < .05 \). This finding suggests that when parents of a child with ASD have family understanding, they are likely to experience chronic sorrow.

Follow-up Question 2: Is there a statistically significant relationship between social support [as measured by the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)] and chronic sorrow [as measured by
the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)] among parents of a child with ASD?

The relationship between social support and chronic sorrow was examined using a Spearman rho correlation. The correlation between the two variables was weak and found not significant \((r = .051, p < .05)\). This finding suggests there is no significant relationship between social support and chronic sorrow among parents of a child with ASD.

**Follow-up Question 3:** Is there a statistically significant relationship between coping behaviors [as measured by the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983)] and chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)] among parents of a child with ASD?

The relationship between coping behaviors and chronic sorrow was examined using a Spearman rho correlation. The correlation between the two variables was weak and found not significant: Coping Patterns I \((r = .004, p < .05)\); Coping Patterns II \((r = .026, p < .05)\) and Coping Patterns III \((r = .033, p < .05)\). This finding suggests there is no significant relationship between coping behaviors and chronic sorrow among parents of a child with ASD.

**Follow-up Question 4:** Is there a statistically significant relationship between competence [as measured by the *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989)] and chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)] among parents of a child with ASD?

The relationship between competence and chronic sorrow was examined using a Spearman rho correlation. There was a medium, negative correlation between the two
variables ($r = -.327$, $p < .05$). This relationship suggests that when parents of a child with ASD feel more competent, they experience less chronic sorrow.

**Chapter Summary**

Chapter four presented the results of the data analyses which included: (a) descriptive statistics, (b) structural equation modeling, and (c) Spearman Rho correlations. The final chapter continues with a discussion of the results, implications for counselors and areas for future research.
CHAPTER 5

DISCUSSION

The purpose of chapter five is to provide an overview of the study and a discussion of the results. Chapter five further discusses findings presented in chapter four and compares these findings to the literature. The findings from the research hypothesis and follow-up analyses are discussed. Additionally, this chapter (a) reviews the study limitations, (b) provides recommendations for areas of future research, and (c) provides implications for counselors and counselor educators in the profession.

Overview of Study

The purpose of this research study was to examine the directional relationships between chronic sorrow as indicated by each of the following: family understanding, social support, coping behaviors, and competence among parents of a child with autism spectrum disorder (ASD). This investigation assessed family understanding [as measured by the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983)], and competence [as measured by the *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989)] with chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)]. More specifically, this examination tested the hypothesized directional relationship that parents of a child with ASD will have low
levels of chronic sorrow due to high levels of family understanding, social support, coping behaviors, and competence.

Despite current understanding of stress and emotions among parents of a child with ASD, there is limited research regarding chronic sorrow among parents of a child with ASD. More specifically, little is known about the direct relationships in which chronic sorrow is associated with the following: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence, specifically among parents of a child with ASD. According to Rossheim and McAdams (2012), counselors appear to be unprepared to assist individuals in dealing with their unique experience of chronic sorrow and may mistakenly treat these symptoms as grief, depression, and anxiety. Therefore, Rossheim & McAdams (2012) caution counselors against equating chronic sorrow with one of its features independently. Given the lack of research and awareness regarding chronic sorrow as it pertains to parents of a child with a disability, both counselors and parents appear unsure as to how to appropriately address chronic sorrow. Therefore, identification of these relationships between chronic sorrow and each of the following: (a) family understanding, (b) social support, (c) coping behaviors, and (d) competence, will increase awareness of chronic sorrow within the field of counseling. More importantly, it will increase knowledge for counselors when fostering guidance and support, specifically among parents of a child with ASD.

The study was approved by the University of South Carolina’s Institutional Review Board. Data collection was conducted from November 2016 through February 2017. The sample for the study included 394 participants who identified as the role of a parent among a child with ASD. The participants completed an online survey through
Qualtrics, which consisted of the following instruments: (a) General Demographic Survey (created by the researcher); (b) Adapted Burke Questionnaire (ABQ; Hobdell, 2004); (c) Family Impact of Childhood Disability Scale (FICD; Trute & Hiebert-Murphy, 2002); (d) Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988); (e) Coping Health Inventory for Parents (CHIP; McCubbin, McCubbin, & Cauble, 1979); and (f) Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989). Structural equation modeling (SEM) was used to analyze the data. Specifically, path analysis and confirmatory factor analysis (Kline, 2011; Crockett, 2012). Additionally, follow-up analyses were examined using descriptive statistics and Spearman’s Rho correlations. Furthermore, participant demographic variables were also examined.

The following sections further examine and expand upon the results presented in chapter four. A review of the demographic data and instrumentation scores pertaining to chronic sorrow are presented. Additionally, the results of the statistical analyses used to analyze the primary research hypothesis and the follow-up analyses are discussed. The chapter concludes with limitations of the study, recommendations for counselors and counselor educators, as well as, areas for future research.

**Participant Demographics**

Most of the participants were female \((n = 227, 58.4\%)\) as opposed to those who identified as male \((n = 162, 41.6\%)\). The participants’ ages ranged from 20 to 65 and the most common age among participants was 35. Ethnicity among participants was 288 \((74.0\%)\) Caucasian, 45 \((11.5\%)\) Black/African American, 29 \((7.5\%)\) Asian, 26 \((6.7\%)\) Hispanic, and 1 \((0.3\%)\) Hawaiian/Pacific Islander. The current relationship status for
participants was 251 (64.5%) married, 78 (20.1%) single, 32 (8.2%) partner, 15 (3.9%) divorced, and 13 (3.3%) separated. The current employment status was 242 (62.2%) full-time, 84 (21.6%) unemployed, and 63 (16.2%) part-time. Each participant identified his or her relationship to the child with ASD which was 200 (51.4%) mother, 126 (31.6%) father, 11 (2.8%) stepmother, 3 (0.77%) grandmother, 3 (0.77%) aunt, 3 (0.77%) uncle, 3 (0.77%) stepfather, 2 (0.5%) foster parent, and 38 (9.8%) unknown because the participant chose not to answer. Moreover, 194 (49.9%) participants reported other family members living in the home with him or her and his or her child with ASD, as opposed to 195 (50.1%) participants reported no one else living in the home.

Additionally, 311 (79.9%) participants reported not having received previous counseling and 78 (20.1%) participants reported receiving previous counseling. Furthermore, 343 (88.2%) participants reported no active participation in a support group and 46 (11.8%) participants reported active participation in a support group.

Previous research pertaining to demographic data, specifically gender and ethnicity, among parents of a child with ASD was somewhat consistent with the current investigation. Specifically, the male perspective in this study is underrepresented by a small difference as compared to the female perspective. May, Fletcher, Dempsey, and Newman (2015) examined co-parenting qualities among both mothers and fathers to address parenting stress and parenting self-efficacy in families with a child with ASD, 80 mothers responded and 72 fathers responded. Griffith, Hastings, and Petalas (2014), investigated sibling adjustment from the parent perspective due to having one child with ASD and one without ASD, 168 mothers and 130 fathers reported.
The ethnicity among participants in this study was 29 (7.5%) Asian, 288 (74.0%) Caucasian, 45 (11.5%) Black/African American, 26 (9.7%) Hispanic, and 1 (0.3%) Hawaiian/Pacific Islander. The majority of the participants identified their ethnicity as Caucasian. Carr and Lord (2012), examined mothers’ perceptions of negative impact of having a child with ASD, 80 Caucasian and 30 African American mothers participated. Jang, Matson, Cervantes, and Konst (2014) examined the relationship between ethnicity and the age at which parents become concerned about their child’s development in toddlers with ASD, Caucasian (n = 799), African-American (n = 552), and other ethnicity including Hispanic and Asian (n = 127) participated in this study and found no relationship between age and ethnicity. Ekas et al., (2016) examined cultural differences in family functioning among mothers of 117 children with ASD (Hispanic n = 73; non-Hispanic White n = 44). Based on a literature search, it appears that the majority of parents among a child with ASD are Caucasian. However, many studies have been conducted, specifically regarding mothers who identify as Caucasian, Hispanic, or African American. Therefore, the demographic data in this study was similar to previous research among parents of a child with ASD.

Instrumentation and Measurement Models

There were five instruments used to measure the constructs examined in this study. Chronic sorrow was measured using the Adapted Burke Questionnaire (ABQ; Hobdell, 2004). Family understanding was measured using the Family Impact of Childhood Disability Scale (FICD; Trute & Hiebert-Murphy, 2002). Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988). Coping behaviors were measured using the Coping
Health Inventory for Parents (CHIP; McCubbin, McCubbin, & Cauble, 1979).

Competence was measured using the Parenting Sense of Competence scale (PSOC; Johnston & Mash, 1989). Confirmatory factor analysis (CFA) was conducted on each instrument to ensure the items were loading independently and to provide a rationale for specification of the measurement model for these data and sample.

To determine overall goodness of fit, the following fit indices and their recommended values were used (Hu & Bentler, 1999; Kline, 2016; Byrne, 2016; Brown, 2015): (a) Chi Square ($x^2$) is the extent to which the overall model predicts the observed covariance, the ratio of $x^2$ to $df$ should be ≤ 2 or 3; (b) Tucker-Lewis Index (TLI) describes the extent to which the specified model performs better than a baseline model, the TLI should be ≥ .95, however .90 is considered acceptable; (c) Comparative Fit Index (CFI), is similar to the TLI but accounts for sample size, CFI should be ≥ .95; (d) Root Mean Square Error of Approximation (RMSEA), compares the fit of an independent model (a model which indicates no relationships between variables) to the fit of the estimated model, RMSEA should be < .06; (e) Goodness of Fit Index (GFI) is the proportion of variance that is determined by the estimated population covariance, GFI should be ≥ .95; and (f) Hoelter’s Critical N addresses the adequacy of the sample size to provide a good model fit for Chi square and should be > 200. The following presents a discussion on each measurement model per variable under examination in this study.

**Overview of Findings**

**Chronic Sorrow**

The 8-item Adapted Burke Questionnaire (ABQ; Hobdell, 2004) was used to measure chronic sorrow. The ABQ is an adaptation of Burke’s Chronic Sorrow
Questionnaire (CSQ; Burke, 1989). Parents rate their current experiences of the intensity of eight mood states including ‘grief’, ‘shock’, ‘anger’, ‘disbelief’, ‘sadness’, ‘hopelessness’, ‘fear’, and ‘guilt’ on a 4 point Likert scale ranging from (0) Absent, (1) Not Intense, (2) Somewhat Intense, to (3) Very Intense. An intensity score is calculated by summing the eight item scores for a possible range of 0 – 24. A higher cumulative score indicates increased chronic sorrow symptoms. Cronbach’s α assessing the internal consistency of the ABQ was .844, indicating an acceptable internal consistency of the scale measuring 8 factors of chronic sorrow among parents (Pallant, 2013).

The measurement model of chronic sorrow was specified using eight indicators (1) Grief, (2) Shock, (3) Disbelief, (4) Anger, (5) Guilt, (6) Sadness, (7) Helplessness, and (8) Fear. The Cronbach’s α assessing the internal consistency of the ABQ was .844. Although the factor loadings met the recommended cutoff of .50, the overall goodness of fit indices did not meet the recommended values. Therefore, I freed errors 2 (Shock) and 3 (Disbelief) based on the modification indices, resulting in a good fit for the measurement model of the ABQ. The respecified model produced a chi-square of 52.040 (df=19, x² ratio=2.739, p=.000), and RMSEA=.067. All other fit indices indicated a good model fit: GFI=.965, CFI=.967, and TLI=.952.

These findings suggest that all of these emotions (grief, shock, disbelief, anger, guilt, sadness, helplessness, and fear) appropriately measure chronic sorrow. However, freeing errors 2 (Shock) and 3 (Disbelief) attributed to a better model fit. Therefore, it can be suggested that shock and disbelief may not account for emotions attributing to chronic sorrow long-term. This finding makes sense regarding shock and disbelief considering chronic sorrow involves features of permanent, pervasive, and progressive sadness.
(Eakes, Burke, & Hainsworth, 1998). Thus, shock and disbelief are typically experienced as an initial response to a situation, as opposed to being maintained throughout the duration of the lifespan. Additionally, parents rated other emotions such as helplessness, sadness, and fear highly as very intense when caring for a child with ASD. Therefore, these particular emotions should be addressed separately in order to decrease chronic sorrow symptoms.

**Family Understanding**

The 15-item *Family Impact of Childhood Disability Scale* (FICD; Trute & Hiebert-Murphy, 2002) was used to measure family understanding. More specifically, the FICD assesses parent perception of the impact of developmental disability on the family (Trute & Hiebert-Murphy, 2002). The scale is comprised of two subscales: Positive Appraisal (PA; 5 items) and Negative Appraisal (NA; 10 items). However, due to researcher error, participants only completed a total of 12 items: PA (3 items) and NA (9 items); resulting in items 3 (PA subscale), 14 (NA subscale), and 15 (PA subscale) not being included in the survey. Again, this was due to researcher error and was not done intentionally. Therefore, the reliability should be interpreted with caution. Participants are asked to identify what consequences have resulted from having a child with a disability in their family on a 4 point Likert scale: (1) Not at all, (2) To a mild degree, (3) To a moderate degree, or (4) To a substantial degree. Example questions include: ‘There has been unwelcome disruption to “normal” family routines’ and ‘The experience has made us come to terms with what should be valued in life’. Cronbach’s α assessing the internal consistency was .550 for the PA subscale, indicating low internal consistency, and .849 for the NA subscale, indicating acceptable internal consistency of the subscale.
Additionally, Cronbach’s α assessing the internal consistency of the total FICD without items 3, 14, and 15 was .793, indicating a good internal consistency measuring family understanding.

The factor loadings were examined using .20 as a cutoff. Initially, the overall goodness of fit indices did not meet the recommended values. Therefore, the model was respecified by deleting item 1 (“There have been extraordinary time demands created in looking after the needs of the child with a disability”), due to a very large covariance value. Additionally, I freed error 10 on item 3 (“It has led to additional financial costs) with error 4 on item 12 (“The situation has led to tension with spouse”) based on the modification indices, resulting in a good fit for the measurement model of the FICD. The respecified model produced a chi-square of 98.057 (df=42, χ² ratio=2.335, p=.000), and RMSEA=.058. All other fit indices indicated a good model fit: GFI=.956, CFI=.947, and TLI=.930. Furthermore, the indicator values were calculated using the results of the respecified models of the instrument. The indicator values were calculated using the results of the CFA for respecified measurement model for Family Understanding: (a) Positive Appraisal subscale score items 4, 6, and 10 (Cronbach’s α = .550) and (b) Negative Appraisal subscale score items 2, 3, 5, 7, 8, 9, 11, and 12 (Cronbach’s α = .840). The total of the items (4, 6, 10, 2, 3, 5, 7, 8, 9, 11, and 12) that were included in the final measurement model were used to measure Family Understanding (Cronbach’s α = .772).

The respecified model suggests a good fit for these data. Item 4 (“Having a child with a disability has led to an improved relationship with spouse”) had the lowest loading (.53) on the positive appraisal subscale, but still met the recommended cutoff of .40. Essentially, based on this finding per this particular item, it is important to acknowledge
that positive appraisal may not be experienced based on an improved spousal relationship. Moreover, financial costs and tensions with spouse may not necessarily lead to negative appraisal when assessing family understanding. Therefore, the subjective evaluation of events based on one’s particular circumstances may not be what one might expect when assessing family understanding among parents of a child with ASD.

Social Support

The 12-item *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988; Appendix D) was used to measure social support. The MSPSS includes three subscales: Family (4 items), Friends (4 items), and Significant Other (4 items). Participants are asked to indicate how they feel about each statement using a 7 point Likert scale: (1) Very Strongly Disagree, (2) Strongly Disagree, (3) Mildly Disagree, (4) Neutral, (5) Mildly Agree, (6) Strongly Agree, or (7) Very Strongly Agree. Example questions include: ‘There is a special person who is around when I am in need’, ‘My family really tries to help me’, and ‘I can count on my friends when things go wrong’.

All of the factors loaded at .90 or above which met the recommended cutoff for the overall fit indices of .70. Therefore, the final measurement model for MSPSS resulted in a good fit for these data with this sample. The specified model produced a chi-square of 131.072 ($df=52$, $x^2$ ratio=2.570, $p=.000$), and RMSEA=.063. All other fit indices indicated a good model fit: GFI=.947, CFI=.975, and TLI=.968. The indicator values were calculated using the results of the CFA for social support. The measurement model for Social Support includes three subscales: (a) Significant Other subscale score includes items 1, 2, 5, and 10 (Cronbach’s $\alpha = .897$), (b) Family subscale score includes items 3, 4,
8, and 11 (Cronbach’s α = .895) and (c) Friends subscale score includes items 6, 7, 9, and 12 (Cronbach’s α = .872). The total score is determined by summing all total subscale scores (Cronbach’s α = .935).

These findings indicated these subscales (significant others, friends, and family) appropriately measured social support for these data. Moreover, it suggested that parents need social support from family and friends which involves discussing problems, sharing emotions, and engaging in collaborative decision making with others in order to alleviate stress. Further, Cuzzocrea, Murdaca, Costa, Filipello, and Larcan (2016) found that the quality of support is more important among parents of a child with ASD, as opposed to quantity. Additionally, Siklos and Kerns (2006) found that parents of a child with ASD believe their needs are better met when working closely with the professionals that support their child with ASD and the entire family. Therefore, this suggested that social support should not be limited to significant other, family, and friends among parents of a child with ASD. Furthermore, evidence suggests that greater social support is perceived among parents of children with autism because of greater family adaptation and decreased parental stress (Gray, 2002; Lin et al., 2008). Thus, social support can involve other types of resources and individuals such as community resources, teachers and staff in the school settings, and professionals working with the child and family outside of the home.

**Coping Behaviors**

The 45-item *Coping Health Inventory for Parents* (CHIP; McCubbin, McCubbin, & Cauble, 1979; Appendix E) was used to measure coping behaviors. The CHIP consists of three subscales: (1) Coping Pattern I - Maintaining Family Integration, Cooperation,
and an Optimistic Definition of the Situation (19 items, maximum score of 57), (2) Coping Pattern II - Maintaining Social Support, Self-esteem, and Psychological Stability (18 items, maximum score of 54), and (3) Coping Pattern III - Understanding the Medical Situation through Communication with Other Parents and Consultation with the Medical Staff (8 items, maximum score of 24). Participants are asked to rate the level of “helpfulness” for each coping behavior on a 4 point Likert scale: (3) Extremely Helpful, (2) Moderately Helpful, (1) Minimally Helpful, or (0) Not Helpful. Example questions include: ‘Doing things with my children’, ‘Entertaining friends in our home’, and ‘Reading about how other persons in my situation handle things’. Higher scores indicate greater usefulness of that particular coping pattern. Due to subscale scoring only, Cavallo, Feldman, Swaine, and Meshefedijian (2009) suggest determining the percentage of the maximum score per pattern to allow for comparison between the three coping patterns. This percentage is calculated by dividing the total score for each coping pattern by the maximum possible score of that specific pattern (Cavallo et al., 2009). Cronbach’s α assessing the internal consistency for each subscale was .863 for Coping Pattern I, .862 for Coping Pattern II, and .785 for Coping Pattern III, indicating acceptable internal consistency.

The factor loadings on this measurement model were examined using .40 as a cutoff. Initially, the overall goodness of fit indices did not meet the recommended values. Therefore, the model was respecified by deleting items (1, 3, 6, 8, 16, 21, 23, 26, 28, 31, 36, 38, 41, 44) on the Coping Pattern I subscale, deleting items (4, 9, 17, 22, 27, 29, 32, 33, 34, 39, and 42) on the Coping Pattern II subscale, and deleting items (10, 25, 30, and 35) on the Coping Pattern III subscale, based on the modification indices, resulting in a
good fit for the measurement model of the FICD for these data. The respecified model
produced a chi-square of 233.933 ($df=101, \chi^2 = 2.316, p = .000$), and RMSEA=0.058.
All other fit indices indicated a good model fit: GFI=.931, CFI=.939, and TLI=.928.
Additionally, the indicator values were calculated using the results of the respecified
models for coping behaviors. The final measurement model includes the following: (a)
Coping Pattern I subscale score items 11, 13, 18, 43, and 45 (Cronbach’s $\alpha = .791$), (b)
Coping Pattern II subscale score items 2, 7, 12, 14, 19, 24, and 37 (Cronbach’s $\alpha = .804$),
and (c) Coping Pattern III subscale score items 5, 15, 20, and 40 (Cronbach’s $\alpha = .667$).
The CHIP does not have a total scale score.

Hall (2012) suggests that parents of children with ASD need a wide range of
suitable coping strategies to put into practice when they encounter challenges. Moreover,
parents with an effective sense of coherence are better equipped to choose a coping plan
that would assist them in managing their family stressors. For example, the use of
positive reframing, which means substituting negative circumstances with either a helpful
idea or act, is a coping technique that can be very helpful to a family with a child with
ASD (Hastings et al., 2005; Pozo et al., 2011).

Although the instrument used to measure coping behaviors (CHIP) involved an
extensive list of coping strategies, these findings indicated many of these coping
strategies did not appropriately measure coping behaviors for this population due to
deleting 29 out of 45 items on the instrument to meet the recommended indices.
Therefore, the remaining coping strategies appeared to be appropriate for parents of a
child with ASD. More specifically, these coping strategies include involvement in social
activities with friends and family, encouraging the child to be more independent, trusting one’s spouse, and reminding oneself of the things he or she has to be thankful for.

**Competence**

The 16-item *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989; Appendix F) was used to measure competence. The PSOC consists of two subscales: Satisfaction (9 items) and Efficacy (7 items). Participants are asked to rate the extent to which they agree or disagree with statements on a 6 point Likert scale ranging from (1) Strongly Disagree, (2) Somewhat Disagree, (3) Disagree, (4) Agree, (5) Somewhat Agree, to (6) Strongly Agree. Example questions include: ‘If anyone can find the answer to what is troubling my child, I am the one’, ‘Sometimes I feel like I’m not getting anything done’, and ‘Being a parent makes me tense and anxious’. A higher total score indicates a higher parenting sense of competency.

The factor loadings on the measurement model for competence were examined using .50 as a cutoff. Therefore, the model was respecified by deleting item 11 (“If anyone can find the answer to what is troubling my child, I am the one”) on the Efficacy subscale and deleting item 5 (“My parent was better prepared to be good parent than I am”), deleting item 8 (“A difficult problem in being a parent is not knowing whether you’re doing a good job or a bad one”), and deleting item 14 (“If being a parent of a child were only more interesting, I would be motivated to do a better job as a parent”) on the Satisfaction subscale, due to not meeting the suggested cutoff. Additionally, error 10 on item 12 (“My talents and interests are in other areas, not being a parent”) and error 11 on item 9 (“Sometimes I feel like I’m not getting anything done”) were freed based on the modification indices. The respecification provided a moderate fit for the measurement
model of the PSOC. The respecified model produced a chi-square of 137.366 ($df=52, x^2$ ratio=2.642, $p=.000$), and RMSEA=.065. All other fit indices indicated a good model fit: GFI=.943, CFI=.926, and TLI=.906. Additionally, the indicator values were calculated using the results of the respecified model which includes the following: (a) Efficacy subscale score items 1, 6, 7, 10, 13, and 15 (Cronbach’s $\alpha = .791$) and (b) Satisfaction subscale score items 2, 3, 4, 9, 12, and 16 (Cronbach’s $\alpha = .804$).

Evidence suggests that parents of youth with ASD are at risk for increased stress levels, social isolation, and family disruption, which leads to lower levels of competence among parents (Higgins, Bailey, & Pearce, 2005; Montes & Halterman, 2007). Therefore, parenting stress needs to be addressed in order to prevent poor competence among parents. Gilmore and Cuskelly (2009) suggests that increased self-efficacy provides parents with increased resiliency regarding both depression and anxiety. Therefore, increased levels of self-efficacy can lead to decreased levels of well-being and contribute to high levels of competence in the parenting role.

These findings from the measurement model suggested that efficacy and satisfaction among parents appropriately measured competence, except for the 3 out of 16 deleted items mentioned above. However, Tobing and Glenwick (2007) found that higher levels of parenting satisfaction predicted lower levels of psychological distress and higher levels of parenting efficacy predicted higher levels of psychological distress. Moreover, the latter finding can be explained possibly due to a greater level of awareness regarding the child’s development (Tobing & Glenwick, 2007). Thus, these findings from the measurement model as compared to previous research suggested that levels of efficacy and satisfaction contribute to competence because of different experiences and level of
awareness among parents. Furthermore, the results suggested that although one may experience an absence of satisfaction and efficacy in one self, her or she may not necessarily lack competence in his or her parenting role. Thus, competence among parents of a child with ASD varied based on the ways in which they perceived satisfaction and efficacy in their parenting role.

**Complete Measurement Model**

The complete measurement model included all measurement models of each construct. Modification indices were reviewed and due to moderate fit, the complete measurement model was not respecified. The specified model produced a chi-square of 418.617 ($df=124$, $\chi^2$ ratio=3.367, $p=.000$), and RMSEA=.078. All other fit indices indicated a moderate model fit: GFI=.890, CFI=.896, and TLI=.871. Furthermore, AMOS did not provide a squared multiple correlation for each independent variable. Therefore, I chose to complete a standard multiple regression to determine how well this set of independent variables was able to predict chronic sorrow and how much each individual variable contributed to the unique variance in explaining chronic sorrow (Pallant, 2013).

These findings from the standard multiple regression suggested that 36.5% of variance in chronic sorrow was explained by all of the independent variables combined (family understanding, social support, coping behaviors, and competence). Moreover, family understanding explained 22% of variance in chronic sorrow, social support explained .18% of variance in chronic sorrow, coping behaviors explained .03% of variance in chronic sorrow, and competence explained 3.8% of variance in chronic sorrow. Therefore, family understanding made the largest unique contribution (beta = .504, $p < .05$) and competence also made a statistically significant contribution (beta = -
.214, p < .05). Although social support and coping behaviors did not make a significant contribution to the prediction of chronic sorrow, these findings suggested that social support and coping behaviors should still be addressed in order to alleviate, or more importantly, prevent chronic sorrow symptoms among parents of a child with ASD.

**Primary Research Question**

Do family understanding [as measured by the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983)], and competence [as measured by the *Parenting Sense of Competence scale* (PSOC; Johnston & Mash, 1989)] among parents of a child with ASD contribute to their level of chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)]?

**Research Hypothesis**

The research hypothesis tested in this examination was: Family understanding [as measured by the *Family Impact of Childhood Disability Scale* (FICD; Trute, & Hiebert-Murphy, 2002)], social support [as measured by the *Multidimensional Scale of Perceived Social Support* (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)], coping behaviors [as measured by the *Coping Health Inventory for Parents* (CHIP; McCubben et al., 1983)], and competence [as measured by the *Parenting Sense of Competence scale* (PSOC; Johnston & Mash, 1989)] among parents of a child with ASD will contribute to their level of chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)]. Specifically, this examination tested the hypothesized directional
relationship that higher levels of family understanding, social support, coping behaviors, and competence among parents of a child with ASD will have lower levels of chronic sorrow (see Figure 1.1).

![Figure 1.1 Hypothesized Path Model](image)

In order to investigate the hypothesis, a structural model was examined and tested based on the complete measurement model. Chronic sorrow (F5) was defined as the endogenous latent variable (dependent variable) and the following were defined as the exogenous latent variables (independent variables): Family Understanding (F1), Social Support (F2), Coping Behaviors (F3) and Competence (F4). Maximum Likelihood (ML) was used to estimate the hypothesized model. Based on examination of the fit indices, it
indicated a poor model fit for these data. Therefore, due to several attempts to respecify the model by deleting indicators and/or freeing errors, I accepted the model was a poor fit for these data with this sample (see Table 4.10 and Figure 4.7). Thus, the hypothesis was not accepted.

Table 4.10 Model Fit Indices for the Hypothesized Structural Model

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</tr>
</thead>
<tbody>
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<td>df</td>
<td>p</td>
<td>CMIN/df</td>
<td>GFI</td>
<td>CFI</td>
<td>TLI</td>
<td>RMSEA</td>
<td>Hoelter</td>
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</tr>
<tr>
<td>593.734</td>
<td>130</td>
<td>.000</td>
<td>4.567</td>
<td>.846</td>
<td>.836</td>
<td>.807</td>
<td>.095</td>
<td>&lt; 200</td>
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Figure 4.7: Hypothesized Structural Model

Additionally, these results of the hypothesized structural model in this study should be interpreted with caution due to the researcher unintentionally omitting three items on the FICD scale used to measure Family Understanding (F1). However, these indicators still loaded at an acceptable fit for this model.
Follow-Up Analyses

All of the follow-up analyses were conducted using a Spearman Rank Order Correlation (rho). According to Pallant (2013), a Spearman rho is particularly useful when data does not meet criteria for Pearson correlations. Moreover, preliminary analyses were performed to examine if the data met the assumptions (normality, linearity, and homoscedasticity) for Pearson product-moment correlation and the data violated these assumptions. Therefore, a Spearman rho correlation was conducted and the relationships were evaluated based on suggested guidelines according to Cohen (1988) including: small $r = .10$ to .29, medium $r = .30$ to .49, and large $r = .50$ to 1.0. The analyses were conducted including all the items in each instrument. Therefore, any items that were removed for SEM analyses were put back into the total scores to ensure that all items were accounted for.

Follow-up Question 1: Is there a statistically significant relationship between family understanding [as measured by the Family Impact of Childhood Disability Scale (FICD; Trute, & Hiebert-Murphy, 2002)] and chronic sorrow [as measured by the Adapted Burke Questionnaire (ABQ; Hobdell, 2004)] among parents of a child with ASD?

The relationship between family understanding and chronic sorrow was examined using a Spearman rho correlation. There was a strong, positive correlation between the two variables ($r = .524$, $p < .05$). This finding suggests that when parents of a child with ASD have family understanding, they are likely to experience chronic sorrow. Therefore, as parents learn about their child’s diagnosis (ASD) and what it means for themselves, as well their families, chronic sorrow symptoms increase. As parents gain a better
understanding of their child’s development as it pertains to ASD, they are likely to experience emotions such as helplessness, sadness, and fear. Thus, chronic sorrow symptoms can be expected as parents learn about the diagnosis of ASD and how it can impact them and their families.

Follow-up Question 2: Is there a statistically significant relationship between social support [as measured by the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988)] and chronic sorrow [as measured by the Adapted Burke Questionnaire (ABQ; Hobdell, 2004)] among parents of a child with ASD?

The relationship between social support and chronic sorrow was examined using a Spearman rho correlation. The correlation between the two variables was weak and found not significant (r = .051, p < .05). This finding suggested there is no significant relationship between social support and chronic sorrow among parents of a child with ASD. Although social support did not influence chronic sorrow among parents of a child with ASD, social support may be effective when combined with other variables in this study.

Follow-up Question 3: Is there a statistically significant relationship between coping behaviors [as measured by the Coping Health Inventory for Parents (CHIP; McCubben et al., 1983)] and chronic sorrow [as measured by the Adapted Burke Questionnaire (ABQ; Hobdell, 2004)] among parents of a child with ASD?

The relationship between coping behaviors and chronic sorrow was examined using a Spearman rho correlation. The correlation between the two variables was extremely weak and found not significant: Coping Patterns I (r = .004, p < .05); Coping...
Patterns II \( (r = .026, p < .05) \) and Coping Patterns III \( (r = .033, p < .05) \). This finding suggested there is no significant relationship between coping behaviors and chronic sorrow among parents of a child with ASD.

**Follow-up Question 4:** Is there a statistically significant relationship between competence [as measured by the *Parenting Sense of Competence* scale (PSOC; Johnston & Mash, 1989)] and chronic sorrow [as measured by the *Adapted Burke Questionnaire* (ABQ; Hobdell, 2004)] among parents of a child with ASD?

The relationship between competence and chronic sorrow was examined using a Spearman rho correlation. There was a medium, negative correlation between the two variables \( (r = -.327, p < .05) \). This relationship suggested that when parents of a child with ASD feel more competent, they experience less chronic sorrow. As parents recognize their abilities and successes, as well as feel satisfied in their parenting role, they are likely to experience less chronic sorrow. Thus, competent parents are likely to experience less sadness, less fear, and less helplessness as they care for their child with ASD, which in turn benefits themselves as parents and more importantly, their child with ASD.

**Limitations**

A primary limitation in the current study was the low, inaccurate overall response rate. Although an effort was made to follow Dillman’s (2000) *Tailored Design Method*, I did not obtain a complete response rate. One limitation of the study was the truthfulness of the participants. Moreover, I recognized due to not having a close network with individuals in the autism community, this may have also contributed to a low overall response rate. Furthermore, although I assumed each participant had a child between the
ages of 3 and 17 with ASD in which they currently resided with, I did not require participants to provide proof as such. Therefore, the participants may not have been honest when completing the questionnaires due to responses being socially undesirable or they may have felt inclined to respond in a certain way.

The utilization of MTurk to collect data is a limitation. Although I reviewed and implemented guidelines to successfully and appropriately collect data using MTurk, concerns still existed. It is questionable as to whether the workers on MTurk were representative of the desired population and concerns about the overall quality of the data that participants provide (Paolacci, Chandler, & Ipeirotis, 2012). Additionally, it was difficult to know if participants on MTurk truly met the criteria to participate in the study. However, that same limitation existed with participants who were invited via a study flyer in person.

The scope may have limited generalizability of the findings. Although the scope of this study examined parents of a child between the ages of 3 and 17 with ASD, the findings of the study may provide insight to all parents of a child beyond the age of 18 with ASD and with other types of developmental disabilities, as well as insight for other professionals such as social workers, medical professionals, etc., who provide parents support in various capacities.

Another limitation may have been the survey instruments. Each instrument utilized a Likert-type scale for participant responses and participants may have needed clarification on questions and/or wanted to provide more information to their responses. However, a Likert-type scale does not permit room for additional responses. Thus, participant responses are limited. In addition, my choice of instruments may be a
limitation. The poorer the reliability of its measures, the greater the degree to which a study’s observed correlation is expected to underestimate the true correlation between constructs of interest (Hoyt, Leierer, & Millington, 2006). Although I thoroughly reviewed the reliability and validity of each instrument, other instruments may provide additional results for this particular study. Furthermore, due to researcher error pertaining to unintentionally omitting three items on the FICD scale, these results should be interpreted with caution.

SEM could be considered a limitation of the study. Although SEM examines correlations among variables, it cannot establish causal effects (Crockett, 2011). Moreover, SEM is a confirmatory technique used to test an a priori theoretical model and is not an exploratory technique for simply identifying relationships among variables (Crockett, 2012; Kelloway, 1998). Therefore, successful application of the SEM techniques relies on the researchers’ theoretical knowledge of each variable (Crockett, 2012; Stage, Carter, & Nora, 2004). Additionally, SEM requires a large sample size of at least 200 to ensure trustworthiness of the results (Kline, 2011).

**Recommendations for Future Research**

Future research should consider the limitations mentioned in the current study. If possible, the researcher may want to collaborate with an organization that works closely with the target population of the study in order to build rapport with potential participants and request participants complete the survey by paper and pencil to increase response rate. Additionally, it may be beneficial to analyze the data using another SEM program such as Mplus or LISREL.
Future research could include different types of instruments to measure these variables under investigation. The current study may have benefited from having more time to collect data. Depending on how large the sample size needs to be generalizable and whether the researcher already has a network with the target population, the researcher needs to consider time and recruitment issues. Additionally, the current study examined five variables. Future studies may want to further examine two variables among the target population if using advanced statistical analyses due to the vast amount of effort needed when analyzing the data. Moreover, the results of family understanding, social support, coping behaviors, and competence among this population may guide future research activities. Further, future research may involve measuring these variables among different populations such as adults with disabilities, parents of a child with different developmental disabilities, and those who acquired a disability due to a tragic event. Additionally, future research may also include utilizing a qualitative approach with a smaller sample size to gain a better understanding of the lived experiences and emotions of parents who have a child with ASD.

Implications

The aim of this study was to determine the relationships between chronic sorrow and each of the following: family understanding, social support, coping behaviors, and competence among parents of a child with ASD. The results of this study indicated that family understanding, social support, coping behaviors, and competence do not influence chronic sorrow. However, each of these variables contributed to the explained variance in chronic sorrow. All of the predictor variables combined (family understanding, social support, coping behaviors, and competence) explained 36.5% of variance in chronic
sorrow. Moreover, family understanding explained 22% of variance in chronic sorrow, social support explained .18% of variance in chronic sorrow, coping behaviors explained .03% of variance in chronic sorrow, and competence explained 3.8% of variance in chronic sorrow. Although, family understanding made the largest unique contribution and competence also made a statistically significant contribution, both social support and coping behaviors still made a small unique contribution. Therefore, all of these variables contributed, whether large or small, to chronic sorrow among parents of a child with ASD. This suggests that family understanding, social support, coping behaviors, and competence among parents of a child with ASD should be addressed to better understand chronic sorrow symptoms. Moreover, family understanding and competence each demonstrated a significant relationship with chronic sorrow. Thus, it is imperative for counselors to address each of the following: family understanding, social support, coping behaviors, and competence, in order to better understand chronic sorrow among this population.

Counselors need to assess for particular emotions when addressing chronic sorrow. Chronic sorrow involves features of permanent, pervasive, and progressive sadness and are triggered based on life events that occur throughout one’s lifespan. (Eakes, Burke, & Hainsworth, 1998). The results of this study indicated that counselors need to assess for emotions such as helplessness, fear, sadness, shock and disbelief when working with parents. Essentially, counselors need to ask specific questions regarding these emotions as they assess for chronic sorrow symptoms among parents.

Counselors should also use caution as they engage in psychoeducation activities with parents about their child’s diagnosis (ASD). The results of the study indicated that
more family understanding attributed to higher levels of chronic sorrow. Therefore, counselors need to be mindful of how much information they choose to disclose to parents about their child’s disability and what it means for them and their families in order to prevent chronic sorrow symptoms from occurring. Furthermore, counselors need to allow parents to subjectively evaluate their particular circumstances as positive or negative on their own, rather than to assume how parents perceive their situations. As counselors attempt to understand how parents perceive their unique situations as a parent of a child with ASD and what it means for their family, counselors become more effective when working with this population.

   Counselors should encourage parents to seek social support. Although social support did not have a significant relationship with chronic sorrow, results indicated otherwise that parents need support. Counselors should urge parents to seek support from friends, family members, significant others, and other professionals outside of the home such as healthcare professionals and their child’s teacher. Therefore, parents should initiate conversations with their child’s school teacher and get involved in school activities to build rapport with others who provide support to their child with ASD. Moreover, the type of social support is important. For example, discussing problems and triumphs, sharing emotions such as joy and sadness, and engaging in collaborative decision making with others is beneficial for parents. Cuzzocrea et al. (2016) suggests that the quality of support is more important as opposed to quantity of support. Therefore, counselors should prompt parents to identify a few individuals in which they can engage in meaningful conversations about their experiences. Thus, social support is most beneficial for parents when they have meaningful conversations with those who care.
Parents of a child with ASD need a wide range of coping strategies when they encounter challenges (Hall, 2012). Although the results of this study did not indicate a relationship between coping behaviors and chronic sorrow, parents still need to be informed of appropriate coping strategies to alleviate stressor. A technique such as positive reframing that involves substituting negative circumstance with either a helpful idea or act is beneficial for parents (Hastings et al., 2005; Pozo et al., 2011). Additionally, involvement in social activities with friends and family, encouraging the child to be more independent, trusting one’s spouse, and reminding oneself of the things he or she should be thankful for are suitable coping strategies for parents of a child with ASD.

Furthermore, counselors should prompt parents to choose suitable coping strategies that meet their needs and develop a coping plan. This coping plan can include a list of challenging situations and substitute each situation with a specific coping strategy. Thus, counselors should encourage parents to identify and engage in suitable coping strategies to cope in difficult situations.

Lastly, parents of a child with ASD need to feel competent in their parenting role. The results of this study indicated that when parents felt more competent, they experienced less chronic sorrow. Moreover, counselors should encourage parents to recognize their abilities and successes, as well as acknowledge moments when they feel satisfied in their parenting role. Counselors should also use a strengths-based approach when assisting parents through difficult situations. It is imperative for parents to reflect on their strengths and accomplishments when they encounter challenges. Furthermore, the results indicated that although a parent may experience an absence of satisfaction and efficacy in one self, her or she may not necessarily lack competence in his or her
parenting role. Therefore, one’s perception of competence may vary based on the ways in which they experience satisfaction and efficacy in their parenting role. Thus, competent parents are less likely to experience chronic sorrow symptoms, specifically sadness, fear, and helplessness, as they care for their child with ASD.

**Conclusion**

Chapter five reviewed and discussed findings from the current investigation. The results of the study did not support the hypothesized theoretical model and should be interpreted with caution due to limitations of the study. More specifically, both family understanding and competence demonstrated a significant relationship with chronic sorrow among the target population. Additionally, the current study contributed to the literature, provided increased awareness of chronic sorrow, and discussed implications for counselors when working with this population. Therefore, it is important for counselors to assess chronic sorrow and the impact it has on parents and their families. Thus, chronic sorrow exists and should be addressed to maintain or improve quality of life among parents of a child with ASD.
REFERENCES


INSTITUTIONAL REVIEW BOARD FOR HUMAN RESEARCH

APPROVAL LETTER for EXEMPT REVIEW

This is to certify that the research proposal: Pro00061375

Title: Examining Chronic Sorrow Among Parents of Children with Autism Spectrum Disorder (ASD)

Submitted by:

Principal Investigator: Tiffany Bordonada

College of Education

Educational Studies / Counselor Education

Wardlaw

Columbia, SC 29208

was reviewed in accordance with 45 CFR 46.101(b)(2), the referenced study received an exemption from Human Research Subject Regulations on 11/7/2016. No further action or Institutional Review Board (IRB) oversight is required, as long as the project remains the same. However, the Principal Investigator must inform the Office of Research Compliance of any changes in procedures involving human subjects. Changes to the current research protocol could result in a reclassification of the study and further review by the IRB.
Because this project was determined to be exempt from further IRB oversight, consent document(s), if applicable, are not stamped with an expiration date. Research related records should be retained for a minimum of three (3) years after termination of the study.

The Office of Research Compliance is an administrative office that supports the University of South Carolina Institutional Review Board (USC IRB). If you have questions, contact Arlene McWhorter at arlenem@sc.edu or (803) 777-7095.

Sincerely,

Lisa M. Johnson
IRB Manager
APPENDIX B: INITIAL REQUEST FOR PARTICIPATION

Subject: Initial Request for Participation in a Research Study

Dear Parent/Guardian:

I am conducting a study under the faculty supervision of Dr. Jonathan H. Ohrt in the College of Education. The purpose of my study is to examine chronic sorrow among parents of children (ages 3-17) with autism spectrum disorder (ASD). You will be asked to rate questions regarding your coping behaviors, social support, emotions, and experiences in your role as a parent of a child with ASD. For example, you will be asked to indicate how you feel on a scale ranging from ‘very strongly disagree’ to ‘very strongly agree’ for questions such as “There is a special person around when I am in need” and “My family really tries to help me.”

The significance of the study will provide counselors with increased knowledge and awareness when fostering guidance and support for parents of children with ASD. Therefore, your responses are greatly valued.

This survey will take 20 minutes to complete and your participation is voluntary. Please type the link below in your internet browser to access the survey.

http://tinyurl.com/parentstudysurvey

Participation and data will be kept confidential. I will be the only person able to access the survey results. However, you will not be asked to include any identifying information. The results of the study may be published or presented at professional meetings, but your identity will not be revealed. Additionally, I will make a $1.00 donation for every completed survey to autism research.

If you have any questions about the study, please contact me (Tiffany at bordonat@email.sc.edu) or you may contact my faculty supervisor, Dr. Jonathan H. Ohrt at ohrt@mailbox.sc.edu. If you have any questions about your rights as a research subject, please contact Lisa Marie Johnson, IRB Manager, Office of Research Compliance, University of South Carolina, 1600 Hampton Street, Suite 414, Columbia, SC 29208, Phone: (803) 777-7095 or LisaJ@mailbox.sc.edu.

Thank you so much for your participation in this study. Your feedback is greatly appreciated.

Sincerely,

Tiffany M. Bordonada, M.S., M.P.A.
Doctoral Candidate, Counselor Education
University of South Carolina
bordonat@email.sc.edu
APPENDIX C: GENERAL DEMOGRAPHIC QUESTIONNAIRE

Please do not write your name on this form. The form will be kept confidential.

List your age ________

Gender

☑ Male
☑ Female

Marital Status

☑ Single
☑ Married
☑ Divorced
☑ Separated
☑ Partner

Ethnicity. Select all that apply.

☑ Asian
☑ Black or African American
☑ Caucasian
☑ Hispanic or Latino
☑ Native Hawaiian or Pacific Islander
☑ Other, please list ____________________

Employment Status

☑ Unemployed
☑ Part-time. List number of hours per week. ____________________
☑ Full-time. List number of hours per week. ____________________
How many children do you have? __________

How many children do you have with ASD? _________

At what age was your child diagnosed with ASD? __________

What is the current age of your child with ASD? _________

Identify the relationship to your child with ASD (i.e., mother, father, grandmother, grandfather, stepmother, uncle, aunt, etc.) ______________

Do other individuals live in the same home with you and your child with ASD?

☐ No
☐ Yes. Please list ________________

Have you or your family received previous counseling?

☐ No.
☐ Yes. Please explain ________________

Do you participate in any social support groups (face-to-face or online)?

☐ No.
☐ Yes. Please explain and list the group(s) ________________
APPENDIX D: ADAPTED BURKE QUESTIONNAIRE

Please rate your intensity for each of the following mood states since your child’s diagnosis.

<table>
<thead>
<tr>
<th>Mood State</th>
<th>Absent</th>
<th>Not Intense</th>
<th>Somewhat Intense</th>
<th>Very Intense</th>
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<td>Anger</td>
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<td>Guilt</td>
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<td>Sadness</td>
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<td>Helplessness</td>
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<td>Fear</td>
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APPENDIX E: FAMILY IMPACT OF CHILDHOOD DISABILITY

SCALE

To what degree have you experienced the following as a result of having a child with a disability in your family?

1. There have been extraordinary time demands created in looking after the needs of the disabled child.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree

2. There has been unwelcome disruption to "normal" family routines.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree

3. The experience has brought us closer to God.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree

4. It has led to additional financial costs.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree

5. Having a disabled child has led to an improved relationship with spouse.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree
6. It has led to limitations in social contacts outside the home.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree

7. The experience has made us come to terms with what should be valued in life.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree

8. Chronic stress in the family has been a consequence.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree

9. We have had to postpone or cancel major holidays.
   - Not at all
   - To a mild degree
   - To a moderate degree
   - To a substantial degree

10. It has led to reduction in time parents could spend with their friends.
    - Not at all
    - To a mild degree
    - To a moderate degree
    - To a substantial degree

11. The child's disability has led to positive personal development in mother and/or father.
    - Not at all
    - To a mild degree
    - To a moderate degree
    - To a substantial degree

12. Because of the situation, parents have hesitated to phone friends and acquaintances.
    - Not at all
    - To a mild degree
    - To a moderate degree
    - To a substantial degree

13. The situation has led to tension with spouse.
    - Not at all
    - To a mild degree
14. Because of circumstances of the child’s disability, there has been a postponement of major purchases.
- Not at all
- To a mild degree
- To a moderate degree
- To a substantial degree

15. Raising a disabled child has made life more meaningful for family members.
- Not at all
- To a mild degree
- To a moderate degree
- To a substantial degree
APPENDIX F: MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle “1” if you Very Strongly Disagree
Circle “2” if you Strongly Disagree
Circle “3” if you Mildly Disagree
Circle “4” if you are Neutral
Circle “5” if you Mildly Agree
Circle “6” if you Strongly Agree
Circle “7” if you Very Strongly Agree

<table>
<thead>
<tr>
<th>1. There is a special personal who is around when I am in need.</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<tbody>
<tr>
<td>2. There is a special personal with whom I can share joys and sorrows.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>3. My family really tries to help me.</td>
<td>1</td>
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<td>4. I get the emotional help &amp; support I need from my family.</td>
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<tr>
<td>5. I have a special personal who is a real source of comfort to me.</td>
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<tr>
<td>6. My friends really try to help me.</td>
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<td>7. I can count on my friends when things go wrong.</td>
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<tr>
<td>8. I can talk about my problems with my family.</td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>9. I have friends with whom I can share my joys and sorrows.</td>
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<td>3</td>
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<td>6</td>
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<tr>
<td>10. There is a special person in my life who cares about my feelings.</td>
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<td>11. My family is willing to help me make decisions.</td>
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<tr>
<td>12. I can talk about my problems with my friends.</td>
<td>1</td>
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APPENDIX G: COPING HEALTH INVENTORY FOR PARENTS

For each coping behavior you used, please record how helpful it was.

3 Extremely helpful
2 Moderately helpful
1 Minimally helpful
0 Not helpful

1. Believing that my child(ren) will get better.
2. Investing myself in my children.
3. Doing things with my children.
4. Believing that things will always work out.
5. Telling myself that I have many things I should be thankful for.
7. Talking over personal feelings and concerns with spouse.
8. Doing things with family relatives.
9. Believing in God.
10. Taking good care of all the medical equipment at home.
11. Believing that my child is getting the best medical care possible.
12. Trying to maintain family stability.
13. Doing things together as a family (involving all members of the family).
14. Trusting my spouse (or former spouse) to help support me and my child(ren).
15. Showing that I am strong.

16. Getting other members of the family to help with chores and tasks at home.

17. Having my child with medical condition seen at the clinic/hospital on a regular basis.

18. Believing that the medical center/hospital has my family’s best interest in mind.

19. Encouraging child(ren) with medical condition to be more independent.

20. Involvement in social activities (parties, etc.) with friends.

21. Being able to get away from home care tasks and responsibilities for some relief.

22. Getting away by myself.

23. Eating.

24. Sleeping.

25. Allowing myself to get angry.

26. Purchasing gifts for myself and/or other family members.

27. Concentrating on hobbies (art, music, jogging, etc.).

28. Working, outside employment.

29. Becoming more self-reliant and independent.

30. Keeping myself in shape and well-groomed.

31. Talking to someone (not professional counselor/doctor) about how I feel.

32. Engaging in relationships and friendships which help me to feel important and appreciated.

33. Entertaining friends in our home.

34. Investing time and energy in my job.

35. Going out with spouse in a regular basis.

36. Building close relationships with people.
37. Developing myself as a person.

38. Talking with other parents in the same type of situation and learning about their experiences.

39. Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center.

40. Reading about how other persons in my situations handle things.

41. Reading more about the medical problem which concerns me.

42. Explaining our family situations to friends and neighbors so they will understand.

43. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis.

44. Talking with other individuals/parents in my same situation.

45. Talking with other doctors about my concerns about my child(ren) with the medical condition.
APPENDIX H: PARENTING SENSE OF COMPETENCE SCALE

Please rate the extent to which you agree or disagree with the following statements.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Somewhat Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.</td>
<td>1</td>
<td>2</td>
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<td>2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age.</td>
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<td>3. I go to bed the same way I wake up in the morning, feeling I have not accomplished a whole lot.</td>
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<td>4. I do not know why it is, but sometimes when I’m supposed to be in control, I feel more like the one being manipulated.</td>
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<td>5. My mother was better prepared to be a good mother than I am.</td>
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<td>6. I would make a fine model for a new mother to follow in order to learn what she would need to know in order to be a good parent.</td>
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<td>7. Being a parent is manageable, and any problems are easily solved.</td>
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<td>8. A difficult problem in being a parent is not knowing whether you’re doing a good job or a bad one.</td>
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<td>9. Sometimes I feel like I’m not getting anything done.</td>
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<td>10. I meet my own personal expectations for expertise in caring for my child.</td>
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<td>11. If anyone can find the answer to what is troubling my child, I am the one.</td>
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<td>12. My talents and interests are in other areas, not being a parent.</td>
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<td>13. Considering how long I’ve been a mother, I feel thoroughly familiar with this role.</td>
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<td>14. If being a mother of a child were only more interesting, I would be motivated to do a better job as a parent.</td>
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<td>15. I honestly believe I have all the skills necessary to be a good mother to my child.</td>
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<td>16. Being a parent makes me tense and anxious.</td>
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