ADULT SIBLINGS OF INDIVIDUALS WITH DEVELOPMENTAL AND PSYCHIATRIC DISABILITIES: RELATIONSHIP QUALITY, COPING, AND PLANS FOR THE FUTURE

by

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This work is dedicated to my sister, Rosario – hermana querida.
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*I will give thanks to you, Lord, with all my heart; I will tell of all your wonderful deeds.*

*Psalm 9:1*
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ABSTRACT

MARGARITA VÉLEZ RICE
ADULT SIBLINGS OF INDIVIDUALS WITH DEVELOPMENTAL AND PSYCHIATRIC DISABILITIES: RELATIONSHIP QUALITY, COPING, AND PLANS FOR THE FUTURE
Under the direction of DON REDMOND, Ph.D.

The following study examines the experience of adult siblings of individuals who have developmental and psychiatric disabilities. Using a mixed methods research design, the researcher evaluated 84 self-reports of adult sibling relationship quality, coping strategies, and responses to qualitative questions regarding relational characterizations and expectations for the future planning and care for brothers and sisters with special needs. This study identified significant correlations between warm sibling relationships and coping strategies. A thematic analysis of the qualitative responses revealed themes that created complementarity to the quantitative findings and indicate directions for future research.
CHAPTER ONE

INTRODUCTION

In the last two decades, a significant amount of research and cultural interest has focused on autism spectrum disorder as an epidemic, which has increased awareness and concern for the impact of brain-related disorders and lifelong disabilities on affected children and their families (CDC, 2014; Fombonne, 2005; Hansen, Schendel, and Parner, 2015; Matson and Kozlowski, 2011). Intellectual, developmental, and psychiatric disabilities are rooted in neurological processes that often arise before an individual’s brain has consolidated into older adulthood, and result in significant functional deficits across the lifespan (American Psychiatric Association, 2013). These disabilities are recognized as mental disabilities, with varying levels of severity and dependency on others for daily care (United States Census Bureau, 2010). Over the past 50 years, in response to civil rights movements and advocacy for persons with disabilities, an expanse of literature has focused on the mechanisms of disability, treatment initiatives, the rights and needs of persons with disabilities, and their impact on families (Albrecht, 2006; Altman, 2001; American Psychiatric Association, 2013; Batshaw, Roizen, and Lotrecchiano, 2013; Breslin and Yee, 2002; Burch, 2009; Marsh, 1992; Voigt, Macias, and Myers, 2010).

Family studies in this area have primarily concentrated on parental dysfunction and adjustment for families with dependents who have pervasive disabilities (Larson and Corrigan, 2008; Pruncho and Meeks, 2004; Raina et al., 2013; Smith, Oliver, and
Innocenti, 2001). Caregiver studies have reported high incidences of parental stress, burden, pessimism, divorce and marital challenges, and anxiety about the future (Angold et al., 1998; Fidler, Hodapp, and Dykens, 2000; Hauser-Cram, Warfield, Shonkoff, and Kraus, 2001; Park and Seo, 2016; Smith, Oliver, and Innocenti; Urbano and Hodapp, 2007). Other research has found that parents of children with these conditions exhibit resilience and positive coping, with opportunities for personal growth and making meaning (Mendenhall and Mount, 2011; Scorgie and Sobsey, 2000; Scorgie, Wilgosh, and Sobsey, 2004; Trute and Hiebert-Murphy, 2002; Trute, Hiebert-Murphy, and Levine, 2007).

While the impact of parental experiences and psychosocial outcomes for caregivers has been widely studied, a growing body of knowledge is beginning to evaluate the implications of developmental and psychiatric disabilities on the sibling experience within the family (Giallo and Gavidia-Payne, 2006; McCullough and Simon, 2011; Stoneman, 2005; Taylor, Greenberg, Seltzer, and Floyd, 2008; Van Der Sanden, Bos, Stuttereim, Pryor, and Kok, 2015). Siblings of persons with these disabilities are a unique population who often experience challenges and opportunities in the family of origin that are different from the typically developing population (Grissom and Brokowski, 2002; Marsh, 1992; Schuntermann, 2009). These siblings usually encounter their brother or sister’s disability at earlier stages in their life than parents or caregivers, may receive differential attention from caregivers, and often assume adult-like responsibilities at younger ages (Benderix and Sivberg, 2007; Stoneman, 2005). Research has revealed that this population is vulnerable to internalizing and externalizing disorders, yet these siblings are likely to exhibit strengths in self-concept, empathy,
compassion, resilience, and social competence (Enns, Reddon, and McDonald, 1999; McHale and Harris, 1992; Schuntermann; Stoneman; Taylor, Greenberg, Seltzer, and Floyd). The following study further examines the experience of siblings of persons with disabilities, and provide insights into the nature of these relationships in adulthood.

Statement of the Problem

Sibling relationships have been characterized in psychological and family systems literature as the origins of peer relations, carrying across the lifespan longer than other human relationships (Orsmond, Kuo, and Selfzer, 2009). Studies have noted that sibling relationships in the family of origin often have a lasting impact on an individual, regardless of whether they are biological siblings, half-siblings, step-siblings, or adoptive siblings (Cicirelli, 2013; Sutton-Smith and Rosenberg, 1970). Research is beginning to understand the impact of childhood and adolescent sibling interactions on psychosocial outcomes, beyond the parent-child dyad.

Family systems theories in counseling view all members of a family having an impact on one another’s mental health and adjustment (Minuchin, 1988). Alfred Adler was one of the first theorists to research the psychology of siblings, with his studies on sibling birth order and how one’s family influences personality development (Adler, 1964). Adler proposed that sibling ordinal position, or the order in which a child is born (i.e., only child, firstborn, second, third, or youngest), was correlated with common personality characteristics. These characteristics arise from common interaction styles and hierarchical systems among parents and siblings (Adler). Moreover, Adler proposed that an individual’s psychological birth order, or ordinal position in which he or she perceives himself or herself, drives an individual’s personality and the way in which he
or she relates to others. The birth order model has been scrutinized and debated (Ernst and Angst, 1983; Sulloway, 1996), yet continues to be a popular topic in understanding the psychology of siblings and inspires conceptual approaches in family therapy (Leman, 2009; Carballo et al., 2013). From Adler’s work, psychological literature on siblings expanded to study the influence of sibship size on individual pathology and health (Birtchnell, 1970), family constellations and individual sibling characteristics (Toman, 1976), and the mapping of family genograms to understand sibling relational patterns through the generations (Bowen, 1978).

These early approaches are grounded in the idea that sibling experiences and behavioral patterns are likely to have a lasting impact on others in the family, which remains relevant today. For example, recent studies have revealed phenomena such as the sibling-spillover effect on academic achievement, with older sibling’s performance influencing educational outcomes for younger siblings (Nicoletti and Rabe, 2014). In a study about sisters, siblings were found to influence reproductive decision-making and pregnancy risk on one another (East, Slonim, Horn, Trinh, and Reyes, 2009). Moreover, McCamish-Svensson and colleagues (1999) conducted a longitudinal study with elderly participants and found that later life satisfaction positively correlates with one’s health and closeness with siblings ($r = .38$, $p < .01$), more than support from friends or children. Sibling relationships are important to consider when examining factors related to an individual’s later life adjustment, attitudes, and coping skills (Hastings, 2007).

Psychological literature has established a substantial foundation for understanding the influence of sibling interactions on the individual and is beginning to create a basis for recognizing the implications for siblings in families with disabilities (Lamb and
Disability is a general term, which has been defined in a variety of ways by governing bodies and diagnostic authorities. For example, there are differing definitions for developmental and psychiatric disabilities among the Diagnostic and Statistical Manual for Mental Health Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013), the International Classification of Diseases (10th ed.; ICD-10; WHO, 2010), the United States Census Bureau (2010) data, the Americans With Disabilities Act (1990), and the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001). In general, disabilities refer to functional deficits, activity limitations, and participation restrictions that influence people’s identities and life situations (Altman, 2001). Lifelong disabilities affect one’s capacity for self-sufficiency and self-direction into older age (Smart & Smart, 2006). Considering this, disability involves an interaction among identity, society, physical environments, and levels of impairment. The spectrum of conditions that are considered disabilities often overlap in their relation to ability and in severity (Altman, 2001).

A person with a disability may experience challenges in various aspects of functioning and ability, from physical to psychological. Physical disabilities include conditions of motor dis-coordination and impairments in movement, and can arise from physiological and metabolic conditions or injury (Altman, 2001). Intellectual disabilities affect one’s cognitive capacity, or ability to reason, and can include brain injuries or cognitive delays (Altman). Developmental disabilities are generally life-long, congenital conditions, which can be physical and cognitive (Altman). Sensory disabilities are those that affect the functioning of the senses and the integration of sensory information from the outside world. Other categorizations of disability include those that influence speech,
language, and learning (Lambie & Milson, 2010), and psychiatric conditions (Overton & Medina, 2008).

With this in mind, researchers in the helping professions work to distinguish the types of conditions studied and consider the family context, among other variables, in order to gain a comprehensive understanding of other abilities and how they operate within family systems. There is a growing body of knowledge for studies on siblings and disabilities, yet most pertains to childhood siblings and experiences in the family of origin. There is a limited amount of information available on adult brothers and sisters of individuals with developmental and psychiatric disabilities in the literature.

Siblings of individuals with mental disabilities may be differentiated from parents and other caregivers in that they usually begin to conceptualize and learn to relate to their brother or sister’s disability at a younger age (Benderix and Sivberg, 2007). These brothers and sisters may also receive less or differential types of attention from caregivers during childhood, due to caregiving demands for their sibling with a developmental or psychological condition (Cicirelli, 2013; Stoneman, 2005). These siblings often ascribe to caregiving or assistive roles at early ages, and have been noted to be increasingly involved in later life planning for the sibling with the neurologically-based disability in adulthood (Heller and Caldwell, 2006; Larson and Corrigan, 2008). Roughly half of these siblings become the primary caregiver, supervisor, advocate, or mediator for their brother or sister after the death of parents (Bigby, 1997). These experiences have been suggested to influence the individual’s personality development and propensity for adaptive attitudes and behavior into adulthood (Burton and Parks, 1994).
The ways in which these early life experiences shape adult personality and behavior have been an increasing focus in the literature (Cicirelli, 2013; Urbano and Hodapp, 2007). Research has examined the influence of proximity and closeness in these sibling relationships (Schuntermann, 2007; Taylor, Greenberg, Seltzer, and Floyd 2008), positive and negative appraisals of disability in the family of origin (Trute, Hiebert-Murphy, and Levine, 2007), and quality of social or familial support on adult outcomes for these siblings (Heller and Keiling Arnold, 2010). Many of these studies reveal mixed outcomes, but researchers are beginning to quantify psychosocial and adaptive behavioral outcomes for these unique experiences on adult siblings.

Purpose and Rationale

This study seeks to further understand the dynamic nature of sibling experiences and evaluate the ways in which lifelong disabilities influence sibling relationships and attitudes for non-disabled siblings into adulthood. Researchers in the helping professions should not overlook that as individuals with disabilities age, their sibling relationships become increasingly important (Heller and Keiling Arnold, 2010). The author presents data from adult siblings who completed relational and coping measures, using a mixed-methods (quantitative and qualitative) design. This information works to expand upon the literature on disabilities in family systems, while providing insights for caregivers and teachers, and inform the practice of helping professionals. This study contributes to the growing body of knowledge in this area, and seeks to clarify specific factors related to adaptive characteristics and positive psychology in these sibling experiences.

Quantitative Research Questions
1. How do adult siblings of people with developmental or psychiatric disabilities characterize their sibling relationship?

2. What forms of coping strategies do siblings of individuals with developmental or psychiatric disabilities exhibit in adulthood?

3. What is the correlation between sibling relationships and coping strategies for this population?

Qualitative Research Question

1. What expectations do adult siblings of persons with a developmental or psychiatric disability express towards long-term care for their sibling?

Definitions

The following terms are defined for the context of this study:

Adjustment: the ability to adaptively cope with life stressors and transitions, and maintain emotional stability into adulthood.

Coping Strategies: behavioral and emotional responses to life stressors, which may be adaptive or maladaptive. These are external and internal problem-solving strategies, which include: acquiring social support, mobilizing family support, passive appraisal, reframing, and seeking spiritual support – according to the F-COPES assessment by McCubbin, Larsen, and Olson (1987).

Developmental Disability: refers to a wide range of chronic neurological disorders that are characterized by mild to profound deficits in physical, intellectual, communicative, and social functioning, which are noted in early childhood and affect an individual’s ability to function across the lifespan (NIH, 2006). These deficits often interfere with an individual’s ability to exhibit receptive and expressive language,
mobility, learning, and capacity for independent living. These conditions include, but are not limited to Angelman syndrome, autism spectrum disorders, cerebral palsy, Down syndrome, fragile X syndrome, intellectual disability (formerly known as mental retardation), Prader-Willi syndrome, Rett syndrome, Smith-Magenis syndrome, Williams syndrome, and other pervasive developmental disabilities.

*Later Life Planning:* (i.e., long-term care). Making plans that support and coordinate the long-term care needs of individuals with disabilities, who depend on others for their care, as they age into later adulthood, according to Varnet (2010). This includes expectations for provision of daily care, housing arrangements, financial support, and legal responsibility. Varnet (2010) identifies that later life planning is an ongoing process that is important to the wellbeing of families with people who have lifelong disabilities.

*Mental Disabilities:* (i.e., neurologically-based disabilities). The author uses this term to refer to developmental disabilities and psychiatric disabilities, both of which are rooted in mental processes.

*Non-Disabled Sibling(s):* A typically developing, or neuro-typical adult brother or sister of an individual who has a disability that involves dependency on others for care, or limits independent living.

*Psychiatric Disability:* (i.e., psychological disorder, mental illness, or mental health condition) refers to wide range of psychological disorders that affect an individual’s emotional regulation, cognition, decision making, self-concept, and/or ability to relate to others (American Psychiatric Association, 2013). These conditions result in significant distress to the individual and deficits in his or her ability to function in
everyday life. These disorders include, but are not limited to schizophrenia spectrum and other psychotic disorders, bipolar and related disorders, depressive disorders, anxiety disorders, obsessive-compulsive and related disorders, dissociative disorders, and personality disorders.

Sibling Relationship: The way in which a sibling relates to, regards and/or behaves towards the other. These are characterizations that encompass relational attitudes, behaviors, and emotions derived from the Adult Sibling Relationship Questionnaire (ASRQ) by Stocker, Lanthier, and Furman (1997). The ASRQ measures scales of acceptance, admiration, affection, antagonism, competition, dominance, emotional support, intimacy, instrumental support, knowledge, maternal rivalry, paternal rivalry, quarreling, and similarity towards a sibling. These scales are combined into three independent dimensions of sibling relationship quality: warmth, conflict, and rivalry.

Organization of the Study

Chapter one introduces the general foundation of the study, problem explored, purpose and objectives, rationale of the research, and research questions. Chapter two discusses relevant literature on the topic and connection to the field of counseling. The methodology for the study, sampling, assessment, data collection and analysis procedures, and hypotheses are described in chapter three. Chapter four provides a comprehensive summary of the results and statistical analyses applied. Chapter five concludes with an evaluation of the research findings, limitations, and future perspectives.
CHAPTER TWO

REVIEW OF THE LITERATURE

Understanding Disability

When investigating sibling experiences with people who have disabilities, it is important to understand the context of disability studies and advocacy needs of this significant population. The concept of disability is a heterogeneous construct, which is largely conceptualized in terms of societal standards, attitudes regarding ability, severity, and individual characteristics (Parker and Patterson, 2012). Individuals may experience disability as a result of genetics, pathological factors and/or extrinsic factors, such as poverty, adversity, discrimination, and cultural conflict (Kiesler, 1980). Disability may also be measured in relation to cultural constructs of normalcy and limitations (Terz, 2013). For example, there are great disparities between an individual whose physical experience is fostered, facilitated, and supported by his or her environment, versus an individual whose physical experience is challenged, stigmatized, and disadvantaged by his or her environment (Overton & Medina, 2008).

There are numerous models of disability which may aid researchers and practitioners in acquiring better insight into the context of individual and family member experiences. Smart and Smart (2006) cite three general models of disability which pervade current studies on disability: the biomedical model, the functional-environmental model, and the socio-political model. These guiding assumptions are useful to
understanding the various dimensions of disability culture and informing ethical standards in research and practice (Smart and Smart).

The biomedical model views disability through the lens of pathology, physiological impairment, or deviation from perfect health (Smart and Smart, 2006). This perspective uses diagnostic language, which defines disability using the vocabulary of western medicine to determine prognoses, courses of treatment, and therapeutic needs (Smart and Smart). Under this model, a seven-year-old who does not speak coherently may be diagnosed as having developmental or speech delay, which can be treated by a speech and language pathologist. The authors suggest that this objective approach may create more of a degrading conceptualization of disability, in which the individual’s identity is defined by his or her diagnostic limitations. In this view, clinical labels such as intellectual disability or bipolar disorder may promote stigmatization or bias by replacing an identity with a medical condition (Dunn and Andrews, 2015). For example, the child with a speech delay may be perceived as less capable than his or her classmates.

The functional-environmental model of disability considers the areas of functioning which are limited by the disabled individual’s environment (Smart and Smart, 2006). This view considers the ways in which people are inhibited or fostered by their surroundings, which can increase or decrease an individual’s experience of disability, respectively (Smart and Smart). This idea also places less emphasis on physiological limitations by viewing disability in relation to the other abilities an individual possesses (Smart and Smart). In this framework, there is more to an individual than a disability, and his or her identity exists beyond a medicalized category (Smart and Smart). An example of this perspective may be identifying a person with Down syndrome as an
athlete in the Special Olympics, a high school student, a volunteer at the veterinarian’s office, and an aspiring photographer.

According to Smart and Smart (2006), the socio-political model recognizes persons with disabilities as a minority group with rights. This model emphasizes that disability is a social construct which lessens an individual’s social value (Smart & Smart). In this approach, stigmatization, exclusion, and prejudices against people with disabilities are an inherent consequence in society (Smart and Smart). This model advocates social action and self-actualization for those with disabilities to reduce the demeaning effect of outdated labels used for people with disabilities, such as cripple or handicapped (Smart and Smart). This model promotes the use of person-first or identity-first language in research and practice, which places an individual before a medical condition, such as describing someone as a man with autism, rather than an autistic man (Dunn and Andrews, 2015). From this perspective, helping professionals are encouraged to use terminology such as client and consumer when referring to those receiving treatment services, rather than patient, which is associated with the biomedical model (Reeder, 1972).

By consolidating these perspectives, researchers and helping professionals can create a framework for understanding how disability is experienced, how biases are created, and how cultural definitions can be internalized (Smart and Smart, 2006). Viewing a person who has a disability as an individual with multiple identities, abilities, roles, functions, and environments facilitates a more comprehensive and realistic representation of his or her life experience (Dunn and Andrews, 2015). These models can be applied to research in the social sciences and helping professions. Considering
these approaches, the author may examine the experience of brothers and sisters using a more cohesive research design that considers physiological, environmental, and social factors.

Prevalence of Disabilities

In an effort to recognize the implications of disability on family dynamics and adult sibling relationships, it is important to consider current statistical demographics and the prevalence of different types of disabilities. The United States Census Bureau (2010) publishes household statistics on Americans with disabilities to inform initiatives that serve to improve the economic conditions of persons with disabilities and facilitate employment opportunities for this large population. Among the 56.7 million individuals in the United States who have disabilities, 38.3 have severe disabilities and 12.3 million are reported to require assistance with activities for daily living (ADLs) or instrumental activities of daily living (IADLs) (United States Census Bureau). ADLs refer to daily personal care and hygiene needs, while IDLs involve daily routine needs and household responsibilities (United States Census Bureau). According to the census, the presence of a severe disability is indicated by a person identifying with any of the following criteria: (a) is over the age of six and deaf, blind, or unable to see, hear, or have speech understood; (b) is over the age 15 and unable to walk, use stairs, lift or carry, or grasp small objects; (c) is over the age of six and uses a wheelchair, cane, crutches, or walker; (d) is over the age of six and needs assistance of another person to perform one or more ADLs; (e) is over the age of 15 and needs assistance of another person to perform one or more IADLs; (f) is between the ages of 16 and 72 and has difficulty finding a job or remaining employed; (g) is over the age of 15 and has Alzheimer’s disease, dementia, or
senility; (h) is under six years old and has developmental delay; (i) is under the age of six and has intellectual disability or developmental disability, such as autism or cerebral palsy; (j) is between the ages of six and 14 and has some other developmental condition that requires therapy or diagnostic services; (k) is over the age of 15 and has one or more selected symptoms that interfere with everyday activities: is frequently depressed or anxious, has trouble getting along with others or concentrating, or has trouble coping with stress (United States Census Bureau). Delineating assistance requirements and severity helps researchers understand the impact and course of disabilities that are likely to require dependency on family members and care providers.

The report also differentiates disabilities across three domains: physical, communicative, and mental (United States Census Bureau, 2010). The census defines these disabilities according to the language used in the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001), in an attempt to consolidate the wide scope of conditions that may be considered disabilities and bridge various models of disability. Respondent’s reports coincided with one, two, or all three domains. According to the data collection procedures, physical disabilities relate to significant mobility restrictions, communicative disabilities refer to sensory and speech problems, and mental disabilities coincided with developmental disorders, learning disabilities, emotional and psychological disturbances, and cognitive degeneration associated with old age (United States Census Bureau). In general, the mental domain corresponds to the target population of siblings in this study. Using these categories, the census found that 16.8 million adults are reported to experience a disability in the mental domain. This number is largely comprised of 3.9 million adults with cognitive delays and learning
disabilities, 2.4 million with cognitive degeneration associated with old age, 1.6 million adults with developmental or intellectual disorders, and 4.7 million with mental illness or emotional disturbances (United States Census Bureau).

The economic characteristics of this population revealed that only 51.9 percent of individuals experiencing mental disabilities are employed, and that number decreases with comorbidity across other domains (United States Census Bureau, 2010). The data also reveals that adults, aged 21 to 64, with severe disabilities are less likely to be consistently employed over a two-year period (19.9 percent), than those with non-severe disabilities (54.8 percent) or no disability (61.1 percent) (United States Census Bureau). Working adults with disabilities in the mental domain made 40.56 percent less in median monthly income that those without disabilities (United States Census Bureau). Moreover, 28.6 percent of individuals, aged 15 to 64, with severe disabilities live in poverty, as compared with 14.3 percent of people without disabilities. Individuals with severe mental or neurologically-based disabilities are largely reliant on family members for financial support and coordination of care (Marsh, 1992), and this caregiving role is likely to shift towards adult siblings as families age (Heller and Keiling Arnold, 2010).

**Historical Context**

Before World War II, individuals with mental disabilities were commonly institutionalized in specialized hospitals which segregated them away from greater society to be cared for by medical personnel (Burch, 2009). These facilities were the primary resource for families with children who had severe disabilities (Burch). Although investigative journalists had published accounts of questionable patient practices in mental asylums before the World War period (Chambers, 1877), it was not
until public awareness of wartime cruelties and the beginning of the American civil rights movements that many of these institutions were exposed on a public scale to practice inhumane and unethical treatments (Torrey, 1997). Some of these interventions included pre-frontal lobotomies, coma-inducing insulin shock-therapy, unhygienic practices, violence, abuse, neglect, and torture (Torrey). Many mental hospitals were grossly overcrowded, with some reaching bed capacities over 960 percent (Blair, 2014; Torrey). Subsequently, mental health treatment reform gained momentum and the deinstitutionalization period began (Burch).

Deinstitutionalization refers to the process of reducing or eliminating large-scale mental hospitals and integrating patients with mental disabilities into society (Burch, 2009). Bachrach (1989) identifies three major goals of deinstitutionalization, which include (a) depopulation, or fragmenting liability by reducing the patient capacities of mental hospitals; (b) diversion, or transferring services from state hospitals to community-based care; (c) decentralization, or delegating services away from institutions to multidisciplinary sources of care. Considering these goals, deinstitutionalization appears to be ongoing process of professional, ethical, and political reform. With the decline of mental asylums, many individuals with serious mental illness had limited options, leaving communities and families poorly prepared, and rates of homelessness increased significantly (Torrey, 1997). Marsh (1992) argues that the deinstitutionalization movement has not achieved what it intended, in that community-based programs and managed care have failed families in providing comprehensive resources that are easily navigated and accessed. Resources for severe mental disabilities have been identified as being deficient in providing continuity of care from treatment
program to home life, leaving relatives and caregivers to navigate and coordinate care for their loved one (Marsh).

Looking Forward

What are the implications for siblings? Sibling relationships are noted as the longest lasting relationship that individuals may carry across the lifespan (Orsmond, Kuo, and Selfzer, 2009). Siblings influence one another’s cognitive development and learning (Azmita and Hesser, 1993; Cicirelli, 2013) and social skills (Downey and Condron, 2004). The sibling effect on a child’s development and adjustment is significant, irrespective of the influence of other important relationships in early life (McHale, Updegraff, and Whiteman, 2012). Downey and Condron argue that children benefit from having a sibling, regardless of gender, sibship size, and time spacing between children. These advantages are most apparent in interpersonal skill development via sibling interactions in the home (Downey and Condron). These trends are noted for typically developing children, and the author considers studies pertaining to siblings of persons with disabilities.

What is it like to grow up with a sibling who has a disability? How are non-disabled siblings affected by their brother or sister’s disability into adulthood? Several researchers have examined these questions (Benderix and Sivberg, 2007; Burton and Parks, 1994; Dyson, 1996; Enns, Reddon, and McDonald, 1999; Grissom and Brokowski, 2002; Heller and Caldwell, 2006; Heller, and Keiling Arnold, 2010; Horwitz, 1993; Kaminsky and Dewey, 2002; Macks and Reeve, 2007; Mandelco, Olsen, Dyches, and Marshall, 2003; Marsh, 1992; McCullough and Simon, 2011; McHale and Harris, 1992; Orsmond, Kuo, and Seltzer, 2009; Schuntermann, 2007; Stoneman, 2005; Taunt and
Childhood Sibling Experience

Challenges

Siblings of people with disabilities experience various challenges in childhood related to their brother or sister’s special needs, and may be susceptible to unique stressors in the home (San Martino and Newman, 1974; Marsh, 1992). Schuntermann (2007) noted that siblings of developmentally disabled children receive differential treatment from caregivers, reduced parental attention, and may be affected by marital stress related to their family’s circumstances. Siblings of individuals with developmental or psychiatric disabilities not only report spending less time with parents, but also increased levels of stress in the home (Macks and Reeve, 2007; Marsh). McCullough and Simon (2011) found that a lack of parental attention may be exasperated by limited caregiving resources and contribute to an early sense of independence on the part of non-disabled siblings.

Major stressors in the home may include being exposed to frightening abnormal behaviors, physical violence, and aggression (Benderix and Sivberg, 2007; Marsh, 1992). Non-disabled siblings have reported experiences of feeling unsafe and hypersensitive, with the need to prepare for sudden outbursts (Benderix and Sivberg). Ross and Cuskelly (2006) noted that siblings of children with autism were at increased risk of internalizing
behavior problems from angry or aggressive interactions with their sibling. Internalized behavioral problems refer to cognitive and emotional problems, such as depression and anxiety. This established pattern of uncertainty in the home, when monitoring for unsafe behavior and quick responding, may potentially influence these siblings’ anxiety regulation and emotional reactivity into adulthood, similar to that of adult children from dysfunctional families (Bogels, van Dongen, and Muris, 2003).

Other difficulties faced by brothers and sisters of individuals with disabilities include isolation from peers and limited opportunities for affective expression (McCullough and Simon, 2011). Families of individuals with disabilities often need to prioritize caregiving activities related to the functional limitations of their special needs child, which is time consuming and costly (Parish, Seltzer, Greenberg, and Floyd, 2004). This tendency to focus on exceptional needs often requires cooperation or assistance from non-disabled siblings, potentially limiting their time in social activities with peers (Kaminsky and Dewey, 2002). Families with children who have disabilities may also feel distanced from peer groups and from regular participation in social activities, which further contributes to isolation, feelings of loneliness, and stigmatization (Larson and Corrigan, 2008). Non-disabled siblings have reported feelings of fear, rejection, and abandonment in relation to their brother or sister with exceptional needs (Van Der Sanden, Bos, Stuttereim, Pryor, and Kok, 2015). These experiences are likely to have implications for problems related to adjustment and coping (Kaminsky and Dewey).

Child siblings of people with mental disabilities experience significant role asymmetry in their sibling relationships, as compared with typically developing siblings which are more egalitarian (Brody, Stoneman, Davis, and Craps, 1991). This disparity
increases with the severity of disability (Dallas, Stevenson, and McGurk, 1993) and over time (Stoneman, Brody, Davis, and Craps, 1989). These factors are likely to have implications for a sibling’s attitudes towards their relationship with their special needs brother or sister (Schuntermann, 2007).

Siblings of children with severe disabilities have reported limited outlets for emotional expression related to feelings of frustration and futility in improving their sibling’s condition or family situation (McCullough and Simon, 2011). Other negative emotions that these children express include anger, sadness, embarrassment, jealousy, and bereavement (Marsh, 1992; Williams et al., 2010). The experience of negative affect appears to increase as a sibling’s sense of obligation and excessive demands from family intensify, which has been identified by Goode (1996) as role strain. In other words, a sibling’s role becomes strained when they feel incapable of meeting familial demands (Goode).

Some non-disabled siblings may feel that an emotional outlet is not viable for their role as a super-achiever or the parent’s mediator, which are roles that are commonly adopted in families with disability (Dyson, 1996). Non-disabled brothers and sisters may, in turn, develop a low self-concept by internalizing these attitudes and beliefs (Dyson). Self-concept refers to how one perceives himself or herself, and the beliefs one holds about the self (Hattie, 2014). Each of these factors may influence emotional regulation and coping strategies into adulthood (Hattie). With this in mind, much of the research on siblings and disabilities has operated from a deficit model, that assumes typically-developing siblings are at risk (Levy-Wasser and Katz, 2004). Opportunities
While the majority of research on this population in childhood is focused on negative manifestations, various authors have studied the positive experiences of having a brother or sister with a developmental or psychiatric disability. For example, Stoneman (2005) examined research themes among various studies related to childhood siblings and individuals with neurologically based disabilities. The author noted a bias in the prevailing research, in which investigators often assumed negative implications for non-disabled siblings in their research questions and methodology. The author’s findings emphasized that having a sibling with disability does not inherently imply pathological outcomes for non-disabled siblings. The author cited results demonstrating that siblings of people with disabilities experience close and positive relationships, with comparable amounts of sibling conflict as control groups. This is consistent with earlier findings by Abramovitch, Stanhope, Pepler, and Corter (1987), and Brody, Stoneman, Davis, and Craps (1991).

Rossiter and Sharpe (2001) conducted a meta-analysis of 25 studies and 79 effect sizes on siblings of individuals with intellectual disability. Effect size is a statistical measure of the strength of a particular phenomenon (Steinberg, 2011), which in this case evaluated measures of psychological functioning for non-disabled siblings (Rossiter and Sharpe). Their analysis concluded that only a small number of siblings experience negative psychological effects as a result of having a sibling with a developmental disability and that these effects were largely produced by direct observation studies ($M_d = - .61$). Self-report studies in this area revealed the smallest effect size ($M_d = - .00$). The authors suggested this difference results from varying degrees of objectivity in reporting. Most notably, the authors revealed that “the magnitude of this negative effect in the
present meta-analysis, suggests the generalized concern about the social and psychological development of the siblings of individuals with mental retardation has been overstated” in the literature (p. 76). Other factors within and outside of the family of origin appear to mediate outcomes for siblings, such as socio-economic factors, education, and individual psychology (Rossiter and Sharpe).

Williams and colleagues (2010) analyzed 40 sibling-related studies that presented reports from parents of children with developmental disabilities. By using content analysis, the authors derived themes from 151 written responses. Their results identified 61.1% negative outcomes, 1.7% no risk, and 37.2% positive outcomes on siblings. Among the positive outcomes for siblings, the parents reported greater family closeness, increased sensitivity and caring, personal growth, and maturity on the part of non-disabled siblings. The parents’ rationales for these positive outcomes were centered on the siblings’ personal attributes and socialization to the needs of people with disabilities (Williams et al.).

Mandelco, Olsen, Dyches, and Marshall (2003) demonstrated that siblings may benefit from growing up with a child who has disabilities. These authors were concerned with family member functioning and child behavioral outcomes. The study evaluated families who had young children with disabilities against a control group. The researchers administered measures of family cohesion and functioning to 78 families, and social skills assessments to their corresponding teachers. Mandelco and her colleagues found that the target siblings demonstrated significantly higher indices of cooperative assertive behavior \( t = 3.69, p < .01 \) and self-control \( t = 2.72, p < .01 \) than the control group. Their results also noted no significant difference between groups in family
functioning and cohesion measures. These findings suggest that child siblings find positive ways to adapt to their brother or sister’s disability.

Taunt and Hastings (2002) conducted a study with parental interviews and surveys presenting questions that sought potential positive impacts of disability on the family experience. Parents reported exposure to disability as a learning opportunity for siblings and extended family members. These parents also reported that non-disabled siblings demonstrated increased sensitivity and caring, more of a willingness to help, greater maturity and a sense of responsibility. These studies suggest that siblings may experience an increased understanding of the culture of disability and appreciation for their sibling (Taunt and Hastings), in addition to opportunities for leadership (Stoneman, 2005) and expressions of compassion (McHale and Harris, 1992).

Adult Sibling Experience

Macks and Reeve (2007) evaluated recent and notable studies on adult outcomes for non-disabled siblings of individuals with disabilities across three domains: behavioral, emotional, and psychological adjustment. These authors found that brothers and sisters of individuals with pervasive developmental disabilities tend to take on more responsibilities and share in caretaking roles. Siblings of individuals with disabilities have reported a negative impact on their lives from the adult-like responsibilities placed on them in early childhood (Benderix and Sivberg, 2007). Researchers have described this precocious sense of responsibility arising from the need to assist or protect the disabled sibling, to whom they feel pity or empathy, and from the desire to alleviate parental distress (Benderix and Sivberg). These siblings have also reported that this
sense of personal responsibility and obligation often increases with age (Benderix and Sivberg).

Non-disabled siblings are likely to be involved with future planning for their special needs sibling and are likely to adopt a caretaking role into adulthood (Heller and Caldwell, 2006; Heller and Keiling Arnold, 2010). Horwitz (1993) noted that the role of non-disabled siblings has become increasingly important with the reduction of institutionalized care for people with severe disabilities, and that research in this caregiving role for adult siblings is limited. Schuntermann (2007) stresses the need to address a sibling’s role in later life planning for people who have disabilities that limit independent living, especially if they are involved in caretaking. Siblings often need to establish “to what extent [the sibling with a disability] will require supervision by siblings, and what legal arrangements may need to be in place to succeed parental authority,” in relation to the brother or sister’s degree of independent living skills (Schuntermann, p. 96). Moreover, Davys, Mitchell, and Haigh (2011) emphasize that non-disabled adults appear to be concerned for the future of their sibling with disabilities, yet are unclear as to what their role will be. More information needs to be sought regarding the expectations of non-disabled siblings in the later life planning of their brother or sister’s care, with regards to their sibling relationship.

One of the few studies to provide a relational context for adult siblings of people with disabilities was conducted by Taylor, Greenberg, Seltzer, and Floyd in 2008. These authors evaluated adult sibling relationships for brothers and sisters of people who had mild intellectual disabilities and psychiatric disabilities. The researchers gathered data from the Wisconsin Longitudinal Study of 10,317 men and women who completed
assessments in 1975, 1992, and 2004. Based on this data set, the target participant’s IQ score indicated the presence of an intellectual disability (n = 268), and participants with psychiatric disabilities (n = 83) were identified by self-report. Psychiatric conditions in this study included depressive disorder, anxiety disorder, episodic mood disorders, schizophrenic disorders, and alcohol dependence syndrome. The authors excluded data from participants with co-occurring intellectual and psychiatric disabilities, to diminish confounding variability.

Using this information, Taylor and colleagues (2008) matched target participant data to 351 corresponding, non-disabled siblings who completed relational and affective assessments in 1977, 1994, and 2005. Their study evaluated sibling relationship across domains of geographic proximity, emotional closeness, frequency of contacts per year, and similarities in outlook of life. The authors also collected data from measures of psychological distress, wellbeing, and personality, among others. Using a two-way analysis of covariance (ANCOVA) the authors were able compare differences in sibling relationships between brothers and sisters of people who have intellectual disabilities, psychiatric conditions, and normed groups. Taylor and colleagues found that adult siblings of individuals with intellectual disabilities experienced higher levels of proximity (M = 0.59, SE = 0.03; ts = 2.53, ps <.05) versus the control group (M = 0.50, SE = 0.02; ts = -2.41, ps <.05), yet lower levels of emotional closeness (M = 3.02, SE = 0.05) than the comparison group (M = 3.16, SE = 0.03). Siblings of people with intellectual disabilities and psychiatric disabilities had less interaction with their brother or sister (M = 35.20 and 27.25, SE = 5.17 and 9.56, respectively; ts = -2.08, ps <.05), than the normed group (M = 47.72, SE = 2.94; ts = 2.05, ps <.05). The non-disabled siblings also reported less
similarity in life views than their sibling with an intellectual or psychiatric condition ($M = 2.87$ and $2.77$, $SE = 0.05$ and $0.09$, respectively; $t_s = -3.20$, $ps < .01$), as compared with the control group ($M = 3.04$, $SE = 0.03$; $t_s = -2.94$, $ps < .01$). Based on these results, Taylor and colleagues concluded that adult siblings of individuals with intellectual disabilities experienced more of an obligatory relationship, which is associated with the provision of structural support and mobilization, rather than emotional exchange.

Additionally, Taylor and colleagues (2008) found that adult siblings of individuals with mental health disabilities reported higher incidences of past psychological distress ($M = 0.31$, $SE = 0.06$; $t = 2.19$, $p < .05$) than the control group ($M = 0.19$, $SE = 0.01$). The authors also found siblings of individuals with psychiatric conditions experienced lower levels of wellbeing, extraversion, and conscientiousness than the comparative group. This information highlights the challenges that many of these siblings face in maintaining close-knit relationships with adult brothers and sisters who often depend on them for support.

Although literature identifies many negative aspects and challenges faced by siblings of people with disabilities, the research is mixed for findings on how these individuals are affected by their experience and how they view their sibling relationship into adulthood. Some studies reveal unfavorable outcomes for adult interpersonal development and attitudes (Kaminsky and Dewey, 2002), while others do not find an increased risk of adjustment difficulties in adulthood (Grissom and Brokowski, 2002; Macks and Reeve, 2007). In fact, Burton and Parks (1994) found that typically developing siblings display resilience and benefit from their relationship with their brother or sister who has a disability in adulthood. Moreover, Enns, Reddon, and
McDonald (1999) encourage helping professionals to view siblings as an important social and therapeutic resource in the lives of people with psychiatric disabilities. Mixed research outcomes may be mediated by the severity of disability, access to supportive resources, genetics and individual psychology (Macks and Reeve; Schuntermann, 2007). With this in mind, the author examines how typically developing siblings characterize their sibling relationship in adulthood and identify their expectations for involvement in their siblings’ long-term care.

Resilience and Coping

Conceptual Framework

McCubbin and McCubbin (1993) developed a theoretical framework for conceptualizing the experience of family members who are supporting and adapting to life with an individual who has significant disability. The resiliency model of family stress, adjustment, and adaptation evaluates family member experience through the lens of resilience (McCubbin and McCubbin). Resilience refers to an adaptive approach, response, or outcome when encountering family crises or difficult circumstances, and serves as an indication of health and harmony within the family (McCubbin and McCubbin). This model assumes that families with a child, or children who have disabilities: (a) experience challenges; (b) develop strengths and adapt to these challenges in proactive ways; and (c) benefit from engaging with community resources and social support (McCubbin and McCubbin). This perspective focuses on how individual family members relate to one another, first adjusting to circumstances, how the family then adapts to circumstances, and later engages with the community.

Coping Strategies
According to McCubbin and McCubbin’s (1993) model, coping strategies play a significant role in the adjustment and adaptation process. Coping skills pertain to the ways in which an individual may respond to life challenges and demands, in order to reduce or manage his or her emotional distress (Pearlin and Schooler, 1978). With this in mind, coping skills may be understood as techniques and interventions that one utilizes to maintain wellbeing when tending to responsibilities and obligations, which in this case pertains to familial demands. It is important to evaluate the coping strategies of adult siblings in response, because they are likely to be care providers in the future, carrying the direct responsibility in meeting daily needs and ensuring the safety or wellbeing of their dependents (Braddock, 1999). Not only do successful caregivers need to attend to the daily and health-related needs of these individuals, but they also provide enrichment, secure financial support, and advocate for their needs (Roberto, 1993). Batshaw, Roizen, and Lotrecchiano (2013) identify common stressors facing caretakers of individuals with developmental disabilities. These include: managing the individual’s daily care, accessing community and human services, financing specialized medical and behavioral interventions, navigating health insurance, and experiencing isolation.

The responsibility of assisting and caring for the livelihood of another human being, who is largely dependent on others, can be overwhelming and an emotionally arduous experience, even for well-adjusted adults (Ostman and Hansson, 2001). Caregivers are also at a higher risk of experiencing burnout (Batshaw, Roizen, and Lotrecchiano, 2013). Mendenhall and Mount (2011) noted that care providers of individuals with dependent disabilities report high incidences of burden and emotional strain. Negative outcomes for family members of people with disabilities are largely
associated with excessive stressors on the family, limited resources and help, and inadequate coping strategies (Batshaw, Roizen, and Lotrecchiano).

McCubbin and Figley (1983) identified that caregivers of individuals with disabilities experience two types of stressors: normative and catastrophic. Normative stressors relate to concerns that occur in conjunction with typical life cycle transitions related to growth and aging. An example a normative stressor may involve locating vocational resources for a young man with Down syndrome who is about to complete his special education program in high school, or securing finances towards occupational therapy services for an adult who is not covered by medical insurance. Catastrophic stressors refer to disruptive crises or dramatic incidents that occur suddenly, with little time for preparation or planning. The authors noted that catastrophic stressors result in a sense of helplessness or emotional distress for care providers. Catastrophic stressors for adult siblings may include the abrupt death of a parent who had not conferred or determined arrangements for the long-term care of his or her child with a dependent disability. Another catastrophic stressor may be resolving a public incident in which the sibling with a disability posed as a danger to himself or others. Adult brothers and sisters of persons with disabilities may respond to these stressors in a number of ways, and helping professionals work to encourage proactive coping and adaptation through these experiences (Marsh, 1992).

Coping skills allow siblings to address challenges related to family dynamics and stresses within sibling relationships. Coping involves behaviors, attitudes, and emotions that can be both positive and negative. Positive coping facilitates improvement within a situation or outlook, while negative coping worsens circumstances or may be self-
destructive (Zeidner and Endler, 1996). Researchers have promoted the need to identify adult sibling coping and stress management strategies to improve interventions in family therapy and for helping professionals working with disabilities (Giallo and Gavidia-Payne, 2006).

McCubbin, Larsen, and Olson (1987) proposed five common coping strategies utilized by family members when facing crises, related to developmental and psychiatric disabilities. These responses include: engaging in social support, mobilizing family assistance, passive appraisal, cognitive reframing, and seeking spiritual support (McCubbin, Larsen, and Olson). Acquiring social support is the action of seeking out family, friends, and others to receive encouragement or emotional relief. Mobilizing family support involves acquiring and accepting caregiving assistance from family members and community resources. Passive appraisal refers to a family member’s ability to accept a situation and reduce reactivity or emotional upset. Reframing is the act of conceptualizing a family situation from a proactive point of view. In seeking spiritual support, family members are seeking a higher power or connection with their religious community to gain perspective and understanding of a situation.

Research on siblings of individuals on coping with developmental and psychiatric disabilities is favorable. Lobato (1983) promoted the idea that having a brother or sister with a disability facilitates the development of resilience and is a positive influence for typically developing siblings. Her research suggests that siblings may display enhanced coping skills in the face of family challenges (Lobato). McCubbin and McCubbin (1991) revealed that many families are likely to behave proactively in face of disability, engaging in adaptive coping strategies and building individual resilience. Trute, Hiebert-
Murphy, and Levine (2007) noted that parents of individuals with disabilities exhibit resilience and positive coping, and experience opportunities for personal growth and creating deeper meaning in their lives, which is likely true for siblings. The following quantitative and qualitative investigation explores attitudes towards the sibling relationship and caregiving, in addition to coping strategies, for adult siblings of individuals with developmental and psychiatric disabilities.
CHAPTER THREE

METHODOLOGY

The following study combines quantitative and qualitative measures for evaluating the experiences of adult siblings of individuals with disabilities. This mixed methods design allows the author to identify coping strategies and characterizations of sibling relationships, while providing a wider context from narrative questions regarding expectations for later-life planning and the subjective nature of these experiences. Combining quantitative and qualitative techniques permits researchers to maximize their interpretations and enhances the significance of the data (Collins, Onwuegbuzie, and Sutton, 2006). A qualitative component provides greater context to quantitative data when evaluating nuanced experiences in special needs research, which often lies on a continuum (Collins, Onwuegbuzie, and Sutton). The purpose of this mixed approach is to create complementarity, which refers to an elaboration or clarification of the results from one method with results from the other method (Greene, Caracelli, and Graham, 1989). This information works to contribute to the growing body of knowledge exploring the experience adult siblings of individuals with disabilities.

Participants

Researchers are required to contact the Institutional Review Board (IRB) before conducting any form of research with human participants (Lincoln and Tierney, 2004). The IRB works to ensure the rights of research participants and minimize any risk that
could occur (Lincoln and Tierney). This study completed a formal IRB review and gained institutional approval from Mercer University in 2017.

This study sought approximately 75 to 100 respondents, who are undergraduate and graduate students at Mercer University in Atlanta, Georgia. Eligibility for the survey was limited to individuals who are 18 years or older and have a brother or sister with a developmental or psychiatric disability. Each participant was asked to complete two quantitative measures and one qualitative survey. Participants were encouraged to respond to items with consideration for their sibling who has a disability. The study presumed that at least 5.43% of the student population has a brother or sister with a developmental or psychiatric disability, based on 2010 national census data on Americans with disabilities in the mental domain (United States Census Bureau, 2010).

Instrumentation

Family Crisis Oriented Personal Scales (F-COPES)

The author gathered data from two quantitative instruments and qualitative questions. The first of these quantitative measures is the Family Crisis Oriented Personal Scales (F-COPES) by McCubbin, Larsen, and Olson (1987), which provides a measure of family member coping skills. This instrument identifies problem-solving and behavioral strategies used by families when faced with problems or crises, between members and outside of family relationships. This measure evaluates internal and external coping skills, which includes five strategies: acquiring social support, mobilizing family support, passive appraisal, reframing, and seeking spiritual support (McCubbin, Larsen, and Olson, 1987). The total coping score indicates the use of a variety of coping strategies (McCubbin, Larsen, and Olson).
The F-COPES (see Appendix C) is a 30 item, self-administered survey that uses a five-point Likert response scale, which ranges from *strongly disagree* (1) to *strongly agree* (5). The assessment measures coping across the five main coping subscales. The F-COPES takes approximately five to ten minutes to complete, and has good internal consistency with a reliability alpha of 0.89. The subscale reliability alphas range from 0.69 to 0.83. The test-retest correlation over a 4-week period is 0.81. The normative group for this assessment included 2,740 family members, which did not specify disabled or non-disabled individuals (McCubbin, Larsen, and Olson, 1987). However, the F-COPES has been utilized in clinical settings and studies pertaining to families coping with medical diagnoses, illness, and intellectual, developmental, psychiatric, and physical disabilities (McCubbin, Thompson, and McCubbin, 1996).

**Adult Sibling Relationship Questionnaire (ASRQ)**

The author also presented a second quantitative measure, which evaluates characterizations of adult sibling relationships. The Adult Sibling Relationship Questionnaire (ASRQ) was published by Stocker, Lantheir, and Furman in 1997 and measures an adult’s perception of their sibling relationship quality. The assessment evaluates sibling relationships in terms of a respondent’s reported behaviors and feelings towards their siblings and attitudes towards their sibling. These perceptions guide and influence interactions between adult siblings (Stocker, Lantheir, and Furman, 1997), which is useful information for understanding how adult siblings characterize their relationship.

Stocker, Lantheir, and Furman (1997) present the ASRQ (see Appendix D) as an 81 item, self-administered questionnaire, using Likert scales ranging from *hardly at all* (1) to
extremely much (5). This assessment can be completed in approximately ten minutes. The ASRQ measures 14 scales of relational attitudes, which include: acceptance, admiration, affection, antagonism, competition, dominance, emotional support, intimacy, instrumental support, knowledge, maternal rivalry, paternal rivalry, quarreling, and similarity. These scores are organized along three independent dimensions of relational quality: warmth, conflict, and rivalry to characterize an adult sibling relationship. There are high levels of internal consistency for each of these scales ($\alpha = 0.74 - 0.92$).

Participant’s scores were stable across a two-week period, with a retest $r$ that ranged from 0.75 to 0.93 ($p < .05$), for all scales. Convergent validity for this measure is 0.49, suggesting that the assessment items are representative of relational attitudes among adult siblings. Discriminant validity for this measure is 0.14, indicating that the test items discriminate across the 14 domains of relational attitudes.

The normative sample for this assessment was comprised of 383 undergraduate, young adults from Colorado and Indiana, with a mean age of 22.40 years (SD = 1.46). Each participant had a biological sibling who was at least 17 years old, with a mean age difference between siblings of 3.63 years (SD = 2.19). The average number of children in participants’ families was 3.03 (SD = 1.31). The normative sample was largely Caucasian (81%), and middle-class to upper-middle class. It is important to note that the normative group did not offer differentiation for disabled, versus non-disabled siblings (Stocker, Lantheir, and Furman, 1997).

Qualitative Survey

The third phase of the data collection included a five-minute qualitative survey for specific factors related to expectations and involvement with later life planning (see
Appendix E). This qualitative component included demographic questions to gather information about each participant’s age, whether they have a sibling with a developmental disability or mental health concern, and the age of that sibling. The participant was asked to identify the type of disability, severity, and how many years he or she lived with the sibling in question. Participants were also be asked to rate his or her sibling’s degree of independent living (i.e., independent, semi-dependent, or completely dependent on others to meet daily living needs). The authors of ASRQ found that normed group correlations between family structure and sibling relationship quality were not large, therefore questions pertaining to a participant’s sibling ordinal position and birth order are not necessarily relevant to this study. Moreover, family constellation variables explain little of the variance in sibling relationship quality (Furman and Buhrmester, 1985; Stocker, Dunn, and Plomin, 1989).

The author presented an ethnographic reflection questions to each participant, which asks to identify a word or phrase to best describe their sibling relationship and their expectations are for his or her involvement their brother or sister’s later life planning and care. The author sought to understand the nature of adult sibling expectations, because they are most likely to be the individuals providing or assisting with long-term care (Heller and Keiling Arnold, 2010). From these responses, the author identified themes regarding the participant’s expected role in relation to the sibling’s long-term planning and care.

Siblings of persons with disabilities often exhibit roles in the family of origin, such as super-achiever or the parent’s mediator, as a way of mitigating the impact of disability on the family or parents (Dyson, 1996). These roles are ascribed in early childhood
(Orsmond, Kuo, and Seltzer, 2009) and often continue into adulthood, ranging from surrogate parent roles with frequent oversight to siblings who maintained virtually no contact and have acrimonious relationships with their sibling (Zetlin, 1986). Participant responses were likely to reflect this range, with categories such as primary caregiver, assistive to primary caregiver, and no caregiving or supportive role.

Research Procedures

Data collection began by contacting departments to gain permission and disseminate online assessments to students of Penfield College, Tift College of Education, McAfee School of Theology, Stetson School of Business and Economics, and the College of Pharmacy at Mercer University (see Appendix A). Students received a link to an online questionnaire, with an introduction from the author (see Appendix B). Each link included a consent statement, which stipulated participant’s rights before participating in the study. Once an individual consented to volunteer for the study they were prompted to respond to items in the online questionnaire, which is comprised of the F-COPES, ASRQ, and qualitative questions. This study utilizes a concurrent time-orientation for gathering data, in which the quantitative and qualitative components of the study are presented at the same time, rather than a sequential design. This is an appropriate time-orientation in that the purpose of the mixed methods design is to create complementarity (Onwuebuzie and Collins, 2007). All participant responses remained anonymous, and were used for the purposes of this study.

Data Analysis

Once the data was collected, the author utilized multiple strategies to analyze and interpret the results of the study, which included quantitative and qualitative statistics. In
an effort to create complementarity (Greene, Caracelli, and Graham, 1989) in this mixed methods design, the qualitative data was analyzed and consolidated with the quantitative results. The author adhered to Onwuegbuzie and Teddlie’s (2003) seven-stage model for data analysis procedures in a mixed methods study. These stages include (1) data reduction, (2) data display, (3) data transformation, (4) data correlation, (5) data consolidation, (6) data comparison, and (7) data integration (Onwuegbuzie and Teddlie). Data reduction in a mixed methods approach works to reduce the dimensionality of the data, which occurs using quantitative and qualitative data analyses. Data from the F-COPES, ASRQ, and demographic questions was analyzed using descriptive statistics for measures of central tendency (i.e., mean, median, mode), and variability and dispersion (i.e., range and standard deviation). These descriptive statistics were indicated given the descriptive nature of the quantitative research questions.

A Pearson product-moment correlation coefficient was calculated to evaluate the correlation between the two quantitative scales. This correlational coefficient, designated by the symbol $r$, indicates the degree to which two variables are related, with scores ranging from -1.0 to +1.0, and whether the relationship is inverse (-) or direct (+) (Steinberg, 2011). Stronger correlations approximate -1.0 or +1.0, while weaker correlations are closer to zero (Steinberg). Correlational statistics allow researchers to make predictions about research variables, and determine where further investigation may be indicated (Steinberg).

Qualitative data was evaluated via thematic analysis, according the framework presented by Bryman (2008). Thematic analysis is a qualitative analysis method for “identifying, analyzing, and reporting patterns (themes) within data” (Brown and Clarke,
Thematic analysis gathers data from qualitative means (i.e., observational data, interview transcripts, or participant statements) and then systematically codes the information into emergent themes across the data (Boyatzis, 1998). These themes are distinctive and should represent what is “important about the data in relation to the research question” and “some level of patterned response or meaning within the data set” (Brown and Clarke, 2006, p. 82). Themes are developed by identifying repetitions, indigenous typologies, metaphors and analogies, similarities and differences, tones, and linguistic connections presented in participant narratives (Bryman). A thorough thematic analysis presents and describes finalized themes, illustrates quotations from the original data, and integrates them into the larger research context (Boyatzis, 1998).

Keeping with Onwuegbuzie and Teddlie’s (2003) seven-stage model, the quantitative data in this study was displayed with tables, matrices, charts, or lists for qualitative data. The third stage of data transformation involved coding qualitative data numerically in order to be represented statistically and correlated with the quantitative data. The data was then consolidated to create potentially new variables or data sets, to compare to the original data sources. The final stage of data integration worked to integrate all data sets into a coherent framework.

Limitations of Study

Various limitations exist within the methodology presented. The university student population from which the sample is being collected is a population that is accessible to the researcher (i.e., convenience sample). Students who are enrolled in continuing education programs in the helping professions, education, or healthcare may be more empathetic towards or inclined to help people with disabilities, which may bias the
results. This study may have gathered more target participants from state and national organizations that work directly with families of individuals who have disabilities. Moreover, this study assumes that the participants do not have severe developmental or psychiatric disabilities themselves. Also, information pertaining to sibling diagnoses is from participant reports, rather than diagnostic or medical records. This means that some of the identified disabilities may be speculative, rather than confirmed by professional documentation. Additionally, the author did not find a quantitative measure to assess sibling relationships that is specific to siblings of people with developmental or psychiatric disabilities. The ASRQ does not specify levels of ability for the normed population. In other words, the ASRQ was not standardized specifically for siblings of people with disabilities, which may affect the results.

A major limitation to this study includes the lack of insight from the identified sibling’s perspective. Having the opportunity to evaluate the sibling relationship with information from both individuals would provide tremendous insights into these dynamics. Patelas, Hastings, Nash, and Duff (2015) conducted one of the few studies in this area that is available from the point of view of siblings with developmental disabilities. These authors assessed the sibling experience with reports from adolescents who have autism. The results of their study underscored that these sibling relationships are typical of the general population and not necessarily pathological (Patelas, Hastings, Nash, and Duff). Information from the other sibling’s point of view would be useful for providing a wider context in understanding adult sibling relationships and expectations for the future.
Summary

This study combines quantitative data with qualitative reports to create a more robust research design that evaluates nuanced and subjective experiences within a specific population. The author examines self-reports from adult siblings of individuals with developmental and psychological disabilities. The author integrates quantitative findings with thematic content from these reports to create a more comprehensive understanding of the adult sibling relationships and expectations for the future. This mixed methods design works to further understand the dynamic nature and outcomes of adult sibling relationships in families with developmental or psychiatric disabilities and contribute to the growing body of knowledge on this population.
CHAPTER FOUR

RESULTS

The following chapter presents an analysis of data from participant reports in this study. The researcher sought to examine the relational perspectives of individuals who have a brother or sister with a developmental and psychiatric disability and how they cope with family-related difficulties. Data from the quantitative measures served to address the research questions concerning (1) how these siblings characterize their sibling relationship, (2) the forms of coping strategies these siblings exhibit in adulthood, and (3) the correlation between sibling relationship and coping strategies in this population. Data collected from the qualitative survey provided insight into the research question regarding the expectation that these adult siblings express towards the long-term care of their sibling. The author presents descriptive statistics for participant demographics, disability-related characteristics, and quantitative measures. A Pearson product moment correlation coefficient is reported to evaluate the correlation between the quantitative scales. Thematic analysis results are presented for the qualitative data.

Demographic Results

Upon receiving research approval from the Institutional Review Board (see Appendix F), the author contacted the deans and administrators of Mercer University’s undergraduate and graduate programs in Counseling, Business and Economics, Pharmacy, Education, Nursing, Theology, and Medicine, to disseminate study participation requests to their respective students. These students received an electronic
participation request that included a link to the online questionnaire (Appendix C). The participation request was also posted to a national listserv for counselor educators (CESNET-L) with the permission of the moderator, Dr. Martin Jencius, and the researcher’s dissertation committee chair, Dr. Don Redmond. Data was collected between April and May 2017. Participants completed electronic questionnaires which were anonymously collected using Qualtrics software (2017).

From these requests, a total of 84 individuals completed the study’s online survey, which comprised of an informed consent document, the Adult Sibling Relationship Questionnaire (ASRQ) by Stocker, Lanthier, and Furman (1997), the Family Crisis Oriented Personal Scales (F-COPES) by McCubbin, Larsen, and Olson (1987), and a qualitative questionnaire. This is an appropriate sample size, according to Onwuegbuzie and Collins (2007) who suggest that a correlational study design in mixed methods research should comprise of a sample size that is at least 64 participants for a one-tailed test and 82 participants for a two-tailed test, in order to have adequate statistical power. These sample sizes are indicated for identifying effect sizes with .80 statistical power with a significance level of .05 (Onwuegbuzie and Collins).

The ages of these participants ranged from 22 to 74 years, with a mean age of 38.67 years and a standard deviation of 12.57 years. Participants reported the age of their identified sibling, or sibling who has a developmental or psychiatric disability, which ranged from 3 to 78 years, with a mean age of 37.74 years and a standard deviation of 14.52 years. The age differences between participants and identified siblings ranged from 0 to 25 years, with a mean difference of 4.42 years and a standard deviation of 3.84 years. Reported years of shared residence with target siblings ranged from 0 to 27 years,
with a mean of 15.64 years and a standard deviation of 6.59. Frequencies for these values are summarized in Table 1.

Table 1

Demographic Frequencies

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22 – 29 years</td>
<td>22</td>
<td>26.20</td>
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<tr>
<td>30 – 39 years</td>
<td>29</td>
<td>34.52</td>
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<tr>
<td>40 – 49 years</td>
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<td>17.86</td>
</tr>
<tr>
<td>50 – 59 years</td>
<td>12</td>
<td>14.28</td>
</tr>
<tr>
<td>60 – 69 years</td>
<td>4</td>
<td>4.76</td>
</tr>
<tr>
<td>70 – 74 years</td>
<td>2</td>
<td>2.38</td>
</tr>
<tr>
<td>Total</td>
<td>84</td>
<td>100.00</td>
</tr>
<tr>
<td>Sibling Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 – 9 years</td>
<td>2</td>
<td>2.38</td>
</tr>
<tr>
<td>10 – 19 years</td>
<td>5</td>
<td>5.95</td>
</tr>
<tr>
<td>20 – 29 years</td>
<td>19</td>
<td>22.62</td>
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<tr>
<td>30 – 39 years</td>
<td>25</td>
<td>29.76</td>
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<tr>
<td>40 – 49 years</td>
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<td>20.23</td>
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<tr>
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<tr>
<td>60 – 69 years</td>
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<td>4.76</td>
</tr>
<tr>
<td>70 – 78 years</td>
<td>3</td>
<td>3.57</td>
</tr>
<tr>
<td>Total</td>
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<td>100.00</td>
</tr>
<tr>
<td>Shared Residence</td>
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<td></td>
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<td>5 – 9 years</td>
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<tr>
<td>10 – 14 years</td>
<td>14</td>
<td>16.67</td>
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<tr>
<td>15 – 19 years</td>
<td>32</td>
<td>38.10</td>
</tr>
<tr>
<td>20 – 24 years</td>
<td>20</td>
<td>23.81</td>
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<tr>
<td>25 – 27 years</td>
<td>6</td>
<td>7.14</td>
</tr>
<tr>
<td>Total</td>
<td>84</td>
<td>100.00</td>
</tr>
</tbody>
</table>
Participant-reported diagnoses for identified siblings revealed that 28 (33.30%) siblings exhibited developmental disabilities (DD), 52 (61.90%) experienced psychiatric disabilities (PD), and 4 (4.80%) were reported to have both types of conditions (DD and PD) (Table 2). Of the diagnoses reported, 1 (1.19%) exhibited a dual diagnosis of more than one developmental disability, 20 (23.80%) had a dual diagnosis of more than one psychiatric disability. Identified developmental conditions included: autism spectrum disorders, cerebral palsy, Down syndrome, fragile X syndrome, intellectual disability, Prader-Willi syndrome, and pervasive developmental disability. Reported psychological conditions included: attention deficit hyperactivity disorder, anxiety disorders, bipolar disorder, depressive disorders, eating disorders, obsessive-compulsive disorder, personality disorders, schizophrenia spectrum and other psychotic disorders, and substance use disorders. Frequencies of disability severity included 3 unknown severity (3.60%), 9 mild (10.70%), 48 moderate (57.10%), and 24 severe conditions (28.60%) (Table 3). Participants reported that their identified sibling experienced the following degrees of dependency on others to meet daily living needs: complete dependence (N = 28, 33.30%), semi-dependence (N = 41, 48.80%), and independent living (N = 15, 17.90%) (Table 4).
Table 2

*Identified Sibling Diagnosis*

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Disabilities</td>
<td>28</td>
<td>33.30</td>
</tr>
<tr>
<td>Psychiatric Disabilities</td>
<td>52</td>
<td>61.90</td>
</tr>
<tr>
<td>Dual Diagnoses (DD and PD)</td>
<td>4</td>
<td>4.80</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>84</td>
<td><strong>100.00</strong></td>
</tr>
</tbody>
</table>

Table 3

*Identified Sibling Disability Severity*

<table>
<thead>
<tr>
<th>Severity</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unknown</td>
<td>3</td>
<td>3.60</td>
</tr>
<tr>
<td>Mild</td>
<td>9</td>
<td>10.70</td>
</tr>
<tr>
<td>Moderate</td>
<td>48</td>
<td>57.10</td>
</tr>
<tr>
<td>Severe</td>
<td>24</td>
<td>28.60</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>84</td>
<td><strong>100.00</strong></td>
</tr>
</tbody>
</table>

Table 4

*Identified Sibling Dependency*

<table>
<thead>
<tr>
<th>Degree of Dependency</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent</td>
<td>15</td>
<td>17.90</td>
</tr>
<tr>
<td>Semi-dependent</td>
<td>41</td>
<td>48.80</td>
</tr>
<tr>
<td>Complete Dependence</td>
<td>28</td>
<td>33.30</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>84</td>
<td><strong>100.00</strong></td>
</tr>
</tbody>
</table>
Descriptive Statistics for Quantitative Instruments

ASRQ

Descriptive statistics were calculated to address the quantitative research question regarding how adult siblings of people with developmental or psychiatric disabilities characterize their sibling relationship. The Adult Sibling Relationship Questionnaire measures scales of acceptance, admiration, affection, antagonism, competition, dominance, emotional support, intimacy, instrumental support, knowledge, maternal rivalry, paternal rivalry, quarreling, and similarity towards a sibling (Stocker, Lanthier, and Furman; 1997). These scores are organized along three core dimensions: warmth, conflict, and rivalry to characterize an adult sibling relationship. Warmth is indicated by scores from the scales of Acceptance, Admiration, Affection, Emotional Support, Instrumental Support, Intimacy, Knowledge, and Similarity. Conflict is derived from the scales of Antagonism, Competition, Dominance, and Quarreling scores. Rivalry is calculated from the Maternal and Paternal Rivalry scales. Z scores for each of the quantitative measures did not exceed the absolute value of 3.29, which indicates that there were no outliers in this data. The mean scores for each of the ASRQ scales are summarized in Table 5.

The mean score on the Acceptance scale of the ASRQ was 3.57 (range of scale = 1 - 5) with a standard deviation of 0.87. The mean score on the Admiration scale was 3.46 (range of scale = 1 - 5) with a standard deviation of 0.98. The mean score on the Affection scale was 3.26 (range of scale = 1 - 5) with a standard deviation of 1.31. The mean score on the Antagonism scale was 2.06 (range of scale = 1 - 5) with a standard deviation of 0.71. The mean score on the Competition scale was 1.77 (range of scale = 1
- 5) with a standard deviation of 0.73. The mean score on the Dominance scale was 1.81 (range of scale = 1 - 5) with a standard deviation of 0.58. The mean score on the Emotional Support scale was 2.82 (range of scale = 1 - 5) with a standard deviation of 1.12. The mean score on the Instrumental Support scale was 2.12 (range of scale = 1 - 5) with a standard deviation of 0.72. The mean score on the Intimacy scale was 2.68 (range of scale = 1 - 5) with a standard deviation of 1.01. The mean score on the Knowledge scale was 3.05 (range of scale = 1 - 5) with a standard deviation of 0.99. The mean score on the Maternal Rivalry scale was 1.15 (range of scale = 0 – 2) with a standard deviation of 0.57. The mean score on the Paternal Rivalry scale was 0.92 (range of scale = 0 – 2) with a standard deviation of 0.69. The mean score on the Quarreling scale was 2.18 (range of scale = 1 - 5) with a standard deviation of 0.87. The mean score on the Similarity scale was 2.19 (range of scale = 1 - 5) with a standard deviation of 0.91. Higher scores indicate more of a given sibling relationship dimension.

Descriptive statistics for the three core areas of sibling relationship were also calculated. The mean score of Warmth was 2.89 (range of scale = 1 - 5) with a standard deviation of 0.85. The mean score of Conflict was 1.96 (range of scale = 1 - 5) with a standard deviation of 0.59. The mean score of Rivalry was 1.03 (range of scale = 0 - 2) with a standard deviation of 0.53.
Table 5

*ASRQ Descriptive Statistics*

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Scale Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Warmth</td>
<td>84</td>
<td>2.89</td>
<td>0.85</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Acceptance</td>
<td>84</td>
<td>3.57</td>
<td>0.87</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Admiration</td>
<td>84</td>
<td>3.46</td>
<td>0.98</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Affection</td>
<td>84</td>
<td>3.26</td>
<td>1.31</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>84</td>
<td>2.82</td>
<td>1.12</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>84</td>
<td>2.12</td>
<td>0.72</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Intimacy</td>
<td>84</td>
<td>2.68</td>
<td>1.01</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Knowledge</td>
<td>84</td>
<td>3.05</td>
<td>0.99</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Similarity</td>
<td>84</td>
<td>2.19</td>
<td>0.91</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Conflict</td>
<td>84</td>
<td>1.96</td>
<td>0.59</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Antagonism</td>
<td>84</td>
<td>2.06</td>
<td>0.71</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Competition</td>
<td>84</td>
<td>1.77</td>
<td>0.73</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Dominance</td>
<td>84</td>
<td>1.81</td>
<td>0.58</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Quarreling</td>
<td>84</td>
<td>2.18</td>
<td>0.87</td>
<td>1 – 5</td>
</tr>
<tr>
<td>Rivalry</td>
<td>84</td>
<td>1.03</td>
<td>0.53</td>
<td>0 - 2</td>
</tr>
<tr>
<td>Maternal Rivalry</td>
<td>84</td>
<td>1.15</td>
<td>0.57</td>
<td>0 - 2</td>
</tr>
<tr>
<td>Paternal Rivalry</td>
<td>84</td>
<td>0.92</td>
<td>0.69</td>
<td>0 - 2</td>
</tr>
</tbody>
</table>

F-COPES

Descriptive statistics were also conducted to address the quantitative research question identifying the forms of coping strategies that siblings of individuals with developmental or psychiatric disabilities exhibit in adulthood. The Family Crisis Oriented Personal Scales (F-COPES) measures five scales of coping strategies used by family members facing challenges (McCubbin, Larsen, and Olson; 1987). These scales include: acquiring social support, mobilizing family support, passive appraisal, reframing, and seeking spiritual support. The total coping score indicates the use of a
variety of coping strategies. The mean scores for each of the F-COPES scales are presented below and summarized in Table 6.

The mean score on the Acquiring Social Support scale of the F-COPES was 3.20 (range of scale = 1 – 5) with a standard deviation of 0.64. The mean score on the Mobilizing Family Support scale was 2.82 (range of scale = 1 – 5) with a standard deviation of 1.12. The mean score on the Passive Appraisal scale was 3.84 (range of scale = 1 – 5) with a standard deviation of 0.75. The mean score on the Cognitive Reframing scale was 3.92 (range of scale = 1 – 5) with a standard deviation of 0.57. The mean score on the Seeking Spiritual Support scale was 2.93 (range of scale = 1 – 5) with a standard deviation of 1.51. The mean score for Total Coping was 3.39 (range of scale = 1 – 5) with a standard deviation of 0.51. Higher scores indicate more use of the identified coping dimension. The data indicates that adult siblings a variety of these problem-solving and behavioral strategies when facing family-related challenges.

Table 6

F-COPES Descriptive Statistics

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Scale Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquiring Social Support</td>
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<td>3.20</td>
<td>0.64</td>
<td>1 – 5</td>
</tr>
<tr>
<td>Mobilizing Family</td>
<td>84</td>
<td>2.82</td>
<td>1.12</td>
<td>1 – 5</td>
</tr>
<tr>
<td>Passive Appraisal</td>
<td>84</td>
<td>3.84</td>
<td>0.75</td>
<td>1 – 5</td>
</tr>
<tr>
<td>Reframing</td>
<td>84</td>
<td>3.92</td>
<td>0.57</td>
<td>1 – 5</td>
</tr>
<tr>
<td>Seeking Spiritual Support</td>
<td>84</td>
<td>2.93</td>
<td>1.51</td>
<td>1 – 5</td>
</tr>
<tr>
<td>Total Coping</td>
<td>84</td>
<td>3.39</td>
<td>0.51</td>
<td>1 – 5</td>
</tr>
</tbody>
</table>
Correlational Analyses

Pearson correlation coefficients were calculated to evaluate the relationships among variables from both quantitative scales. Correlation analyses were indicated to address the quantitative research question regarding whether there is a relationship between coping strategies and adult sibling relationship characterizations for this population. Two-tailed tests were indicated to evaluate the null hypothesis (i.e., non-directional hypothesis) that there was no relationship between these sibling relationship and coping factors. Pearson cor relational analyses allow one to determine the linear relationship between quantitative values, in terms of strength and direction (i.e., positive or negative), ranging from -1.0 or +1.0 (Steinberg, 2011). The strength of a correlational relationship may be low (i.e., the absolute value of the correlation coefficient ranging from .00 and .25), moderate (i.e., $r$ ranging from .26 to .40), or high (i.e., $r$ ranging from .41 or greater) (Steinberg). Statistically significant correlations indicate a rejection of the null hypothesis. Correlational values help researchers make predictions on how variables may be associated and evaluate the directions of future research (Steinberg).

Quantitative Scale Correlations

Results from the correlational analyses between each of the quantitative measures, for sibling relationship and coping, are summarized as a matrix in Table 7. Statistically significant correlational values in this matrix ranged from low to moderate strength. The statistically significant values revealed a positive relationship between the coping style of Passive Appraisal and the sibling relationship scores of Admiration ($r = .220$, $p = .045$), Emotional Support ($r = .225$, $p = .039$), Knowledge ($r = .216$, $p = .049$), and the general sibling relationship dimension of Warmth $r = .223$, $p = .041$). No statistically significant
relationship was indicated between the coping scores for Mobilizing Family Support and the sibling relationship scales.

There was a significant, positive relationship between the coping style of Cognitive Reframing and sibling relationship scores for Acceptance ($r = .309, p = .004$), Admiration ($r = .367, p = .001$), Affection ($r = .356, p = .001$), Emotional Support ($r = .327, p = .002$), Instrumental Support ($r = .394, p = .000$), Intimacy ($r = .277, p = .011$), Knowledge ($r = .285, p = .009$), and the general sibling relationship dimension of Warmth $r = .362, p = .001$). No statistically significant relationship was indicated between the coping scores for Acquiring Social Support and the sibling relationship scales. There was a significant, positive relationship between the Seeking Spiritual Support coping style and the sibling relationship scores for Admiration ($r = .230, p = .035$), Affection ($r = .215, p = .050$) and Instrumental Support ($r = .235, p = .031$).

There was a significant, positive relationship between the Total Coping score (i.e., the use of a variety of coping strategies) and sibling relationship scores for Acceptance $r = .255, p = .019$), Affection $r = .232, p = .034$), Emotional Support $r = .240, p = .028$), Instrumental Support $r = .339, p = .002$), and Intimacy $r = .237, p = .030$). There was also a significant, positive relationship between Total Coping score and the general sibling relationship dimension of Warmth $r = .229, p = .036$).

No statistically significant relationships were observed within the general sibling relationship dimensions of Conflict or Rivalry. The only statistically significant correlations observed for general sibling relational dimensions were within the Warmth category, namely with the coping styles of Passive Appraisal, Cognitive Reframing, Seeking Spiritual Support, and Total Coping Score. Based on these results, there is a
statistically significant relationship between sibling relationship characterizations of Warmth and the coping behaviors of Passive Appraisal, Cognitive Reframing, Seeking Spiritual Support, and Total Coping, therefore the null hypothesis can be rejected for these variables.

Table 7

Correlation Matrix of Quantitative Scales

<table>
<thead>
<tr>
<th>Variable</th>
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<th>Passive</th>
<th>Refra.</th>
<th>Social</th>
<th>Spiri.</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Warmth</td>
<td>-.016</td>
<td>.223*</td>
<td>.362**</td>
<td>.034</td>
<td>.178</td>
<td>.229*</td>
</tr>
<tr>
<td>Acceptance</td>
<td>-.126</td>
<td>.207</td>
<td>.309**</td>
<td>-.094</td>
<td>.019</td>
<td>.063</td>
</tr>
<tr>
<td>Admiration</td>
<td>-.071</td>
<td>.220*</td>
<td>.367**</td>
<td>.083</td>
<td>.230*</td>
<td>.255*</td>
</tr>
<tr>
<td>Affection</td>
<td>-.036</td>
<td>.182</td>
<td>.356**</td>
<td>.043</td>
<td>.215*</td>
<td>.232*</td>
</tr>
<tr>
<td>Emo. Support</td>
<td>.072</td>
<td>.225*</td>
<td>.327**</td>
<td>.031</td>
<td>.169</td>
<td>.240*</td>
</tr>
<tr>
<td>Inst. Support</td>
<td>.143</td>
<td>.202</td>
<td>.394**</td>
<td>.118</td>
<td>.235*</td>
<td>.339*</td>
</tr>
<tr>
<td>Intimacy</td>
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<td>.211</td>
<td>.277*</td>
<td>.104</td>
<td>.159</td>
<td>.237*</td>
</tr>
<tr>
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<td>.216*</td>
<td>.285**</td>
<td>.005</td>
<td>.130</td>
<td>.169</td>
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<td>.068</td>
<td>.176</td>
<td>-.058</td>
<td>.040</td>
<td>.039</td>
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<tr>
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<td>.001</td>
<td>.018</td>
<td>.087</td>
<td>-.015</td>
<td>.024</td>
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<tr>
<td>Antagonism</td>
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<td>.015</td>
<td>-.009</td>
<td>.024</td>
<td>-.058</td>
<td>-.042</td>
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<tr>
<td>Competition</td>
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<td>-.028</td>
<td>.021</td>
<td>.079</td>
<td>-.063</td>
<td>.005</td>
</tr>
<tr>
<td>Dominance</td>
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<td>.048</td>
<td>.128</td>
<td>.062</td>
<td>.049</td>
<td>.074</td>
</tr>
<tr>
<td>Quarreling</td>
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<td>-.015</td>
<td>-.046</td>
<td>.112</td>
<td>.023</td>
<td>.045</td>
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<tr>
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<td>-.001</td>
<td>.003</td>
<td>.007</td>
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<tr>
<td>Maternal</td>
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<td>.012</td>
<td>.014</td>
<td>.092</td>
<td>-.141</td>
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</tr>
<tr>
<td>Paternal</td>
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<td>-.010</td>
<td>-.006</td>
<td>-.065</td>
<td>-.195</td>
<td>-.036</td>
</tr>
</tbody>
</table>

** correlation is significant at the 0.01 level (2-tailed)
* correlation is significant at the 0.05 level (2-tailed)
Thematic Analyses

After completing the ASRQ and F-COPES, each participant completed a questionnaire that included the following qualitative questions: (1) “what word of phrase would you use to describe your relationship with this sibling (i.e., your brother or sister who has a developmental disability or mental health condition)?”; and (2) “what do you expect your involvement to be in your brother or sister’s later life planning and care?”.

The first question was presented to create complementarity with the quantitative research question regarding how adult siblings characterize their relationship with their brother or sister who has special needs. The second question was posed to evaluate the qualitative research question looking to identify the expectations that adult siblings of persons with a developmental or psychiatric disabilities express towards long-term care for their sibling.

Thematic analyses were conducted with the qualitative data using Bryman’s (2008) model of thematic analysis in social research. This approach begins with the researcher reading each complete narrative to identify what is stated and potential themes that are being relayed (Bryman, 2008). A theme refers to a word or phrase that best represents what is being expressed in a text (Bryman). This way researchers may identify distinct issues or events that appear and group them into types or categories, pertaining to the research questions. The second phase of thematic analysis requires the researcher to re-read each narrative, marking the text and highlighting key words or phrases that appear, making annotations to label passages in the narrative (Bryman). Following this step, the researcher codes the text by systematically indicating each section’s theme, reviewing the commonly occurring themes and patterns, and indexing them into mutually exclusive categories (Bryman). This involves identifying recurring and similar themes, and
eliminating repetition to refine the themes. The final phase presents the identified themes and relates them to the research questions, results, and overall literature (Bryman). Participant responses to both qualitative questions were reviewed and organized using this approach.

Sibling Relationship Themes

Participant responses for the first qualitative question (n = 84) concerning descriptions of their sibling relationship provided 87 word and phrase combinations from which to derive themes. From these responses, the researcher identified six major themes which are summarized in Table 8. The first theme was Closeness, which comprised 34.48% of the responses, and was indicated by words and phrases such as “my best friend,” “loving,” “aligned,” and “very close.” The second theme was Assistance (18.39%), which was indicated by words and phrases such as “caring,” “supportive,” and “helpful.” The third theme was Acceptance (5.75%), which was indicated by words and phrases such as “good,” “acceptable,” and “typical.” These first three themes were categorized as positive representations of the adult sibling relationship, which comprised of 58.62% of the overall participant responses.

The fourth theme was Tumultuousness, which comprised 19.54% of the responses, and was indicated by words and phrases such as “strained,” “challenging,” “frustrating beyond belief,” and “dangerous.” The fifth theme was Estrangement (16.09%), which was indicated by words and phrases such as “distant,” “cut-off mostly,” and “detached.” The sixth theme was Disproportion (5.75%), which was indicated by words and phrases such as “one-sided” and “uneven.” These three themes were categorized as negative representations of the adult sibling relationship, which comprised of 41.38% of the
overall participant responses. Most of the sibling relationship characterizations were positive, which is consistent with the findings from the ASRQ measure that indicated more Warmth in sibling relationship perceptions, versus Conflict or Rivalry.

Table 8

*Qualitative Themes for Sibling Relationship Characterizations*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td>51</td>
<td>58.62</td>
</tr>
<tr>
<td>Closeness</td>
<td>30</td>
<td>34.48</td>
</tr>
<tr>
<td>Assistance</td>
<td>16</td>
<td>18.39</td>
</tr>
<tr>
<td>Acceptance</td>
<td>5</td>
<td>5.75</td>
</tr>
<tr>
<td>Negative</td>
<td>36</td>
<td>41.38</td>
</tr>
<tr>
<td>Tumultuousness</td>
<td>17</td>
<td>19.54</td>
</tr>
<tr>
<td>Estrangement</td>
<td>14</td>
<td>16.09</td>
</tr>
<tr>
<td>Disproportion</td>
<td>5</td>
<td>5.75</td>
</tr>
</tbody>
</table>

Expectations of for the Future and Themes

Participant responses for the second qualitative question concerning expectations of involvement for later life planning and care of their sibling provided 84 word, sentence, and paragraph statements from which to derive themes. These statements revealed 89 individual and combination themes. From these responses, the researcher identified six major thematic categories which are summarized in Table 9. The first theme was Primary Support, which comprised 26.97% of the responses, and was characterized by descriptions of providing primary caregiving, responsibility, housing,
and overall involvement. This theme was indicated by statements such as “I will be 100% responsible,” “I will take care of him,” and “Should anything happen to our father, I have agreed to accept full guardianship for my brother.”

The second theme was Auxiliary Support (24.72%), which was characterized by descriptions of financial support, legal support, collaboration of care with other family members or professional care, and periodic assistance. This theme was indicated by statements such as “whatever is needed, but she has her immediate family to take care of her,” “I expect to share responsibility with my two brothers,” and “I will be in charge of my brother’s finances/financial decisions and will provide any other needed support as applies.”

The third theme was Emotional Support (8.99%), which was characterized by descriptions of being an emotional resource for the identified sibling during challenging times. This theme was indicated by statements such as “I feel I am only a support person for her emotionally,” “I expect to be the primary source of emotional support for my sibling during periods of heightened anxiety or panic,” and “she does not need assistance when it comes to basic human needs, but she is constantly going through a ‘crisis’ and calls upon myself and parents to ‘rescue’ her and get her out of her crisis.” Three of the statements in the Emotional Support category also contained elements of advocacy or being an advocate for the identified sibling’s later life care. For example, one of the responses stated: “I talk to her weekly and will continue to do this…I am monitoring the situation, working with advocates, and will continue to advocate for my sister to receive the best care.”
The fourth theme was Limited Involvement (13.48%), which was characterized by descriptions of minimal involvement, avoidance, and boundary setting. This theme was indicated by statements such as “if she needs care I am willing to help, but with strong boundaries,” “my brother is pretty self-sufficient, so my involvement is likely to be minimal,” and “we do not have a close relationship, so my involvement will be limited.” It is important to note that the themes of Primary Support, Auxiliary Support, and Limited Involvement contained emotional descriptions of obligation with regards to their sibling’s care. For example, “I will feel obligated to be there for her in a way that my mom does by making more time for time for her,” and “after our parents are no longer with us, I will have to shoulder some of the responsibility in housing and looking after him.”

The fifth theme was Noninvolvement (17.98%), which was characterized by reliance on other family members to assist, estrangement, or the identified sibling’s degree of independence. This theme was indicated by statements such as “I will not be involved, because he has chosen to remove himself from our family interactions” “nothing, because she is completely independent,” and “mother to take care of her, because I don’t want to help her.” It is important to recognize that reports of noninvolvement were not necessarily associated with negative attitudes towards identified brothers or sisters. Some of these expectations were held by participants whose identified sibling lives independently of them and does not appear to be interested in sibling assistance for later life planning.

The final theme was Uncertainty (7.87%), which was characterized by indecision about plans for the future, ambiguity, fear, and worry. This theme was indicated by
statements such as “it will depend on how her life goes,” “I’m not sure and I’m frightened that I will become fully responsible for her in later life, since she has no pension or savings,” and “I am really scared for the long-term and I’m not sure what’s going to happen.” The majority of the participants (60.68%) appeared to be actively involved in the long-term care and planning for their sibling with a mental disability, versus those who described minimal involvement and uncertainty for those plans (39.32%). These themes expanded upon the findings from the quantitative results and are discussed in the following chapter.

Table 9

Qualitative Themes for Expectations of Involvement in Later Life Care

<table>
<thead>
<tr>
<th>Theme</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Support</td>
<td>24</td>
<td>26.97</td>
</tr>
<tr>
<td>Auxiliary Support</td>
<td>22</td>
<td>24.72</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>8</td>
<td>8.99</td>
</tr>
<tr>
<td>Limited Involvement</td>
<td>12</td>
<td>13.48</td>
</tr>
<tr>
<td>Noninvolvement</td>
<td>16</td>
<td>17.98</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>7</td>
<td>7.87</td>
</tr>
</tbody>
</table>
CHAPTER FIVE

DISCUSSION

This final chapter presents a discussion over the major findings and implications of this study. The author evaluates the quantitative and qualitative results in consideration of the original research questions. This leads to a discussion of potential implications for helping professionals, counselor educators, and client populations. The author then identifies limitations in the study and directions for future research. The chapter concludes with a summarization of the study and its significance.

Major Findings

This study sought to evaluate three quantitative research questions regarding perceptions of adult sibling relationship quality and coping strategies. These questions were addressed with the results of the Adult Sibling Relationship Questionnaire (ASRQ) by Stocker, Lantheir, and Furman (1997) and the Family Crisis Oriented Personal Scales (F-COPES) assessment by McCubbin, Larsen, and Olson (1987). Information from qualitative reports was also considered in conjunction with the quantitative findings.

Sibling Relationship Quality

The first research question examined how adult siblings of people with developmental or psychiatric disabilities characterize their sibling relationship. This question was addressed by responses from the ASRQ, which measured 14 subscales of relational attitudes. These relational attitudes are comprised of scales for acceptance, admiration, affection, antagonism, competition, dominance, emotional support, intimacy,
instrumental support, knowledge, maternal rivalry, paternal rivalry, quarreling, and similarity. These scales were consolidated into three main dimensions of relational quality: warmth, conflict, and rivalry to characterize an adult sibling relationship (Stocker, Lantheir, and Furman, 1997).

Participants were found to characterize their sibling relationship in a variety of ways, according to the comparison of respondent scores among each relational subscale. The highest scores were observed within the relational dimension of warmth, which includes the subscales of acceptance, admiration, affection, emotional support, instrumental support, intimacy, knowledge, and similarity. The strongest of these subscales were acceptance, admiration, affection, and emotional support. Lower scores were observed for the relational dimension of conflict, which is comprised of subscales for antagonism, competition, dominance, and quarreling. The lowest scores were observed for the relational dimension of rivalry, which is comprised of maternal rivalry and paternal rivalry.

Stocker, Lantheir, and Furman (1997) describe that typical adult sibling relationships are less likely to exhibit conflict or rivalry due to more autonomy in their relationships and in deciding how much interaction they are willing to have. The author was curious about these dimensions because siblings with mental disabilities are more likely to rely on their family members for assistance (Schuntermann, 2007). Adult siblings of people with mental disabilities also experience more of an obligatory relationship with their sibling who has special needs (Taylor, Greenberg, Seltzer, and Floyd, 2008). This notion of compulsory contact or need to provide assistance does not
appear to create a large trend for conflict-ridden or rivalrous sibling relationships for this population.

This positive representation of adult sibling relationships, with the characterization of warmth in sibling relations when one sibling has a developmental or psychiatric disability, is promising. These relational attitudes are likely to guide and influence the interactions between adult siblings (Stocker, Lantheir, and Furman, 1997). It is important to note that adult siblings do not have to live near a brother or sister with disabilities to feel warmth towards their relationship. Warmth in sibling relationships can exist regardless of proximity or frequency of contact (Bank and Khan, 1982).

These positive trends were also supported by findings in the qualitative data. Information pertaining to characterizations of sibling relationship was evaluated thematically, revealing that the majority of participants described their adult sibling relationship in positive ways. These positive themes include characterizations of closeness, assistance, and acceptance. These findings are consistent with Williams and colleagues (2010) who identified that family member closeness and caring are positives outcomes for this sibling population. The minority of participants in this study relayed negative characterizations of their sibling relationship. Negative themes include: tumultuousness, estrangement, and disproportion. In considering all of these perceptions of sibling relations, the participants expressed a continuum of relationship quality with more of an emphasis on positive characterizations.

Coping Strategies

The second quantitative research question sought to identify the forms of coping strategies these siblings exhibit in adulthood. This area was addressed by responses from
the F-COPES measure, which identifies the problem-solving and behavioral strategies used by family members when facing challenges. This assessment examines coping strategies, with scales for acquiring social support, mobilizing family support, passive appraisal, reframing, and seeking spiritual support (McCubbin, Larsen, and Olson, 1987). From these scales, a total coping score was calculated to measure the use of a variety of coping skills (McCubbin, Larsen, and Olson).

Participants were found to utilize a variety of coping strategies, with regards to family-related challenges. The highest scores were observed for the scales of cognitive reframing and passive appraisal. Moderate scores were observed for acquiring social support, seeking spiritual support, mobilizing family assistance. According to McCubbin, Larsen, and Olson (1987) cognitive reframing is the process of re-evaluating family challenges from a proactive point of view. Assessment items for this measure included statements such as “knowing we have the strength within our own family to solve our problems” and “defining the family problems in a more positive way, so that we do not become too discouraged” (McCubbin, Larsen, and Olson).

Participant responses also indicated more of a tendency use the coping strategy of passive appraisal, which refers to a family member’s ability to accept a situation and reduce reactivity (McCubbin, Larsen, and Olson). Unlike the other forms of coping on this measure, which are positively engaged forms of coping, passive appraisal is a resigned or detached way of facing challenges. Lazarus and Folkman (1984) describe passive appraisal in terms of cognitive distraction, which is a way to limit one’s mental focus on a problem in order to reduce emotional upset. Items on this scale include statements such as “feeling that no matter what we do to prepare, we will have difficulty
handling problems” and “believing if we wait long enough, the problem will go away” (McCubbin, Larsen, and Olson).

The average total coping score in this study indicates that these siblings utilize a variety of coping strategies when facing family-related problems. Participant reports also revealed that these siblings utilize the coping strategies of seeking social support, mobilizing family assistance, and connecting with their spirituality or religious community to gain an understanding of and cope with difficult family situations. These findings relay that these adult siblings utilize both internal and external coping strategies, in working to maintain a positive attitude, while being realistic about family challenges and stressors. These siblings are also likely to stay connected with their support systems.

Correlational Relationships

The final quantitative research question examined whether there is a correlation between sibling relationships and coping strategies for this population. This question was addressed by conducting correlational analyses between the ASRQ and F-COPES items. These analyses revealed statistically significant, positive relationships between the sibling relational dimension of warmth and the coping strategies of cognitive reframing, passive appraisal, and total coping score, that were low to moderate. In other words, there is a significant, positive correlation between adult siblings of individuals with developmental and psychiatric disabilities who characterize their sibling relationship in terms of warmth and exhibiting the cognitive coping strategies of reframing (moderate strength) and passive appraisal (low strength). There is also a statistically significant, moderate, positive correlation between the sibling relationship characterization of warmth and
utilizing a variety of coping and problem-solving strategies in the face of family challenges.

Significant correlations between sibling relational scales within the warmth dimension and coping styles included those for acceptance, admiration, affection, emotional support, instrumental support, intimacy, and knowledge. The only scale within with warmth dimension without significant correlations to coping was similarity. This finding may be observed because siblings of people with mental disabilities experience more role asymmetry in their sibling relationships (Brody, Stoneman, Davis, and Craps, 1991). No significant relationships were observed between sibling relational perceptions of conflict and coping strategies, or rivalry and coping strategies. This may be due to low participant scores on indices of conflict and rivalry with regards to their brother or sister who has a mental disability.

Qualitative Findings

In addition to the quantitative research questions, the author also sought to address a qualitative research question using a qualitative survey. This question looked to identify the expectations that adult siblings of persons with mental disabilities express towards the long-term care for their brother or sister. Research is limited for studies on adult sibling roles in later-life planning and care for siblings with disabilities (Horwitz, 1993). Participant responses were evaluated using thematic analysis which revealed six major themes: primary support, auxiliary support, emotional support, limited involvement, noninvolvement, and uncertainty. The majority of these siblings reported being actively involved in the long-term care and planning for their sibling with a mental disability, which was indicated by the themes of primary, auxiliary, and emotional
support. The minority of these siblings described noninvolvement and uncertainty with future planning.

These trends are congruent with supporting literature that views non-disabled, adult siblings as important figures in the later-life planning and care of their special needs sibling (Heller and Caldwell, 2006; Heller and Keiling Arnold, 2010). Other studies have identified that these adult siblings are concerned for the future and uncertain as to how they will be involved (Davys, Mitchell, and Haigh, 2011). This theme was reflected in the qualitative reports, with a smaller percentage of respondents relaying feelings of fear and worry regarding long term care, and indecision for their sibling’s future plans. This also indicates an area of future research.

Professional Implications

Newman and colleagues (2003) identify potential goals of mixed methods research which include: adding to a knowledge base, impacting or informing groups or institutions, measuring change, predicting outcomes, testing or generating new ideas, and understanding complex phenomena or the past. Among these goals, this study sought to expand the knowledge base of adult sibling relationships when one sibling experiences a developmental or psychiatric disability. This area of research is largely limited to child and adolescent siblings. This study also sought to understand the expectations of adult siblings related to their brother or sister’s future care and later life planning. Lastly, this research served to inform helping practitioners and educators who work with populations who have developmental disabilities or mental health concerns. This includes counselor educators, clinical mental health counselors, rehabilitation counselors, school counselors, counseling supervisors, and other helping professionals.
Findings from this study reveal that adult siblings of brothers and sisters who have mental disabilities approach their sibling relationship in number of ways. Many exhibit warmth towards their brother or sister, while fewer see their relationship as conflictual or rivalrous. Most siblings interpret their relationship as close and accepting, while others find them challenging and difficult. Those who feel warmth towards their sibling relationship tend to show more coping abilities in the face of family challenges. This study also revealed trends concerning the expectations of sibling involvement in long-term care. Many siblings expect to be involved and supportive in later life planning and care, while fewer are uncertain or noninvolved. These findings emphasize that these adult sibling relationships are complex and the ways in which siblings deal with family challenges are multi-faceted. The severity of a sibling’s disability, the type of disability, and the availability of assistive resources are likely to mediate relational outcomes with these adults (Davys, Mitchell, and Haigh, 2011; Schuntermann, 2007; Taylor, Greenberg, Seltzer, and Floyd, 2008). Helping professionals and educators should consider these trends, in clarifying assumptions about the role that adult siblings play in the lives of individuals with mental disabilities.

There are many questions yet to be answered for this population, and the results of this study suggest that adult siblings may benefit from adopting a positive view of their sibling relationship. Those who characterize their sibling relationship with warmth and cope well with family stressors may be more inclined to approach a brother or sister’s disability proactively. Perhaps this proactivity has been shaped by early experiences and learning about mental disabilities, or an enhanced capacity for compassion towards disabilities – which suggests further areas of inquiry. With this in mind, helping
professionals working with family members of persons with mental disabilities should consider the importance of promoting compassion towards a sibling’s disability, with regards to family-related challenges, obligations, and caregiving.

This study encourages helping professionals working with individuals who have disabilities and their families to adopt a holistic view of how mental disabilities influence not only the individual, but also sibling dynamics in adulthood. Adult siblings can be an important social and therapeutic resource in the lives of people with mental disabilities (Enns, Reddon, and McDonald, 1999). According to the prevalence of mental disabilities in the United States, counselors are highly likely to work with clients who have a sibling experiencing a mental disability (United States Census Bureau, 2010). This offers opportunities for advocating about disabilities, educating clients about the role adult siblings play, learning adaptive coping strategies, and encouraging healthy family relations.

Limitations

Various limitations exist within this study design. This research collected responses from a convenience sample that was available to the researcher. This sample may have been biased towards ethical attitudes in relation to experiences of disability in that they are affiliated with programs in higher education. Participant reports for the quantitative instruments may have also been influenced by social desirability in responding. These factors may influence the objectivity and external validity (i.e., external replication, or transferability) of the study’s findings.

The study utilized a criterion-based sampling scheme, in which potential participants were encouraged to complete the study because they represented the
population of interest (i.e., adult siblings of persons with developmental or psychiatric disabilities). This approach is a form of non-probability sampling, which is common to mixed methods design, and allows researchers to obtain insights into dynamics or a group of people (Onwuegbuzie and Collins, 2007). Criterion-based sampling is useful to meet the researcher’s goal of further understanding adult sibling dynamics and perspectives in this unique population. However, this purposive sampling approach limits the generalizability of the findings to the general population (Onwuegbuzie and Collins).

This study did not gather demographic information concerning gender, race, ethnicity, sexual orientation, marital status, employment, religion, or socioeconomic status, in an effort to focus the data on the research questions and reduce questionnaire completion time. This information may have been useful to considering multicultural differences in this sibling population. For example, Horwitz (1993) noted that adult siblings of Hispanic and African American heritage experienced more contact and social interaction with their sister or brother with a disability, than did white siblings. Socioeconomic and other cultural factors may also mediate outcomes for these siblings into adulthood (Rossiter and Sharpe, 2001). More cultural differentiation in the demographic analysis may have increased the internal validity (i.e., internal replication, or credibility) of the study’s findings.

The data analyses conducted with the ASRQ and F-COPES did not differentiate between siblings of persons who have developmental or psychiatric disabilities. This study approached these categories as a whole, in terms of mental disabilities in general. The study also did not differentiate scores from the measures of relational perspectives, coping styles, and qualitative reports among degrees of disability severity or dependency.
This information may have been useful to further delineate potential differences among participants who scored higher or lower on quantitative measures, and reports in the qualitative data. This limitation suggests an important area for future studies.

The researcher did not employ an additional rater for conducting the thematic analysis. A secondary rater with training in thematic analysis, may have drawn alternative themes to that of the researcher. An evaluation of inter-rater reliability in deriving themes from the participant’s qualitative responses may have provided this study with higher reliability (i.e, confirmability) in the qualitative findings.

Future Directions

Information pertaining the sibling relationships with this population is primarily limited to studies with children or parental reports. Adult siblings of people with mental disabilities are often overlooked in the literature, which provides an opportunity for researchers in the helping professions to connect with this population and approach families of people with special needs more holistically. This study contributes to the growing body of research with these adult siblings, and potential directions for future research are identified below.

1. The correlations identified in this study suggest areas for future research. The next phase of a study such as this one could seek to understand why sibling relationships that are characterized by warmth are positively correlated with the use of coping skills, versus those that are conflict-ridden or rivalrous not being significantly correlated with coping skills. Could non-disabled siblings who have a more positive attitude towards their brother or sister with a mental disability also be more resilient and adaptable to responding to stressors?
Does the ability to be better at coping with stress make one more accepting, compassionate, and warm towards siblings with special needs? Are siblings who resent their brother or sister’s disability also more likely to not cope well with challenges? Does the experience of growing up or interacting with a sibling who has special needs make one more resilient towards dealing with family-related problems? These are interesting areas to explore based on the results of this study.

2. The thematic analysis used with the qualitative data utilized a deductive approach, which identifies themes in relation to the original research questions and links the themes back to previous or similar research in the area (Boyatzis, 1998). An inductive approach in thematic analysis derives themes directly from qualitative data, without using a pre-existing framework, to ultimately create research questions (Boyatzis). An inductive approach to narrative information provided by these siblings may reveal more specific needs and directions for future research. For example, interviews with adult brothers and sisters using open ended questions about their sibling relationship may indicate areas of need that are most important to this population as they age with their brother or sister, and how the helping-professions can best support them.

3. A replication of this study may contrast reports from the siblings in this study with a control group, to evaluate the similarities and differences in the ways these relationships are characterized and experienced in adulthood.
4. The thematic analysis conducted with the qualitative responses did not examine the degrees of clarity or stability in plans that adult siblings expected for the long-term care of their brother or sister. Schuntermann (2007) emphasizes a need for clarity in these plans, particularly in relation to supervision and legal arrangements. Future studies may evaluate the specific degrees of clarity in planning for the future, and determine at what point a sibling should begin considering and coordinating these plans, and potential benefits to their involvement.

5. The F-COPES measure was oriented towards constructive coping strategies and did not measure indices for negative coping responses, such as substance abuse, indulgent behavior, or negative thinking. Participants may have reported engaging in these behaviors if it was available in the assessment. Further studies may evaluate whether negative coping is correlated with facing challenges related to having a sibling who has a mental disability.

6. In examining adult sibling relationships within the field of disability studies, information from the identified brother or sister who has a mental disability would provide an important perspective in understanding these relationships and how they are approached. Reports from the sibling who has a disability could also identify the ways in which non-disabled siblings can be most helpful or supportive during adulthood.

7. As noted in the limitations of this study, future studies with this population should evaluate whether there is a difference among sibling relational perspectives or coping, cultural demographics, and the types or severity of
mental disabilities. This approach may give more clarity as to how adult siblings experience their relationships along diverse planes, determine whether there is a moderating effect, and provide helping professionals with multicultural applications.

8. Future research with this population should be considered for integration into the curricula for programs in counselor education and supervision, clinical mental health counseling, school counseling, and rehabilitation counseling, when exploring the experiences of families of people who have mental disabilities and developing competencies with these populations.

Final Conclusions

The ultimate goal of a mixed methods research in the social sciences is to increase the empathic understanding of human behavior (Onwuegbuzie and Leech, 2004). The quantitative and qualitative approaches utilized in this study worked to enhance the interpretation of the results to contribute to a more comprehensive understanding of a population that has been largely overlooked in the supporting literature, while informing the practice of helping professionals and educators. Those working with adult siblings of individuals who have mental disabilities should not overlook how sibling relations and expectations for the future impact the lives of their clients, and the importance of these relationships.
REFERENCES


APPENDICIES
APPENDIX A

PROGRAM DIRECTOR SOLICITATION E-MAIL
Dear Faculty,

My name is Margo Velez Rice. I am a doctoral candidate in the Counselor Education and Supervision Program at Mercer University. I am conducting a research study about adult sibling relationships and disabilities. I am contacting you to ask if you will consider inviting students in your college to participate.

Below, you will find a message soliciting participation in my study. Please consider forwarding it to your students.

Thank you in advance for your time and consideration. Feel free to contact me if you have any questions.

Best Regards,

Margo Velez Rice, MA
Doctoral Candidate
Counselor Education & Supervision Program
Mercer University

margarita.s.velez@mercer.edu
APPENDIX B

STUDY PARTICIPATION SOLICITATION E-MAIL
Dear Mercer University Student,

My name is Margo Velez Rice. I am a doctoral candidate in the Counselor Education and Supervision Program at Mercer University. I am conducting a research study about adult sibling relationships and disabilities. I am emailing to ask if you would like to participate by completing a brief survey. Eligibility for the survey is limited to individuals who are 18 years or older and have a brother or sister with a mental health concern or a developmental disability. Your participation in the survey is completely voluntary and all of your responses will be kept confidential. No personally identifiable information will be associated with your responses to any reports in the data. Mercer University’s IRB requires investigators to provide informed consent to the research participants. If you would be interested in taking this survey, please click on this link and provide your consent to take the survey:

https://merceruniversity.co1.qualtrics.com/jfe/form/SV_cBaAwvBNgKrsV4p

If you have any questions about the study contact the investigator: Margo Velez Rice, MA; margarita.s.velez@mercer.edu. Mercer University’s Institutional Review Board (IRB) reviewed study (IRB#H1703093) and approved it on March 23, 2017. If you have questions about your rights, as a participant or are dissatisfied at any time with any part of this study, you can contact the Institutional Review Board by phone at (478) 301-4101 or email at ORC_Research @Mercer.edu.

Thank you in advance for your time and participation.
APPENDIX C

F-COPES ASSESSMENT ITEMS
F-COPES by McCubbin, Larsen, and Olson (1987)

Purpose:
The Family Crisis Oriented Personal Evaluation Scales are designed to record effective problem-solving attitudes and behavior, which families develop to respond to problems or difficulties.

Directions:
First, read the list of response choices on at a time. Second, decide how well each statement describes your attitudes and behaviors in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Use the following five-point scale:

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Neither agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

WHEN WE FACE PROBLEMS OR CRISIS IN OUR FAMILY, WE RESPOND BY:

1. Sharing our difficulties with relatives.
   1  2  3  4  5

2. Seeking encouragement and support from friends.
   1  2  3  4  5

3. Knowing we have the power to solve major problems.
4. Seeking information and advice from persons in other families who have faced
the same or similar problems.

5. Seeking advice from relatives (grandparents, etc.).

6. Seeking assistance from community agencies and programs designed to help
families in our situation.

7. Knowing that we have the strength within our own family to solve our problems.

8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.).

9. Seeking information and advice from the family doctor.

10. Asking neighbors for favors and assistance.

11. Facing the problems “head-on” and trying to get solutions right away.

12. Watching television.

13. Showing that we are strong.
   1 2 3 4 5

15. Accepting stressful events as a fact of life.
   1 2 3 4 5

   1 2 3 4 5

17. Knowing luck plays a big part in how well we are able to solve family problems.
   1 2 3 4 5

18. Exercising with friends to stay fit and reduce tension.
   1 2 3 4 5

19. Accepting that difficulties occur unexpectedly.
   1 2 3 4 5

20. Doing things with relatives (get-togethers, dinners, etc.).
   1 2 3 4 5

21. Seeking professional counseling and help for family difficulties.
   1 2 3 4 5

22. Believing we can handle our own problems.
   1 2 3 4 5

23. Participating in church activities.
   1 2 3 4 5

24. Defining the family problems in a more positive way so that we do not become too discouraged.
   1 2 3 4 5
25. Asking relatives how they feel about problems we face.

1 2 3 4 5

26. Feeling that no matter what we do to prepare, we will have difficulty handling problems.

1 2 3 4 5

27. Seeking advice from a minister.

1 2 3 4 5

28. Believing if we wait long enough, the problem will go away.

1 2 3 4 5

29. Sharing problems with neighbors.

1 2 3 4 5

30. Having faith in God.

1 2 3 4 5
APPENDIX D

ASRQ ASSESSMENT ITEMS
ASRQ by Stocker, Lanthier, and Furman (1997)

Responses will use Likert scales ranging from hardly at all (1) to extremely much (5).

1. How much do you and this sibling have in common?
2. How much do you talk to this sibling about things that are important to you?
3. How much does this sibling talk to you about things that are important to him or her?
4. How much do you and this sibling argue with each other?
5. How much does this sibling think of you as a good friend?
6. How much do you think of this sibling as a good friend?
7. How much do you irritate this sibling?
8. How much does this sibling irritate you?
9. How much does this sibling admire you?
10. How much do you admire this sibling?
11. Do you think your mother favors you or this sibling more?
12. Does this sibling think your mother favors him/her or you more?
13. How much does this sibling try to cheer you up when you are feeling down?
14. How much do you try to cheer this sibling up when he or she is feeling down?
15. How competitive are you with this sibling?
16. How competitive is this sibling with you?
17. How much does this sibling go to you for help with non-personal problems?
18. How much do you go to this sibling for help with non-personal problems?
19. How much do you dominate this sibling?
20. How much does this sibling dominate you?
21. How much does this sibling accept your personality?
22. How much do you accept this sibling’s personality?
23. Do you think your father favors you or this sibling more?
24. Does this sibling think your father favors him/her or you more?
25. How much does this sibling know about you?
26. How much do you know about this sibling?
27. How much do you and this sibling have similar personalities?
28. How much do you discuss your feelings or personal issues with this sibling?
29. How much does this sibling discuss his or her feelings/personal issues with you?
30. How often does this sibling criticize you?
31. How often do you criticize this sibling?
32. How close do you feel to this sibling?
33. How close does this sibling feel to you?
34. How often does this sibling do things to make you mad?
35. How often do you do things to make this sibling mad?
36. How much do you think that this sibling has accomplished a great deal in life?
37. How much does this sibling think that you have accomplished a great deal in life?
38. Does this sibling think your mother supports him/her or you more?
39. Do you think your mother supports you or this sibling more?
40. How much can you count on this sibling to be supportive when you are feeling stressed?
41. How much can this sibling count on you to be supportive when he or she is feeling stressed?
42. How much does this sibling feel jealous of you?
43. How much do you feel jealous of this sibling?
44. How much do you give this sibling practical advice?
45. How much does this sibling give you practical advice?
46. How much is this sibling bossy with you?
47. How much are you bossy with this sibling?
48. How much do you accept this sibling's lifestyle?
49. How much does this sibling accept your lifestyle?
50. Does this sibling think your father supports him/her or you more?
51. Do you think your father supports you or this sibling more?
52. How much do you know about this sibling's relationships?
53. How much does this sibling know about your relationships?
54. How much do you and this sibling think alike?
55. How much do you really understand this sibling?
56. How much does this sibling really understand you?
57. How much does this sibling disagree with you about things?
58. How much do you disagree with this sibling about things?
59. How much do you let this sibling know you care about him or her?
60. How much does this sibling let you know he or she cares about you?
61. How much does this sibling put you down?
62. How much do you put this sibling down?
63. How much do you feel proud of this sibling?
64. How much does this sibling feel proud of you?
65. Does this sibling think your mother is closer to him/her or you?
66. Do you think your mother is closer to you or this sibling?
67. How much do you discuss important personal decisions with this sibling?
68. How much does this sibling discuss important personal decisions with you?
69. How much does this sibling try to perform better than you?
70. How much do you try to perform better than this sibling?
71. How likely is it you would go to this sibling if you needed financial assistance?
72. How likely is it this sibling would go to you if he or she needed financial assistance?
73. How much does this sibling act in superior ways to you?
74. How much do you act in superior ways to this sibling?
75. How much do you accept this sibling's ideas?
76. How much does this sibling accept your ideas?
77. Does this sibling think your father is closer to him/her or you?
78. Do you think your father is closer to you or this sibling?
79. How much do you know about this sibling's ideas?
80. How much does this sibling know about your ideas?
81. How much do you and this sibling lead similar lifestyles?
APPENDIX E

QUALITATIVE SURVEY ITEMS
Qualitative Survey

Please respond to the following the demographic questions:

1. What is your age?
2. Do you have a sibling with developmental disability or mental health condition?
   Yes/No
3. Please identify the age of your sibling with a developmental disability or mental health condition.
4. Please identify your sibling’s disability or mental health condition (i.e, diagnosis).
5. Please identify the severity of your sibling’s disability or mental health condition: Mild, Moderate, Severe, or Unknown.
6. Please identify the degree of dependency on others that your sibling experiences to meet his or her daily living needs: Completely Dependent, Semi-Dependent, or Independent.
7. How many years did/have you shared a residence with your brother or sister who has a disability or mental health condition?

Qualitative Questions

8. What word or phrase would you use to describe your relationship with this sibling?

9. In the space below please tell us in your own words your thoughts about the following question: What do you expect your involvement to be in your brother or sister’s later life planning and care? Please limit your response to one paragraph.
APPENDIX F

MERCER UNIVERSITY INSTITUTIONAL REVIEW BOARD APPROVAL
Thursday, March 23, 2017

Ms. Margarita V. Rice
Mercer University
Other
3001 Mercer University Dr
Atlanta, GA 30341

RE: Adult Siblings of Individuals with Developmental and Psychiatric Disabilities relationship Quality, Coping, and Plans for the Future (H1703093)

Dear Ms. Rice:

On behalf of Mercer University’s Institutional Review Board for Human Subjects Research, your application submitted on 09-Mar-2017 for the above referenced protocol was reviewed in accordance with Federal Regulations 21 CFR 56.110(b) and 45 CFR 46.110(b) (for expedited review) and was approved under category(ies) 7 per 63 FR 60364.

Your application was approved for one year of study on 23-Mar-2017. The protocol expires on 23-Mar-2017. If the study continues beyond one year, it must be re-evaluated by the IRB Committee.

Item(s) Approved:
Contribute to the growing body of knowledge on the population, while informing interventions for families of disabled individuals, teachers, and helping professionals

NOTE: Please report to the committee when the protocol is initiated. Report to the Committee immediately any changes in the protocol or consent form and ALL accidents, injuries, and serious or unexpected adverse events that occur to your subjects as a result of this study.

We at the IRB and the Office of Research Compliance are dedicated to providing the best service to our research community. As one of our investigators, we value your feedback and ask that you please take a moment to complete our Satisfaction Survey and help us to improve the quality of our service.

It has been a pleasure working with you and we wish you much success with your project! If you need any further assistance, please feel free to contact our office.

Respectfully,


Ava Chambliss-Richardson, Ph.D., CIP, CIM,
Associate Director of Human Research Protection Programs (HRPP)
Member
Institutional Review Board

"Mercer University has adopted and agrees to conduct its clinical research studies in accordance with the International Conference on Harmonization’s (ICH) Guidelines for Good Clinical Practice.”

Mercer University IRB & Office of Research Compliance
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