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Factors Related To Quality Of Life In Families Of Children With Autism Spectrum Disorder

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FACTORS RELATED TO QUALITY OF LIFE IN FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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DEDICATION

To my family – my husband, Mark, and my dear daughter, Lily, – words will never be able to fully capture my gratitude for encouraging me to pursue this dream. Thank you for your unending support and love throughout this journey.

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CHAPTER I

INTRODUCTION

Background

The purpose of this study is to explore how caretakers of children diagnosed with an Autism Spectrum Disorder (ASD) are able to move through adverse circumstances with which they are confronted while raising their child with considerable developmental needs and challenges, demonstrating resilience. Family resilience in this study includes family adaptations, locus of control, sense of coherence, uncertainty, severity, and demands.

Autism spectrum disorders (ASD) refers to a wide collection of complex developmental disorders where symptoms are typically apparent during the first 3 years of life. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders DSM-5; American Psychiatric Association, APA, 2013) recently revised the diagnosis. Under the DSM-IV-TR (APA, 2000), ASDs were separated into five subtypes: autistic disorder, Asperger's syndrome (AS), childhood disintegrative disorder (CDD), Rett's syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS). The newly revised DSM-5 lists one single category of Autism Spectrum Disorder. However, the three main features of ASD continue to be impairments in social interactions, impairments in verbal and nonverbal communication, and restricted and repetitive patterns of behavior (APA, 2013). The DSM-5 criteria are more stringent than DSM-IV-TR. The DSM-5 criteria for ASD that must be met for a diagnosis of ASD include: (a) persistent deficiencies in social communication and interaction across settings; (b) restricted and repetitive behaviors, interests, or activities; (c) symptoms must be present early in childhood (but may be delayed to a later age when social

demands exceed the limits of the child); and (d) symptoms limit and impair functioning daily (APA, 2013). ASD affects approximately 1 in every 88 children and is growing at a rate of 10% to 17% per year (The Center for Disease Control and Prevention, n.d.) and is the fastest growing developmental disability. In addition, the CDC has estimated that every year, approximately 26,670 children would be diagnosed with ASD (CDC, 2007). Compared to other disabilities, ASD is more common than Down Syndrome (1 out of every 800 births), childhood cancer, diabetes, and AIDS combined (CDC). The Autism Society of America (ASA, 2012) estimates that the occurrence of ASD could reach 4 million Americans in the next decade. This development and its implications have provoked a mounting interest in the impact of autism on the family.

Increasing evidence has found that families of children with disabilities, such as ASD, demonstrate strength and articulate positive contributions of their family's life and well-being (Hastings et al., 2005; Scorgie & Sobsey, 2000; Taunt & Hastings, 2002). Summers et al. (1988), in calling for an approach that is more strength-based to studying families of children with disabilities, explained that many families with children with severe disabilities did well with or without intervention from service providers. This approach has been referred to as "resilience" (Summers et al., 1988). Turnbull, Turnbull, Erwin, and Soodak (2006) have stated that the family system must be examined as a whole, and understanding family patterns of interaction is necessary to understand a child with a disability.

A child with developmental delays may pose multiple parenting challenges (Blacher & Baker, 2007). In general, families develop positive ways of coping with these challenges and demonstrate considerable resilience in previous studies (Bayat, 2007), parents have also reported increased stress, especially in areas related to child rearing

(Crnic, Gaza & Hoffman, 2005). Families raising a child with special needs face difficult circumstances. Over the past decade, family researchers (Fernandez, Schwartz, Chun & Dickson, 2013; Patterson, 2002; Thompson, Hiebert-Murphy, Trute, 2013) have been interested in determining why some families facing adversity manage to function appropriately and emerge stronger, while others when faced with a similar situation do not. This research interest has led to the development of a field of inquiry called family resilience.

Family resilience has been described as “the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful” (Walsh, 1998). The concept of family resilience and its focus on factors leading to a family’s well-functioning in view of a crisis is part of a movement in positive psychology (Seligman & Csikszentmihalyi, 2000). This movement is concerned with identifying factors of health instead of factors of pathology (Antonovsky & Sourani, 1988).

Family resilience has been looked at either as an interaction of two groups of risk and protective factors (Rutter, 1987), or as a flexible process that indicates the family’s strength at different points during the life cycle of the family and within various circumstances (Walsh, 2003). The latter approach considers a family resilient when it demonstrates strength, even if it may not demonstrate the same attribute at another point in time (Walsh, 2003). Family resilience cannot be measured directly, instead is the combined effects of family adaptations, locus of control, sense of coherence, uncertainty, severity, and perceived stress.

Family adaptation has become an area of growing interest due to the broad range of concerns that are being reported by parents. Adaptation concepts may provide opportunities for a new approach toward disabilities and focus on broader

environmental impacts and contexts of life underscore the importance of applying these concepts to the area of family quality of life (Brown & Brown, 2003; Turnbull et al., 2004).

An individual's belief about their locus of control, and coping strategies that emerge from this belief, can be influenced by the predictability of life's events and outcomes (Mednick & Koocher, 2012; Williams & Koocher, 1998), as well as cultural, familial, and historical views regarding control (Rolland, 1994). When a child is diagnosed with ASD, these views of predictability and stability are considerably disturbed for the family. While families may maintain beliefs about their personal control over other facets of their lives, their views regarding their control over the family member's ASD course and outcome may be uncertain.

Antonovsky (1998) defined sense of coherence (SOC) as "global orientation expressing the extent to which the individual perceives the stimuli deriving from one's internal and external environments as predictable, manageable, and meaningful." A strong SOC is assumed to help people to manage stress and stay healthy. Research findings show a close relationship between SOC and psychogenic aspects of health (Vossler, 2012). If a parent or caretaker of a child with ASD has a strong SOC, he/she tends to experience lower stress, higher levels of adaptation, and increased family cohesion (Margalt & Kleitman, 2006).

While parental illness-related uncertainty has been associated with psychological distress, continual uncertainty may serve as a catalyst for positive psychological change and personal growth in the context of family resilience and raising a child with ASD. Children with ASD vary in developmental ability, symptomatology, as well as emotional and behavioral patterns. The large variance in behavioral and emotional patterns poses

a major challenge to parents and clinical workers while interacting with children with ASD (Chen et al., 2012). The association between psychiatric problems and ASD traits are linked closely. Pine, Guyer and Leibenluft (2008) examined reports from parents of 352 children and adolescents with a variety of mood and anxiety disorders to assess for the presence of ASD symptoms using the Children's Communication Checklist (Bishop 1998), the Social Communication Questionnaire (Rutter et al., 2003), and Social Responsiveness Scale. Children and adolescents with mood disorders reported significantly more ASD symptoms (Pine et al., 2008).

Parenting stresses have consistently been found to be higher in parents of children with intellectual disabilities, such as ASD, yet, some families are able to be resilient and thrive in the face of these challenges. Despite the considerable research on stress in families of ID, there is still little known about the stability and compensatory factors associated with everyday parenting stresses (Gerstein, Crnic, Blacher & Baker, 2009).

Theoretical Framework

The Family Adjustment and Adaptation Response model (FAAR; Patterson, 1988, 1998, 2002, 2005; Patterson & Garwick, 1994) is the theoretical framework that was used to guide the current study's areas of inquiry. The FAAR is a process model that combines resilience theory with family stress theory. This model presents the process by which families adapt to stress or crisis through their management of the demands placed upon them (i.e., risk factors), the family's capabilities (i.e., protective factors), and family beliefs. The theory includes key components of the Double ABCX model (McCubbin & Patterson, 1983) in a process model that describes how families

advance from pre-crisis adjustment to post-crisis adaptation (See Figure 1; Patterson, 1989).

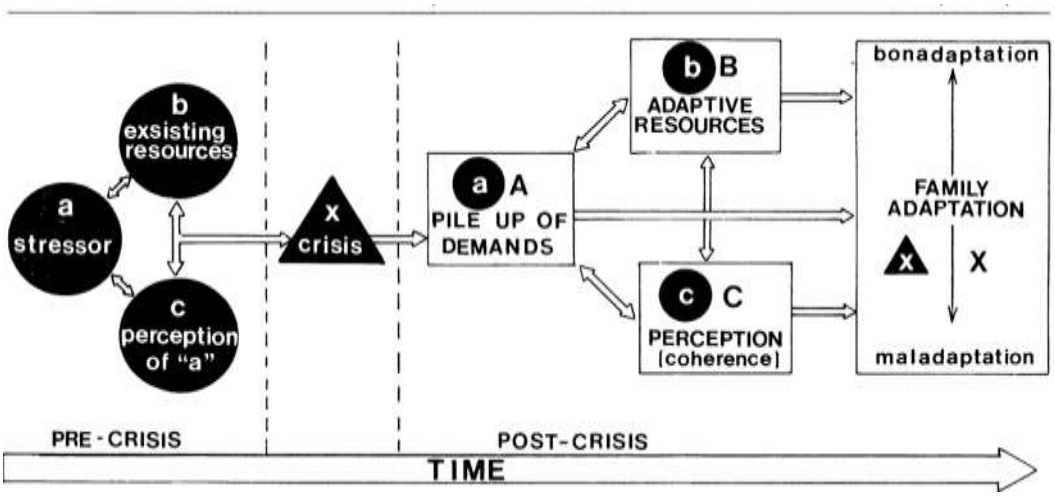

Figure 1: The Double ABCX Model of Family Stress and Adaptation (Lavee, McCubbin, & Patterson, 1985, p. 812.

This model also is an explicit endeavor to emphasize the links between family stress models and family resilience theory (Patterson, 1988, 2002). The FAAR describes the process by which a family responds to a crisis by focusing on four main components, (i.e., family demands, family capabilities, family meaning, and adaptation) and their relationship among one another (Patterson, 1988, 1989, 2002).

According to the FAAR model, individual and family adaptation to a stressful and taxing condition depends on the family's efforts to manage their demands, the family's capacity to address these demands, and mediated or moderated by family beliefs or meanings (Patterson, 1989, 2005). As family demands become increasingly larger or a major stressor event occurs, the family then moves into crisis, or a state of disorganization and disruption (Patterson, 1988, 1989). From this state of disorganization, families attempt to adapt by restoring balance to their system

(Patterson, 1988, 1989).

Family meanings or beliefs can be either mediators or moderators of family demands, capabilities, and overall family adjustment or adaptation (Patterson, 1988, 1989, 1993, 2002, 2005). Family meanings are beliefs held by individual family members in addition to those held by the family as a whole. Family meanings are theorized to exist on three levels: how families define their demands and capabilities; how the family defines themselves as a family; and how the family views itself in relation to broader systems (i.e., family world view; Patterson, 1993, 2005; Patterson & Garwick, 1994). These meanings are thought to influence how the family understands and responds to exposure to risk and its ability to protect itself (Patterson, 2002). Fundamentally, family beliefs or meanings influence the relative impact family capabilities and demands have upon the family's ultimate adaptation to crisis events. The family beliefs selected for examination in the present study include parents' control beliefs regarding their child's ASD, and the parents' feelings of mastery.

As such, this study proposed that family beliefs, particularly those of parents or primary caregivers, have both direct and indirect influence on how a family adapts to their family member's ASD. Specific family beliefs as perceived by the caretakers, those of control and mastery, were the focal point of this study. These beliefs are the primary focus of this study given their theoretical importance, which will be further detailed in Chapter 2, as well as the importance placed upon them within the broader literature on chronic illness and disability.

As well as the direct influence family beliefs can have on overall family adaptation, family beliefs are also thought to influence the relative impact that risk factors have upon outcomes indirectly (Patterson, 2002, 2005; Rolland, 1994, 2003).

Namely, these beliefs shape how families define and perceive their capabilities, the nature of the demands placed upon them, as well as their ability to adapt effectively. As a result, to examine the degree to which family beliefs have an indirect influence on the relationship between risk factors and family adaptation in families of individuals diagnosed with an ASD, this study also looked at the level to which family beliefs act as mediators for specified risk factors. The risk factors chosen for this current study were the uncertainty and perceived severity of the child's ASD. Given the unpredictability of day-to-day and overall symptom manifestation, unpredictable individual outcomes, and scope of severity inherent to ASDs, these two risk factors have particular significance with reference to the family's experience.

Statement of the Problem

The question of why certain people manage well with stress while others facing very comparable stress do not**,** needs to be a focal point of research. Some parents seem to handle life's disruptions in stride while others falter (Heiman, 2002). One's ability to cope or to be seemingly resilient is a commendable feature and identifying what it is that constitutes their resilience is of great importance if others wish to mirror their success (Mundy & Sigman, 1989). Therefore, it is imperative to recognize essentials that allow these families to cope effectively and emerge from a crisis or continual stress. Resilience undoubtedly does emerge in some parents of children with autism (Heiman, 2002).

This study investigated how caretakers of individuals diagnosed with ASD display resilience by investigating the role of family beliefs in the family's adaptation to a child's ASD. Given the significance of the caretaker(s) in child treatment outcomes, the effect ASDs can have upon the family unit, and the need to support lifelong resilience in this

population, this study presumed that family adaptation, as measured by family quality of life, is an outcome that should be focused upon in the ASD literature. Based upon the FAAR model (Patterson, 1988, 1989, 2002, 2005), this study anticipated that a direct relationship existed between the caretakers' beliefs (specifically locus of control and sense of coherence) and family adaptation. Given the theorized influence that caregivers' beliefs can have on the relationship between demands placed on the family and family adaptation, this study also examined the extent to which the relationship between caregiver demands (i.e., stress) and the family's adaptation is mediated by caregivers' beliefs. Figure 2 presents the model for the present study.

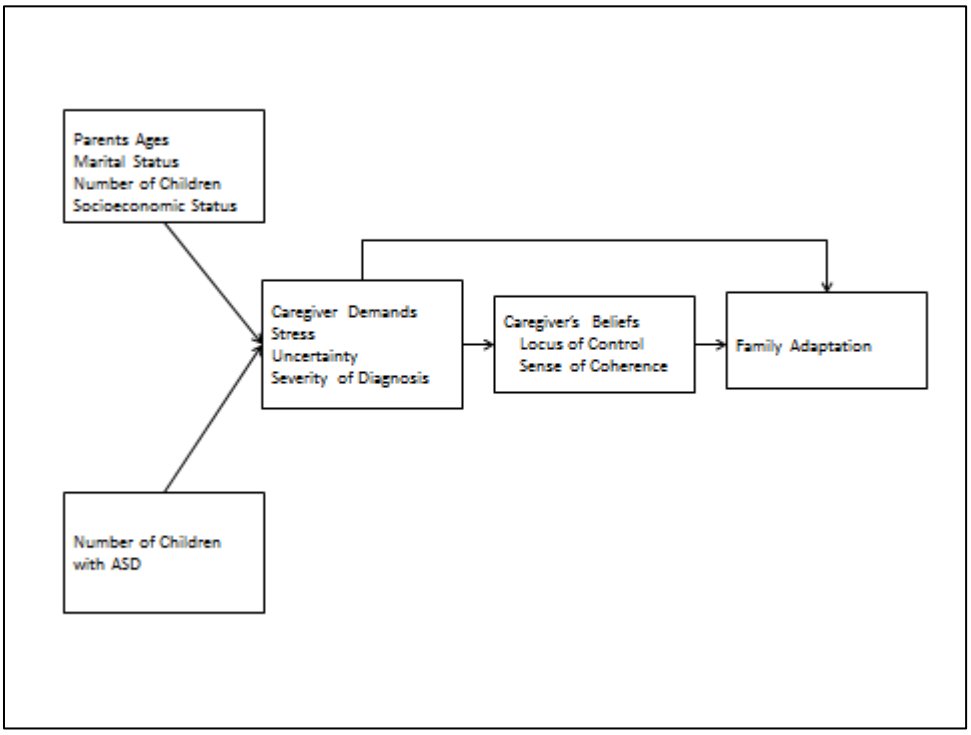

Figure 2: Model of the Present Study

The purpose of this study is to explore how caretakers of children with an Autism Spectrum Disorder are able to move through an adverse set of circumstances with which they are confronted while raising a child with considerable developmental needs

and challenges, demonstrating resilience. This occurrence of caretakers of children with autism displaying resilience exists.

Research Questions

Research Question 1. Can family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control?

Research Question 2. Will caregiver sense of control (locus of control and sense of coherence) mediate the relationship between uncertainty and family adaptation?

Research Question 3. Will caregiver sense of control (locus of control and sense of coherence) mediate the relationship between severity of ASD and family adaptation?

Significance of the Study

The emerging picture of the lifecycle of families with autism is one that can be grim and filled with stressors and life-altering factors. However, this view has shifted during the last decade, due to the research in the fields of social work and family therapy (e.g., Walsh, 1996, 1998, 2003) focusing on family resilience, as well as contributions from the field of positive psychology (Antonovsky, 1987; Seligman & Csikszentimihalyi, 2002). Today a disability, such as ASD, no longer carries a deficit-focused assumption, instead it has been replaced by a multidimensional perspective of strengths and challenges.

Family resilience is considered a construct at the level of the family unit. As formulated by Walsh (2010), family resilience involves struggling with, and effectively working through and learning from adversity, affirming strength, maintaining a positive outlook, as well as having spirituality and a belief system. Although studying resilience

in families of children with ASD is relatively new, evidence exists both in research and in clinical practice that many families of children with ASD meet the criteria by which Walsh defines resilience and possess key processing factors of and capabilities for resilience with autism.

Understanding the process of meaning-making is central in promoting resilience in families of children with ASD. The role of perceptions and meaning-making in resilience is best understood by integrating both family stress theory and family resilience (Patterson, 2002), as in the FAAR model. According to this model, the process of meaning making in the family is central to the family's ability to successfully cope and adapt to the demands of the disability. The way the family members makes meaning out of the disability determines if they are able to use the family's resources (protective factors), arrange its structure, and ultimately balance – or fail to balance – the family's resources against demands and stressors (risks) of having a child with a disability. In some cases, the event is experienced as stressful according to the meaning that one attributes to the event. This study proposed to raise awareness of family beliefs that contribute to their protective factors in raising a child with an ASD.

Summary

With an increasing rate of identification of children with ASD, families may be facing stress and challenges in overcoming this adversity. These stressors and challenges may revolve around care-taking as well as the behavioral, and physical demands of a child with autism. The intent of this study was to identify resilience characteristics of caretakers of a child with an ASD. Using the FAAR model as a theoretical framework, this study focused on parental beliefs, specifically locus of control and sense of coherence, and examined how these beliefs mediate the relationship

between demands, such as uncertainty and disability severity. Consistent with the FAAR model, this study attempted to identify the relationship between caretaker demands, caretaker beliefs, and family adaptation. Family quality of life, discussed in further detail in Chapter 2, represents family adaptation, and the outcome variable.

CHAPTER II

LITERATURE REVIEW

Introduction

This section defines pervasive developmental disorder (PDD) and specifically focuses on the term, autism, as it is classified within pervasive developmental disorder. The Center for Disease Control and Prevention (2012) suggested assessment and diagnosis for children who exhibit symptoms associated with autism spectrum disorders (ASD) should involve an experienced multi-disciplinary team. Presently, there is no "cure" for autism. However, there are highly effective treatments and intervention approaches offered that may contribute to both individuals with this disorder, as well as their families and caregivers. The majority of children with autism can attend school with varying degrees of support or specialized programming (Sivberg, 2002).

Brief History of Autism

While children with autism are seldom institutionalized; this was not always the case. Historically, a diagnosis of autism meant a child would be institutionalized (Whitman, 2004). Institutionalization was considered best practice for these youngsters as the belief that a suppressed environment in which social experience could be limited and controlled was essential to control the atypical behaviors of children with autism (Whitman, 2004).

The term "autism" was first employed by Kanner in his 1943 influential work that discussed children with disturbances of affective contact. Basing his work on developmental theory and work of Gesell, Kanner described a group of children who lacked the ability to successfully navigate and interact in the social world, effectively isolating them socially. Kanner (as cited in Volkmar & Klin, 2005) termed this group as

“autistic” and noted other clinical features of these children, including profound difficulties in communication, sensitivity to stimulation in the environment, and resistance to change. Even today, Kanner’s observations continue to illustrate important clinical characteristics of autism spectrum disorders (Wing, Gould, & Gillberg, 2011).

While Kanner’s interpretation highlighted essential clinical aspects of autism, several of Kanner’s conclusions have been refuted over time (Mesibov, Adams, & Schopler, 2000; Pinchevski, 2005). First, Kanner originally believed that most children with autism had average to above-average intelligence and the potential for normal language development. Modern studies estimate that the average IQ score of children diagnosed with autism is approximately 50; additionally, at least 40% do not develop functional expressive language (Phetrasuwan, Miles, Mesibov, & Robinson, 2009; Pinchevski, 2005). Furthermore, Kanner theorized that autism was more prevalent in highly educated or affluent families, while more recent studies resolutely suggested that autism’s prevalence is distributed proportionally across educational level, social class, and race (Fountain, King, & Bearman, 2011; Mesibov, Adams, & Schopler, 2000). Finally, Kanner implicated insufficient parenting in the formation of autism. However, this idea has been discredited in numerous studies (Baker, 2010; Mesibov et al., 2000; Volkmar & Klin, 2005). From Kanner’s observations and hypotheses, difference of opinions have emerged regarding the causes of autism. A proponent of psychoanalytic views of autism etiology, Bettelheim (1967) theorized that autistic children were the product of emotional deprivation from non-nurturing parents, particularly what were termed refrigerator mothers. He argued that the only way to treat autistic children effectively was to remove them from their parents who were the cause of their disorder and provide them with nurturance (Mesibov et al., 2000). While the impact of parental

behaviors upon the etiology of autism has been firmly discredited, this view of parental responsibility for the disorder unfortunately continues to persist in certain cultures and in some families' understanding of their experience (Mesibov et al., 2000; Neely-Barnes & Graff, 2011; Volkmar & Klin, 2005).

As Bettelheim was making his false declarations regarding the cause of autism, ideas concerning the potential organic nature of autism were formulating. By 1969, Kanner withdrew his views of parental cause in view of the mounting evidence of biological and genetic influences (Mesibov et al., 2000). While all existing conceptualizations of autism etiology recognize its origins to be organically based, rather than socially derived, research continues to clarify the specific mechanisms by which children develop autism and related disorders (Dodds, Fell, Shea, Armson, Allen, & Bryson, 2011; Pelphrey, Shultz, Hudac, & Vander Wyk, 2011).

Diagnostic Criteria

The diagnostic criteria for autism have undergone revision since Kanner's initial work. With the Diagnostic and Statistical Manual (DSM)'s recent and fifth revision, changes were made to ASD (American Psychiatric Association [APA], 2013). As a "spectrum" disorder, autism affects each individual differently and each of the three main areas to varying extents. Consequently, manifestation of symptomatology may appear extremely different from one child to the next.

The DSM-5 Neurodevelopmental Disorders Work Group was a team of clinicians and researchers who examined the scientific literature and research, conducted field trials, and reviewed feedback from others in the scientific community and the public to formulate the content for the new DSM. Through their work, there have been many changes to the diagnosis of autism, but the biggest may be the singular diagnosis of

ASD (McGuinness, 2013). The DSM-5's criteria incorporates multiple diagnoses from the DSM-IV (Asperger's disorder syndrome, autistic disorder, childhood disintegrative disorder, and PDD-NOS) into ASD.

The DSM-5 Neurodevelopmental Disorders Work Group found that the diagnostic criteria for DSM-IV-TR PDDs, particularly PDD-NOS and Asperger's disorder, were inconsistent and varied across assessment locations and providers (Gibbs, Aldridge, Chandler, Witzlsperger, &Smith, 2012). To consistently and accurately diagnose autism, the three categories of impairment for autistic disorder used in the DSM-IV-TR (social interaction, communication, and fixated interests in repetitive behaviors) were reduced to two areas of focus in the DSM-5: a social communication domain and a behavioral domain, which includes fixated interests and repetitive behaviors.

The DSM-IV-TR's social and communication domains have been combined for the DSM-5, as population based and twin studies of ASD have demonstrated that difficulties in social interaction and communication were part of the same domain (Ronald et al., 2010; Rosenberg et al., 2009). The proposed criteria that must be met for the DSM-5 are: (a) persistent deficiencies in social communication and interaction across settings; (b) restricted and repetitive behaviors, interests, or activities; (c) symptoms must be present early in childhood (but may be delayed to a later age when social demands exceed the limits of the child); and (d) symptoms limit and impair functioning daily. Although the DSM-IV-TR required only one symptom of fixed interests and repetitive behaviors for diagnosis, the DSM-5 requires at least two (APA, 2000, 2013).

The DSM-IV-TR required that symptoms must have occurred before age 3. The new guidelines do not specify an age, allowing consideration that individuals with autism with higher functioning may not have displayed impairment until their social demands were increased by formalized education systems or other changes in environment. Conversely, with behavioral interventions or improved environment, some symptoms of autism may improve or abate. Under the DSM-5 criteria, because a diagnosis may be made by history, even though an individual no longer exhibits behavioral criteria, the ASD diagnosis is still retained.

As collaborative work with families of individuals diagnosed with an autism spectrum disorder (ASD) has progressively become a standard of comprehensive practice, identifying suitable systems-focused theories to assist in directing effective family-level intervention and treatment has become more important. Theory offers researchers and practitioners a conceptual map, enlightening the "what," "why," and "how" of inquiry, prevention and intervention.

Stressors Associated With Diagnosis

Many family and parental pressures have been related to a diagnosis of autism. Turnbull and Turnbull (1990) stated that the lived experiences of one family member affect or influence all other members in the family unit. For example, when a family with a child with autism attempts to go out in public, the other members of the family may be embarrassed or feel uncomfortable if the child displays atypical or strange behaviors characteristically related to autism (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006).

Various members of society unacquainted with the latest findings of ASD research may still blame the child's parents for these unusual behaviors. Public

exhibitions of problem behavior can cause some parents to isolate themselves from society as a potential defense mechanism (Miller & Sammons, 1999). According to Dunlap and Fox (1999), “the juxtaposition of the child’s physical typicality and extreme behavioral deviance can make a parent’s sense of humiliation even more acute” (p. 79), consequently compounding the parent’s isolation.

Parents of children with autism have many stressors related to the diagnosis. Moreover, sometimes even obtaining an accurate diagnosis can be a difficult and arduous process (Matson, Beighley, & Turygin, 2012; Sivberg, 2003). As no best options for treatment are available that have been found to be successful for all children with autism and diagnosis is deferred sometimes due to uncertain prognosis predictors can multiply the stress associated with the diagnosis process. Human beings try to make sense of stressful events by searching for explanations and meaning (Dale, Jahoda & Knott, 2006).

The experience of being told that something is not right with your child can be unpredictable and emotionally difficult. Upon hearing the diagnosis, parents’ initial hopes and dreams for their child may be destroyed unexpectedly (Boushey, 2001). Most prospective parents are eager about preparing for the future, but realizing that their child has a disability can create both positive and negative reactions (Alper, Schloss & Schloss, 1994; Mulligan, MacCulloch, Good, & Nicholas, 2012). However, some families exhibit a healthy adaptation or resilience despite the adversity and numerous challenges of parenting a child with autism.

Post Diagnosis

To appreciate various experiences of family members, researchers have examined the relationship between stress and negative outcomes (e.g., depression)

and between support systems of strategies (e.g., respite services, social networks) and positive outcomes (Boyd, 2002; Jones & Passey, 2004; Meadan, Halle, & Ebata, 2010; Shu & Lung, 2005). Prior to 2000, researchers who conducted investigations (e.g., Sanders & Morgan, 1997; Sharpley, Bitsika, & Efremidis, 1997) and authors who conducted reviews of investigations (e.g., Glasberg, Martins, & Harris, 2006) related to stress and coping among family members of individuals with ASD found that: (a) mothers of children with ASD reported more stress than mothers of children with Down's syndrome (DS) and with typically developing children; (b) mothers of children with ASD experienced greater stress, anxiety, and depression than fathers of children with ASD; (c) social support countered stress in parents of children with ASD; and (d) contradictory findings were related to the adjustment of siblings of children with ASD.

Hastings, Kovshoff, Ward, Espinosa, Brown, and Remington (2005) reported that "the majority of research to date has considered the child with autism as a source of stress and other family members' well-being as the outcome" (p. 636). This viewpoint illustrated unidirectional relationships between individuals with ASD and their family members. Yet, these relationships could be bidirectional, indicating that individuals with ASD could influence their family members and family members could influence the individual with ASD (e.g., marital stress or maternal depression could influence the child's behavior). Additionally, relationships among other family members (e.g., mother-father, parent-typically developing children) also could affect family members' stress levels. For instance, Hastings (2003) found that mothers' stress was related to behavior problems of a child with ASD, while in the same families, fathers' stress was related to their partners' depression.

Theory Guiding Current Study

If the child diagnosed with ASD is going to experience the most favorable long-term outcomes, the family context of the child also must be an explicit target for intervention. The Family Adjustment and Adaptation Response model (FAAR; Patterson, 1988, 1998, 2002, 2005; Patterson & Garwick, 1994) forms the theoretical basis for this study. The FAAR is a process model that combines resilience theory with family stress theory. The process by which families adapt to stress or crisis through their management of the demands placed upon them (i.e., risk factors), the family's capabilities (i.e., protective factors), and family beliefs is clarified with this model.

Family adjustment and adaptation response (FAAR) model.

At its core, the FAAR model is a mixture of features from resilience theory and family stress theories. Resilience theory considers factors and processes by which an individual displays competence in overcoming adversity (Masten & Coatsworth, 1998). Within this definition of resilience, competence is a pattern of effective adaptation in one's context or environment, with success defined as either accomplishment in broad developmental tasks or in specific domains of achievement (Masten & Coatsworth, 1998). While once considered to be exhibited by only special, or invulnerable, individuals, resilience is now commonly accepted to be an ordinary, dynamic process (Masten, 2001).

Family resilience is defined as the family's capacity to successfully manage difficult or challenging life circumstances (Walsh, 1998). Consequently, family resilience is the "characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations" (McCubbin & McCubbin, 1988, p. 247). Similar to research on individual resilience,

major stressors, or an accumulation of several different stressors, can influence a family's functioning and their ability to adapt successfully to ensuing problems (Boss, 2001; McCubbin & Patterson, 1983).

Similar to the literature on family resilience, family stress theories developed from research investigating conditions under which families are affected adversely by stressful circumstances (Patterson, 1989). The first major family stress theory was Hill's ABCX family crisis model (Hill, 1949, 1958). This model evolved from examining the impact of separation and reunification due to war upon the family. Hill hypothesized that a stressor event ('A') interacted with the family's crisis-focused resources ('B') that interacted with how the family defined the event ('C'), producing the crisis ('X') (Hill, 1958). During the 1970s, family stress researchers employing Hill's ABCX model suggested additional factors that could influence the family's adaptation to crisis (Patterson, 1989). Consequently, the Double ABCX model was developed (McCubbin & Patterson, 1983). This model adapted the original ABCX model by including added factors, such as demand pile-up (i.e., multiple demands upon the family), the role of coping strategies in managing these demands, and the role of family perceptions that influence adaptation (McCubbin & Patterson, 1983).

The family adjustment and adaptation response model (FAAR; Patterson, 1988, 1989, 1993, 2002, 2005; Patterson & Garwick, 1994) was developed to integrate key elements of the Double ABCX model (McCubbin & Patterson, 1983) into a process model that depicts how families advance from pre-crisis adjustment to post-crisis adaptation (Patterson, 1989). This model also is an overt attempt to emphasize links between family stress models and family resilience theory (Patterson, 1988, 2002). The FAAR depicts the process by which a family responds to a crisis by focusing on four

main components (i.e., family demands, family capabilities, family meaning, and adaptation) and their relationship with one another (Patterson, 1988, 1989, 2002).

According to the FAAR model, individual and family adaptation to a stressful condition is dependent on the family's efforts to manage their demands and the family's capabilities to address these demands, as mediated or moderated by family beliefs or meanings (Patterson, 1989, 2005). Demands and capabilities are balanced as if on a see-saw, under the umbrella of family beliefs or meanings. As family demands become greater ("pile-up") or a major stressor event occurs, the family could slip into crisis, or a state of disorganization and disruption (Patterson, 1988, 1989). From this state of disorganization, families attempt to adapt by restoring balance to their system (Patterson, 1988, 1989).

Family demands are conditions that result in family changes the through creating tension (Patterson, 1988, 1989). Demands include both stressors and strains that challenge the family's functioning. In this theory, "stressors" are defined as life events that occur at a particular time, while "strains" are conditions that do not have a discrete beginning (Patterson, 1989). The nature of these two types of demands influence how families cope with them; namely, while change is directed at managing a stressor, change is used to eliminate on-going strain (Patterson, 1989). Consequently, the onset of a chronic health condition, such as autism, can be considered a stressor, while the residual tension resulting from not being able to resolve the condition is considered a strain. Combined, demands include normative and non-normative stressors, ongoing family tensions, and minor daily hassles (Patterson, 2002). Demands continue until some family resource is directed towards addressing the demand (Patterson, 1989).

Consistent with resiliency theory, demands also can be conceptualized as risk

factors that negatively affect family functioning (Patterson, 2002). As with risk factors, demands exist on a variety of systemic levels, including individual, family, community, and society. For instance, risks or demands that can influence functioning negatively in families challenged with chronic health conditions include the family member's diagnosis, marital discord, stigma associated with the chronic condition, loss of social relationships, and lack of policy or funding for appropriate research and treatment (Patterson, 2002). At the same time, risk factors along with the accumulation of demands can interact to effect individual and family functioning negatively (Patterson, 2002).

Family capabilities are structures that the family has available to meet a demand (Patterson, 1989). Family capabilities are defined in two categories: family resources (i.e., what a family has) and family coping behaviors (i.e., what a family does; Patterson, 1989, 2002). Family resources can include concrete items or intangible characteristics or competencies (Patterson, 1989). Family coping behaviors are problem-solving behaviors that include explicit actions made by individuals or the collective family to reduce a demand (Patterson, 1989). By employing available resources and coping behaviors, the family makes an effort to preserve or re-establish balance between demands and capabilities.

As with demands, capabilities also are conceptually comparable to protective factors within resilience theory (Patterson, 2002). Numerous resources and coping behaviors as protective factors also have been identified within resilience theories (Patterson, 2002). For instance, both the stress literature and the literature on resilience recognized similar factors that promote positive outcomes, including intelligence; knowledge and skills; personality traits such as humor, physical health, emotional

health, individual self-esteem; family cohesion and organization; boundaries; and communication skills (Masten & Coatsworth, 1998; Patterson, 1989; Walsh, 1998).

Family meanings or beliefs are critical mediators or moderators of family demands, capabilities, and overall family adjustment or adaptation (Patterson, 1988, 1989, 1993, 2002, 2005). Family meanings are beliefs held by individual family members, as well as those held by the family as a whole. Family meanings are conceptualized to exist on three levels: (a) how families define their demands and capabilities; (b) how family members defines themselves as a family; and (c) how the family views itself in relation to broader systems (i.e., family world view) (Patterson, 1993, 2005; Patterson & Garwick, 1994). These meanings influence how the family understands and responds to its exposure to risk and its ability to protect itself (Patterson, 2002). Essentially, family beliefs or meanings influence the relative effect that family capabilities and demands have on the family's ability to adapt to crisis events.

Through shared family beliefs, families reduce the vagueness and uncertainty regarding demands they face and help in coordinating responses to those demands (Patterson, 2005). Additionally, family beliefs or meanings help families interpret their reality and their assumptions that influence how they define their capabilities and demands, their crisis situations, and actions they take to adapt to these situations (Patterson, 2005). Considered the core of family resilience (Walsh, 1998), the beliefs or meanings that families hold can include optimism, relativism (i.e., living in the present), shared control (i.e., balancing individual control with trust in others), shared purpose, and collectivity (i.e., family as part of something larger than itself; Patterson, 1989, 2005). In families faced with chronic illness or disability, such as ASD, family beliefs or

meanings can also include how a family defines the chronic condition (i.e., ASD), strains associated with the condition, and the perceived resources the family has to manage the condition (Patterson, 2005).

The FAAR model postulates that families flow in and out of two phases throughout their life cycles. The first, adjustment, is the phase in which families use fairly consistent patterns of interaction on a daily basis to balance their capabilities and demands (Patterson, 1988, 1989). This phase continues until demands outweigh their capabilities, either due to the pile up of strains or the introduction of a stressor. When this happens, the family experiences a state of crisis, a turning point for the family that induces a state of disorganization and disruption (Patterson, 1988, 1989). Crises are thought to generate changes in the family by facilitating either improved or poorer family functioning (Patterson, 1988, 1989).

The process by which families restore balance and organization after a state of crisis is called adaptation, the second phase of the FAAR model (Patterson, 1988, 1989). Adaptation does not have a single definition that is consistently used in the theoretical or empirical literature, though it is often defined as families doing favorably on a selected outcome measure, such as indices of depression, marital satisfaction, or stress. In the FAAR model, Patterson (1988, 1989) specifically viewed adaptation as a process that resulted in restoring balance between families' capabilities and demands on two specific systemic levels: (a) between individuals within the family unit, and (b) between the family and the wider community (Patterson, 1988, 2002). Thus, successful family adaptation includes the promotion of both individual family members' optimal development, as well as the family unit's ability to manage tasks across time successfully (Patterson, 1988).

Patterson (1988) found similarities between family adaptation and family resilience. Within the family resilience literature, resilience consists of a family's ability to manage difficult life circumstances successfully (Walsh, 1998). Within the FAAR model, positive family adaptation to crisis was defined similarly (Patterson, 1988, 1989, 2002). In families faced with chronic illness or disability, an additional feature of family resilience or adaptation includes the family's ability to meet the needs of their vulnerable family member (Patterson, 2002). However, this aspect unaccompanied by other features of adaptation cannot be considered an indicator of family resilience, given the potential for families to allot resources to the vulnerable family member at the expense of meeting other family members' needs (Patterson, 2002).

This impression that successful adaptation requires both within system (i.e., family) and between systems (i.e., family and community) outcomes has important implications for families of ASD individuals. By defining adaptation in this way, positive adaptation includes both individual and family functioning as treatment goals. While the promotion of positive gains in the individual diagnosed with ASD continues to be the primary focus of treatment, family resources (e.g., physical, financial, emotional, time, etc.) that are allocated to that individual is then balanced with the whole family's needs. This resource allocation can be particularly important when the family overextends itself and becomes so caught up in treatment of the family member diagnosed with ASD that they may overlook the rest of the family's needs, relationships, or experiences. In the same way, for families underinvolved in their ASD member's treatment, the individual's and family's optimal adaptation may call for additional family involvement in treatment. Successful adaptation of the family becomes associated with promoting optimal functioning of individuals for the purpose of achieving good quality of life for the family.

The FAAR model also highlights links between family functioning and its relationship with the community. These associations can be conceptualized in a variety of ways, such as positive, supportive relationships between the family and community members, including service providers. Furthermore, many families are confronted with seeking and employing appropriate services for their family member diagnosed with an ASD across that individual's lifespan. The extent to which a family can aptly advocate for this family member, competently navigate the various systems involved in treatment, and feel empowered to effect change at a variety of levels, is important.

Family Beliefs

According to the FAAR model (Patterson, 1988, 2002, 2005; Patterson & Garwick, 1994), beliefs that family members hold about a family member's illness or disability-related condition are important factors that can influence family adaptation, coping, and resilience (DeHaan, Hawley, & Deal, 2013; Lazarus & Folkman,1984; McCubbin & McCubbin, 1993; Roland, 1994; Walsh, 1998). As such, this study will determine if family beliefs, particularly those of parents or primary caregivers, have both direct and indirect influence on how a family adapts to their family member's ASD. Specific family beliefs regarding control and mastery as perceived by the caretakers will be the focal point of this study. These beliefs are important theoretically, as shown in the research on chronic illness and disability.

Control

An individual's belief about personal control, and the coping strategies that emerge from this belief, are influenced by the predictability of life's events and outcomes (Mednick & Koocher, 2012; Williams & Koocher, 1998), as well as cultural, familial, and historical views regarding control (Rolland, 1994). When a child is

diagnosed with an ASD, these views of predictability and stability are considerably disturbed. While families may maintain beliefs about their personal control over other facets of their lives, their views regarding their control over the family member's ASD course and outcome may be uncertain.

Studies of locus of control have found that uncertainty also can be a substantial factor in development of familial stress. Rotter (1966) proposed that individuals have either an external or internal locus of control. People who possess an internal locus of control believe that they can control outcomes of situations. In contrast, people with an external locus of control suppose that outcomes are controlled by external forces and that they cannot control the outcomes of the situations. In a 2001 study on parents of children with autism, parents with an external locus of control reported greater stress than those with an internal locus of control (Dunn et al., 2001). Parents with an external locus of control also tended to feel socially isolated. Comparable results were established in a study of mothers of children with intellectual disabilities (Hassall, Rose, & McDonald, 2005): internal locus of control mothers experienced less stress and had higher self-esteem.

Findings from the chronic illness and disability literature support the importance of internal health locus of control for caregivers of individuals diagnosed with a chronic health condition. Specifically, results suggested that caregivers of individuals with chronic health conditions who have an internal locus of control tend to be less depressed and better adjusted than caregivers with a more external locus of control (Bennett et al., 2012; Bookwala & Schulz, 1998; Braithwaite, 1996; Miller et al., 1995). Internal health locus of control in these caretakers also was associated with increased well-being (Lee et al., 2012; Lloyd & Hastings, 2009; Thompson & Kyle, 2000).

Other studies on families faced with disabilities or chronic illnesses reported similar findings using related measures of locus of control. For example, in a study of 141 mothers of children diagnosed with mental retardation (MR), Friedrich, Cohen and Wilturner (1988) noted that global locus of control buffered the impact of physical incapacitation. The authors also noted that mothers with an internal locus of control were less depressed than mothers with an external locus of control (Friedrich, Cohen, & Wilturner, 1988).

Likewise, in a study of parents of children with a wide range of developmental disabilities, Jones and Passey (2005) found that parents who had an internal locus of parenting control (i.e., control parents feel they have over a child's behaviors or actions) had lower levels of stress than parents with an external locus of parenting control. Hassall, Rose, and McDonald (2005) reported similar findings in a study of 46 mothers of MR children. Specifically, the authors found that mothers with an external parenting locus of control were more likely to experience higher stress levels. This same study also found that mothers with higher levels of parenting self-esteem were likely to have a more internal locus of parenting control (Hassall, Rose, & McDonald, 2005).

Given that the family system is important in caring for and nurturing optimal long-term outcomes in individuals diagnosed with an ASD, a better understanding of the relationship between health-related beliefs and family outcomes in families of individuals diagnosed with an ASD is desirable. Thus, this study will examine the impact parental locus of control beliefs have upon family-level outcomes.

Mastery

In the family systems literature, control and mastery are considered equally important in understanding the family's overall definition of a chronic condition and their

beliefs regarding their experiences with the chronic illness or disability (Rolland, 1994). While these two concepts may appear similar at first glance, overt distinctions exist in the way these concepts are defined. As noted previously, control includes beliefs regarding the extent to which an individual has personal agency over life events, including a particular disability or illness (Dohrenwend & Dohrenwend, 1981). Mastery, conversely, involves beliefs regarding the extent to which life events are manageable or comprehensible (Antonovsky, 1987; Antonovsky & Sourani, 1988).

A substantial body of research has been published on the concept of mastery for individuals with chronic illnesses and disabilities. In this research, the concept of mastery often is defined as sense of coherence (SOC). SOC is a global orientation in which individuals feel confidence that:

> 1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable; 2) the resources are available to one to meet the demands posed by these stimuli; and 3) these demands are challenges, worthy of investment and engagement. (Antonovsky, 1987, pp. 19).

Collectively, the three components of SOC (i.e., comprehensibility, manageability, and meaningfulness) symbolize mastery-related ways that individuals can make meaning of their experiences.

For example, Antonovsky argued that when individuals believe that when their environment is comprehensible (or orderable), the nature of stressors and the problems that arise from them are manageable (Antonovsky, 1987). Likewise, when individuals perceive the demands created by stressors are manageable, they could be more likely to seek appropriate available resources (Antonovsky, 1987). When individuals perceive their life as meaningful, they have the motivational drive needed to actively combat stressors (Antonovsky, 1987).

SOC is based on the belief that illness is a normative human experience rather than a pathological one, with most individuals and families having to cope with health issues at some point in their lives. Developed by Antonovsky (1987), SOC adheres to a salutogenesis perspective, which is defined as a perspective in which health and functioning are highlighted rather than the causes of sickness (Antonovsky, 1987). Antonovsky (1987) asserted that various factors help families cope with chronic health conditions. Recognizing how these factors work to lessen the potential destructive impact of illness is valuable.

The concept of SOC could have a role in how parents comprehend and handle their experiences with a family member's diagnosis of ASD. In addition, they could understand how these mastery-related beliefs could influence the family's overall adaptation. For instance, given the relatively uncertain nature of ASDs and variability in the severity of symptomology, one could make a case that the more disordered or mysterious a family perceives their everyday experience to be with their family member's ASD, the more difficult it is for a family to identify and comprehend their experiences and develop and use suitable strategies to manage stresses and demands. Likewise, the more difficult and unmanageable a family perceives the demands that occur from caring for their family member with an ASD, the harder it could be for those families to access and employ appropriate resources to cope with those demands. If families view their lives with their family member diagnosed with an ASD as catastrophic and with no redeemable aspects, rather than as challenging but meaningful, families could encounter greater difficulty in motivating themselves to tackle demands actively. Thus, families with greater SOC could be more motivated and active in their family member's ASD treatment and attaining appropriate services, view their experience as

more controllable, and have better cognitive clarity regarding issues that result from demands associated with ASD.

As an important theoretical construct, SOC is receiving greater attention in the literature on families of children diagnosed with developmental disabilities and/or chronic illnesses. In a recent study, Oelofsen and Richardson (2006) used the sense of coherence construct to examine group differences among 59 families of children with a developmental disability and 45 families of typically developing children in the United Kingdom. This study assumed the importance of SOC on outcomes and focused on describing differences between the two groups. They found that parents of children with a developmental disability reported consistently higher levels of parenting stress and a weaker sense of coherence than parents of typically developing children (Oelofsen & Richardson, 2006).

Other studies have gone beyond describing group differences by examining how SOC affects individual outcomes within specific populations, such as families of children diagnosed with chronic illnesses or developmental disabilities. For example, Margalit and Kleitman (2006), looked at SOC while examining families employing a specific early intervention program in Israel. Quantitative analysis of responses from 70 mothers of children considered “at risk for developing a developmental disability” (p. 277) demonstrated that mothers’ level of stress was significantly associated with their SOC scores. Specifically, the authors noted that mothers with higher SOC scores had lower levels of stress at both the start of the intervention and at its conclusion (Margalit & Kleitman, 2006). This finding, specifically the negative relationship between SOC score and level of individual parental stress, has received additional backing (Margalit, Al-Yagon, & Kleitman, 2006).

Within the autism-specific literature, three studies focused on SOC with families of children diagnosed with an ASD. For instance, Olsson and Hwang (2002) conducted a quantitative study in Sweden of 216 families of children with autism, intellectual disabilities, and typically developing children. The authors then compared SOC levels across the three groups, along with the influence SOC had on parents' level of depression within each group. Similar to the findings of Oelofsen and Richardson (2006), Olsson and Hwang found that mothers of children with autism had lower SOC levels than mothers of children with an intellectual disability, who in turn had lower SOC levels than mothers of typically developing children (Olsson & Hwang, 2002). The authors noted that mothers with low SOC scores had higher depression scores than mothers with high SOC scores (Olsson & Hwang, 2002). Finally, mothers of children with either an intellectual disability or autism who had low SOC scores scored higher on depression indices than parents of typically developing children who had low SOC scores. The authors found that fathers' SOC scores and depression scores did not vary significantly among the three groups (Olsson & Hwang, 2002).

Sivberg (2002) also examined the relationship between SOC, coping styles, and family strain in parents of children with an ASD. This quantitative study, conducted in Sweden, compared 66 parents of children diagnosed with an ASD and 66 parents of typically developing children. Results of the study found a negative relationship between the level of strain on the family and the level of SOC (Sivberg, 2002). Lower levels of SOC were associated with higher levels of strain (Sivberg, 2002). The study findings indicated that families of autistic children demonstrated higher levels of strain than families of typically developing children (Sivberg, 2002).

Mak, Ho, and Law (2007) examined the relationship between SOC, parenting

attitudes, and stress in families of children diagnosed with an ASD. In their study, which took place in Hong Kong, the authors surveyed 157 parents of children diagnosed with an ASD. The study's results found that mothers with higher levels of SOC reported less stress than mothers with lower levels of SOC (Mak, Ho, & Law, 2007). The study also indicated that SOC acted as a moderator between autistic symptom severity and parenting stress (Mak, Ho, & Law, 2007).

As this body of literature implied, SOC is an important concept in promoting positive individual and family outcomes in families managing chronic health conditions. Families of children with special needs have consistently demonstrated lower levels of SOC than families of typically developing children. Additionally, families of individuals diagnosed with an ASD also demonstrated lower levels of SOC than families with children in other special needs groups. These findings potentially placed families of children diagnosed with an ASD at increased risk for negative outcomes. Given the influence that SOC can have on intervention effectiveness and family's involvement in treatment (e.g., Margalit & Kleitman, 2006) understanding the role of SOC in promoting resilience and positive adaptation within families of individuals diagnosed with an ASD is key.

Family Adaptation

Families of individuals diagnosed with an ASD play a central role in the treatment of ASDs. Current best practice paradigms for working with individuals diagnosed with an ASD noted that families are essential elements of optimal interventions with children diagnosed with an ASD and children with other disabilities (e.g., Marcus, Kunce, & Schopler, 2005; National Research Council, 2001). Favorable treatment outcomes of children with special needs are dependent on features related to the particular

illness/disability or characteristics of that individual child, as well as features of the family system (Patterson, 2005; Rolland, 1994).

Chronic illness and/or disability influence both the individual and the entire family system (Patterson, 2005; Summers et al., 2005; Turnbull, Turnbull, Erwin, & Soodak, 2006). This influence is true for families of individuals diagnosed with an ASD. Many features of the family's experience, such as financial resources, emotional resources, parenting practices, family relationships, and relationships with non-family members and can be influenced by a family member's ASD (Nissenbaum, Tollefson, & Reese, 2002). Family members of individuals diagnosed with an ASD may assume extra roles beyond those found in typical families; including educator, advocate, and lifetime direct caregiver. These functions require proficiencies that may be in addition to those associated with families of typically developing children. Consequently, typical parenting may not adequately address the domain deficits found in ASDs (Bristol & Schopler, 1984; Casey et al., 2012). The taxing demands placed upon the families of ASD individuals may require adaptation in the roles and relationships that family members assume (e.g., different sibling relationships, more traditional parenting roles, etc.) or limit family members in some manner (e.g., social connections, recreational activities and time, work status, etc.; Bristol & Schopler, 1984; Brown et al., 2006; Gray, 2002).

Appreciating the influence a child's ASD has upon the family system, as well as how best to support the family's adaptation to their family member's condition is essential to family functioning. Consequently, the concept of family quality of life may be a functional gauge of family adaptation. The following section first defines family adaptation and family quality of life, and then considers literature on family quality of life within ASD and chronic illness.

Family Quality of Life

In using the definition of family adaptation presented in the FAAR model (Patterson, 1988, 2002), looking beyond individual mental health outcomes as measures of adaptation and incorporating family outcomes into measure of adaptation is important. Conventional research examining the impact of children with disabilities on their families focused on the psychosocial functioning of family members or specific family relationships (e.g., marital satisfaction). However, the FAAR model proposed that measures of family adaptation must extend beyond individual-focused outcomes to reflect both positive individual growth and relationships between family members (i.e., within-family). The family must be able to meet its vulnerable family members' needs within the community successfully (i.e., family-community; Patterson, 1988, 2002). As a result, adaptation becomes more strength-focused; facilitative, rather than pathological; and context sensitive.

Consistent with this definition of family adaptation is the concept of family quality of life (FQOL). Optimal FQOL is defined as conditions in which the family's needs are met, family members are able to accomplish things that are important to them, and they enjoy their life together as a family (Park et al., 2003; Turnbull, Turbiville, & Turnbull, 2000). In this framework, the phrase 'family' is used to signify individuals who define themselves as part of a family, whether they are actually related or not and who care for and support each other (Park et al., 2003; Turnbull, Turbiville, & Turnbull, 2000).

Family quality of life includes four main principles: (a) family members influence each other; (b) domains of FQOL interact and affect each other; (c) FQOL can change over time; and (d) the definition of FQOL is dependent upon what a family defines as "quality" (Park, Turnbull, & Turnbull, 2002). While the practical sense of FQOL may vary

from family to family, consistent and fundamental aspects of quality of life are thought to exist across families. Several authors have proposed that these basic aspects can be categorized into five general domains for families managing chronic illnesses and disabilities: (a) family interactions, (b) parenting, (c) emotional well-being, (d) physical and financial well-being, and (e) disability related support (Park et al., 2003; Turnbull et al., 2004; Wang et al., 2004). These five domains are consistent for the within-family (e.g., parenting, emotional well-being, physical and financial well-being, and family interactions) and family-community (e.g., disability related support) factors promoted by the FAAR model.

Although the literature on family quality of life remains in its beginnings, some studies within the chronic illness and disability literature have examined this topic. Several of these studies supported the notion that having a family member with a chronic illness or disability has the potential to negatively influence FQOL when compared to families of typically developing children. For instance, Browne and Bramston (1996) conducted a study that compared 44 parents of intellectually disabled (ID) children with 58 parents of typically developing children. The study found that while there was no difference between these two groups on how each group rated the importance of quality of life (QOL) domains, families of children with an ID had lower overall QOL scores than families of typically developing children. Families of children diagnosed with an ID also had significantly lower scores than families of typically developing children on specific QOL domains, including maternal well-being, health, intimacy, and community involvement (Browne & Bramston, 1996). Other studies have found similar results. Namely, families of children with a disability reported lower scores on FQOL measures when compared to families of typically developing children (Brown,

MacAdam-Crisp, Wang, & Iaroci, 2006; Ones, Yilmaz, Cetinkaya, & Caglar, 2005).

Additional studies within the chronic illness or disability literature have investigated the relationship between more disability-specific factors and FQOL. Williams and colleagues (2003) conducted a study with 200 parents of children diagnosed with epilepsy to examine the relationship between several disability-specific factors and overall FQOL. Results indicated that the family's quality of life was negatively impacted by the uncertainty of epileptic episodes (i.e., poorly controlled epilepsy) and the presence of comorbid conditions (Williams et al., 2003). Furthermore, in a study of 130 fathers and 234 mothers of children with an array of disabilities, Wang and colleagues (2004) found that the severity of the disability was a significant predictor of both mothers' and fathers' reports of satisfaction with family quality of life (Wang et al., 2004).

Some studies examined the relationship between parental factors and FQOL in families of individuals with chronic illnesses or disabilities. Williams and colleagues (2003) found that FQOL was negatively influenced by heightened parental anxiety (Williams et al., 2003). Similarly, in a study of 46 mothers of children diagnosed with cerebral palsy and 46 mothers of typically developing children, Ones et al. (2005) noted a negative relationship between quality of life and parental depression. Particularly, for mothers of children with cerebral palsy, mothers with greater depression symptoms were more likely to have lower rating for quality of life (Ones et al., 2005).

Two studies were found that examined the family's quality of life in families of individuals diagnosed with an ASD. The first study examined factors that influenced a mother's quality of life within families of children diagnosed with an ASD. Shu and Lung (2005) conducted a study in China that examined effects of a support group intervention

for mothers of children diagnosed with an ASD. In general, they noted that subjective well- being and employment status had a significant influence on mother's quality of life. Mothers with higher levels of well-being and who were employed reported greater satisfaction with their quality of life (Shu & Lung, 2005).

The second study explored family quality of life across families of both typically and atypically developing children. Brown et al. (2006) examined group differences in family quality of life between families of children with Down Syndrome, children diagnosed with an ASD, and typically developing children. This study found that families with typically developing children demonstrated significantly higher levels of quality of life than the other groups (Brown et al., 2006). Furthermore, the authors commented that, in all but one domain of family quality of life, the area of spiritual and cultural beliefs, families of children diagnosed with an ASD had the lowest satisfaction with FQOL domains (Brown et al., 2006). The domains the families of children diagnosed with ASD had the lowest satisfaction score on included career, leisure, community/civic involvement, financial well-being, health, family relations, support from other people, support from disability-related services (Brown et al., 2006).

Taken as a whole, this body of literature suggested that family quality of life can be impacted by a child's disability. Additionally, numerous factors, including the uncertainty of a health condition, severity or 'pile-up' of symptoms related to a condition, and parental well- being can influence the degree to which quality of life is impacted.

As these studies indicated, factors such as severity of a disability and the level of uncertainty regarding a disability's symptom expression can influence family quality of life directly. However, these studies have not specifically examined the effect that specific family demands have on the quality of life of families of children diagnosed with

an ASD. Thus, this study also will examine if the relationships that were described in the broader chronic illness and disability literature also pertain to families of individuals diagnosed with an ASD.

Finally, as proposed by the FAAR model, family beliefs are thought to mediate the relationship between demands, such as uncertainty and disability severity, and family adaptation.

Summary

While the trials of parenting a child can be intense; the trials of parenting a child with autism are immense and transcend most imaginations (Sivberg, 2002). Most parents and families with a child with autism hold out constant hope that treatments, resources, and programs will progress that can have a positive influence on the quality of life for their children (Wheeler, Baggett, Fox & Blevins, 2006).

This chapter has reviewed the theoretical and empirical literature on the experiences of families with children diagnosed with an ASD. These experiences are both similar to, and different from, experiences of families of children with other disabilities or chronic health conditions (Bristol & Schopler, 1984; Casey et al., 2012). Given the historical view of the family of individuals diagnosed with an ASD, past research and interventions with this population have either pathologized the family and their experiences or neglected their potential role in influencing long-lasting positive change in the individual diagnosed with an ASD's treatment.

This study uses the FAAR model to identify specific factors for inquiry, as well as examine the hypothesized relationships between the identified factors. Specifically, this study aims to investigate the relationship between known demands, family beliefs, and family adaptation in families of individuals diagnosed with an ASD. The variable family

quality of life (FQOL) was selected to represent family adaptation, the outcome variable. FQOL is considered a good fit for the definition of family adaptation used in this study given the dynamic relationship that individuals diagnosed with ASD have with their families (e.g., Bristol & Schopler, 1984; Brown et al., 2006; Gray, 2002), as well as the present recommendation for family-centered practice in individuals diagnosed with an ASD's treatment (e.g., Marcus, Kunce, & Schopler, 2005; National Research Council, 2011).

Beliefs held by family members play an essential role in mediating or moderating the relative impact demands have on overall family adaptation (Patterson, 2005). As this study proposes that locus of control and sense of coherence are mechanisms through which demands influence family adaptation, this study focuses on the extent to which these factors mediate the relationship between demands upon the family and family adaptation. To test this mediational relationship, this study will examine the influence of two specific demands, the uncertainty related to a family member's ASD and the level of perceived severity of the ASD on family quality of life (FQOL), and then examine the extent to which locus of control (LOC) and sense of coherence (SOC) mediate this relationship. The specific hypotheses that will be tested in this study are:

Research Question 1: Can family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control?

H_1: Family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control.

Research Question 2: Will caregiver sense of control (locus of control, and sense of coherence) mediate the relationship between uncertainty and family adaptation?

H_3: Caregiver sense of control will mediate the relationship between uncertainty and family adaptation.

Research Question 3: Will caregiver sense of control (locus of control, and sense of coherence) mediate the relationship between severity of ASD and family adaptation?

H_4: Caregiver sense of control will mediate the relationship between severity of ASD and family adaptation.

CHAPTER III

METHODOLOGY

This chapter details the methods that were used to collect and analyze data needed to address the research questions. The topics included in this chapter are restatement of the problem, research design, participants, instrumentation, data collection procedures, and data analysis.

Restatement of the Problem

The purpose of this study was to explore how caretakers of children with an Autism Spectrum Disorder are able to move through an adverse set of circumstances with which they are confronted while raising a child with considerable developmental needs and challenges, demonstrating resilience.

Research Design

A nonexperimental, correlational research design was used in this study. This type of study examines the relationship among variables that have been shown to predict or explain a phenomenon (i.e., family quality of life). Data were collected from families where at least one school-age child had been identified (through a special education certification of Autism Spectrum Disorder) as having an ASD. The primary data collection tool was six surveys that measure parent demographic characteristics, child characteristics including severity of disability, parental sense of coherence, uncertainty related to a family member's ASD, social support, personal and family system resources, parental locus of control, and a measure of family quality of life

Participants

The participants in this study were the primary caregivers of children diagnosed with ASD. These caregivers typically were either the mother or father of the child or a person who has custody of the child. The inclusion criteria included: parents must have a child diagnosed with ASD, the child must be enrolled in an educational setting, and parents must be able to read and comprehend English. The type of ASD diagnosis will not be a factor in either exclusion or inclusion in the study.

Sample

Parents who are members of the Autism Society of Oakland County were asked to participate in the study. The Autism Society of Oakland County has been in existence since 1985 and currently has 1,638 registered members. The members of this organization have at least one child diagnosed with ASD. The President of the organization gave permission to solicit the members to participate in the study. The members were sent a link to the survey which will be available for completion on SurveyMonkey.

Sample size.

To determine the appropriate sample size for the study, G*Power 3.1 was used. For a regression equation with six predictor variables, an effect size of .15, an alpha level of .05, and a power of .80, a sample of 98 participants is needed. Additional participants will increase the power of the analysis, with a sample of approximately 150 increasing the power to .95. Figure 3 presents the graphical representation of the number of participants at various levels of power.

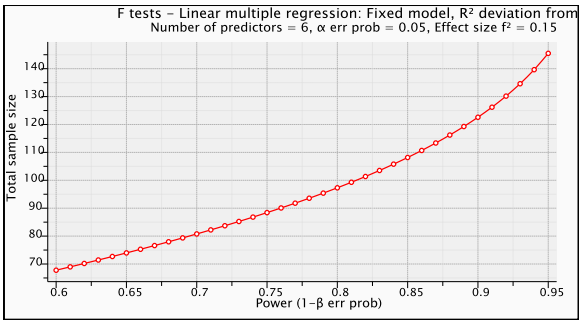

Figure 3: Power Analysis

Variables in the Study

Family adaptation.

The family's quality of life as perceived by the caretaker to a family member's ASD was the outcome of focus in this study. Family quality of life has been defined as the extent to which the family's needs are met, family members are able to do things that are important to them, and family members enjoy their life together as a family (Park et al., 2003; Turnbull, Turbiville, & Turnbull, 2000).

Measures.

Six instruments were administered to all participants via email in a single packet along with a demographic survey. The variables measured for this study included: child characteristics including severity of disability, parental sense of coherence, uncertainty related to a family member's ASD, social support, personal and family system resources, parental locus of control, and a measure of family quality of life.

Demographic survey.

A demographic survey was designed to gather information on marital status, parent's age and gender, child's specific diagnosis within the spectrum of ASD, living arrangements, and a measure of personal and family system resources, including socioeconomic status and parent's level of education. The items on this survey used a forced-choice format to provide consistent responses for each item.

Family quality of life.

This study used the Family Quality of Life Survey (FQOL; Beach Center on Disability, 2003, 2005). The FQOL is a 25-item measure that assesses the quality of life of families of individuals with disabilities. The survey consists of five subscales: (a) family interaction, (b) parenting, (c) emotional well-being, (d) physical/material well-being, and (e) disability-related support. While scores can be reported either in aggregate or for each subscale, the present study used the total FQOL score. While the FQOL asks participants to rate both the importance of, and satisfaction with, a particular item, satisfaction is the primary response format and can be used alone (Wang et al., 2004). An example of an item is "My family enjoys spending time together."

Scoring. For this study, the satisfaction ratings were used to generate a total FQOL satisfaction score, with higher scores reflecting greater satisfaction with family quality of life. The items are rated using a 5-point Likert scale, ranging from 1 for very dissatisfied to 5 for very satisfied. The numeric responses were summed to obtain a total score, which can range from 25 to 125.

Reliability and validity. Overall, the FQOL has demonstrated good psychometric properties. Cronbach's alpha coefficients for the FQOL were reported to be 0.94 for the Importance ratings and 0.88 for the Satisfaction ratings (Hoffman,

Marquis, Poston, Summers, & Turnbull, 2006). Support for the convergent validity of satisfaction on the overall FQOL and subscales of the FQOL has been reported. The FQOL was found to correlate ($p < .001$) with relevant existing measures, including the Family APGAR scale that measures adaptation, partnership, growth, affection, and resolve. The Family Resource Scale that measures family resources was significantly correlated ($p < .001$) with the items on the Physical/Material Well-Being subscale (Hoffman et al., 2006). Additionally, Wang et al. (2006) tested the stability of this measure across mothers and fathers and found that both mothers and fathers had statistically identical ratings of both importance and satisfaction, and thus concluded that a single parent's scores may be used as representative of family scores in situations in situations where scores of other family members would be difficult to collect (Wang et al., 2006).

Control of mastery.

Family beliefs are beliefs that family members hold about a family member's health condition. These beliefs are thought to directly and indirectly influence the adaptation, coping, and resilience of families (e.g., Lazarus & Folkman, 1984; McCubbin & McCubbin, 1993; Roland, 1994). Specifically, two family beliefs were selected for this current study: control and mastery. Control beliefs are defined as the beliefs that individuals hold regarding their personal influence over the course or outcome of their family member's ASD. Mastery beliefs encompass the extent to which individuals feel their lives are comprehensible, manageable, and meaningful. Measures operationalizing these concepts are described as follows.

Control.

This study used the Multidimensional Health Locus of Control scale – Form C

(MHLC-C; Wallston, Wallston, & DeVellis, 1978; Wallston, Stein, & Smith,1994) to operationalize the concept of control beliefs. The MHLC-C is one of a series of scales that assess individual's health-related control beliefs. The MHLC-C is designed to assess an individual's locus of control beliefs regarding an existing illness or disease, rather than general health beliefs (Wallston, 2005). The MHLC-C is comprised of 18 items that reflect four dimensions or subscales: (a) internal health locus of control (i.e., HLCInt); (b) chance health locus of control (i.e., HLCExt); (c) doctors/professionals (i.e., HLCP); and (d) other people (i.e., HLCO). Chance, doctors/professionals, and other people reflect subtypes of external health locus of control.

The MHLC-C was selected for this study specifically because it is a generic, easily modifiable scale created specifically to assess a variety of illnesses or disabilities (Wallston, 2005). Accepted language substitutions include exchanging the word "condition" with the specific illness or disability, and exchanging "powerful others" for either "doctors" or "professionals" depending on the condition (Wallston, Stein, & Smith, 1994). For this study, the MHLC-C was adapted to reflect the experience of families of individuals diagnosed with an ASD. Using the recommendations of Wallston and colleagues (Wallston, Stein, & Smith, 1994), the word 'condition' was replaced with 'autism spectrum disorder' and 'powerful others' was replaced by 'professionals.'

Sample items include "Other people [Professionals] play a big role in whether my child's autism spectrum disorder improves, stays the same, or gets worse" and "Following professionals' advice to the letter is the best way to keep my child's condition [autism spectrum disorder] from getting worse." Table 1 presents the subscales and items included on each subscale.

Table 1

Multidimensional Health Locus of Control (Form C) Subscales

Subscale	Items	Possible Scores*
Internal	1, 6, 8, 12, 13, 17	6 – 36
Chance	2, 4, 9, 11,15, 16	6 – 36
Doctors	3, 5, 14	3 – 15
Other People	7, 10, 18	3 – 15

Higher scores indicate greater agreement with the subscale.

Scoring. The 18 items on the MHLC-C are rated using a 6-point Likert scale ranging from 1 for strongly disagree to 6 for strongly agree. The items on each subscale are summed to create a summed score, Scores are calculated for each subscale, with higher scores indicating greater attribution of control to that particular source. While scores of the four dimensions often have been used separately (e.g., internal v. chance), others have begun to include interactions between dimensions (e.g., high internal & high powerful others; Green, 2004). Higher scores on each of the subscales indicate greater agreement with the subscale.

Reliability and validity. The MHLC-C is considered to be reliable, with Cronbach alphas for the subscales ranging between 0.70 – 0.87 (Wallston, Stein, & Smith, 1994). Strong evidence for convergent, construct, and criterion-related validity has been reported (Wallston, 2005). Specifically, Wallston and colleagues note that concurrent validity was established with the original MHLC-B since the MHLC-C subscales correlated with their respective subscale counterparts in the MHLC-B: the correlations between Form B and Form C subscales did not exceed 43% shared variance (Wallston, Stein, & Smith, 1994). Wallston and colleagues (Wallston, Stein, & Smith, 1994) also reported that significant relationships exist between the subscales of

the MHLC-C and corresponding subscales on the Levenson locus of control scale (Levenson, 1973). Wallston and colleagues further report that predicted correlations exist between the MHLC-C and the distinct, but related constructs of helplessness and depression (Wallston, Stein, & Smith, 1994).

Mastery.

This study used the short version of the Orientation to Life Questionnaire, also known as the Sense of Coherence Scale (SOC-13; Antonovsky, 1987; Antonovsky & Sourani, 1988) to operationalize the concept of mastery beliefs. The SOC-13 is a 13-item scale that rates individuals' sense of the comprehensibility, manageability and meaningfulness of that person's life events and is thus congruent with the definition of mastery that will be utilized in this study. Since this study will only use the total SOC score, using the SOC-13 over the SOC-29 is warranted. Higher total scores reflect greater sense of coherence. Sample items of the scale include, 'How often do you have feelings that you're not sure you can keep under control?' and 'How often do you have the feeling that there's little meaning in the things you do in your daily life?'

Scoring. Respondents are asked to rate the extent to which they endorse the 13 statements on a seven-point Likert scale, from (1) 'very often' to (7) 'very seldom' or 'never.' Unlike the full version SOC (SOC-29), the short version is only used to gain a total score and should not be used for subscale scores. Possible scores on this scale could range from 13 to 91.

Reliability and Validity. The SOC-13 has shown good psychometric properties in previous studies. In a systematic review of the reliability of the SOC-13, Eriksson and Lindstrom found that across 127 studies, Cronbach's alphas ranged from 0.70 to 0.92 and test-retest correlations ranged from 0.69 to 0.78 (Eriksson & Lindstrom, 2005). In

124 studies using SOC-29, the Cronbach's α ranged from 0.70 to 0.95 (Eriksson & Lindstrom, 2005). Test-retest correlation show stability and range from 0.69 to 0.78 (1 year), 0.64 (3 years), 0.42 to 0.45 (4 years), 0.59 to 0.67 (5 years) to 0.54 (10 years). The means of SOC-29 ranged 100.50 (SD 28.50) to 164.50 (SD 17.10) points and SOC-13 from 35.39 (SD 0.10) to 77.60 (SD 13.80) points (Erikkson & Lindstrom, 2005).

Evidence of the validity of the full SOC-29 and the short form SOC-13 includes moderate to good correlations with scores on related constructs, including measures of health and well- being (e.g., General Health Questionnaire, Health Index, Hopkin's Symptom Checklist, Mental Health Inventory), depression, anxiety, and self-esteem (Eriksson & Lindstrom, 2005).

Demand factors.

Demand factors are factors that place stress or strain upon the family and challenge the family's overall functioning. Three demand factors were selected for this current study: uncertainty, perceived stress, and perceived severity of an individual's ASD. Uncertainty encompasses the extent to which the participant is able to predict what will happen to their child, what consequences are associated with a diagnosis of ASD, and what the diagnosis of ASD means. Perceived stress includes how the individual perceives their stress levels and the relationship between stress and pathology. Perceived severity encompasses the extent to which the participant views the functional or behavioral symptoms of their child's ASD as problems. Measures operationalizing these concepts are described as follows.

Uncertainty.

This study used the Parent Perception of Uncertainty Scale (PPUS; Mishel, 1983), also known as the Mishel Uncertainty in Illness Scale – Parent/Child Form, to

operationalize the concept of uncertainty. The PPUS is a 31-item scale that is designed to measure the amount of uncertainty a parent has about their child's illness or other health related condition. Uncertainty encompasses four factors: ambiguity, lack of clarity, lack of information, and unpredictability. Ambiguity refers to the absence or vagueness of information regarding the planning and carrying out of care for the child (Mishel, 1997). Lack of clarity refers to the extent to which information about the child's treatment and the system of care is perceived as intricate and ill-defined (Mishel, 1997). Lack of information refers to the absence of information concerning the diagnosis and seriousness of the illness or condition (Mishel, 1997). Unpredictability refers to the inability to make daily or future predictions concerning the condition's symptomatology and outcome (Mishel, 1997).

The PPUS has been used to assess parental uncertainty within populations faced with a variety of health-related conditions, including Spina Bifida, cystic fibrosis, cancer, multiple sclerosis, irritable bowel syndrome, and various mental health issues (Mishel, 1997). Mishel provides guidelines for limited language substitution so as to better reflect a specific condition. For example, Mishel notes that items referring to 'pain' can be changed to 'symptoms' or the specific symptom most prevalent in the condition being addressed (Mishel, 1997). For this study, these guidelines were used to adapt the PPUS to better reflect ASDs. Specifically, the word 'illness' was changed to 'autism spectrum disorder,' the word 'pain' was changed to 'symptom,' and 'doctor' to 'professional.' Sample items include "The purpose of each treatment is clear to me" and "I can depend on the professionals working with my child to be there when I need them."

Scoring. Respondents rate items on the PPUS using a 5-point scale ranging from (1) strongly disagree to (5) strongly agree. Scores from the four factors of the

PPUS (i.e., ambiguity, lack of clarity, lack of information, and unpredictability) can be reported separately from each other. The PPUS also yields a total uncertainty score that is the sum of all dimensions. The possible range of total scores is from 31 to 155, with higher scores indicating greater uncertainty. For this study, only the total uncertainty score was used.

Reliability and validity. Psychometric data for the PPUS note coefficient alphas for specific factors to be in the moderate to high range (coefficient alpha = .67 - .89) (Mishel, 1997). In addition, the PPUS total scale is reported to have high internal consistency (.91) and strong reliability (.86 to .93) (Carpentier, Mullins, Chaney, & Wagner, 2006; Mishel, 1983). Face validity of Mishel's uncertainty scales was established by a group of doctors, nurses, and medical and surgical patients who checked the wording of the questions (Mishel, 1997). Factor analysis of the PPUS also supports its construct validity (Mishel, 1983, 1997). In addition, a significant positive relationship between uncertainty and a parent's judgment of the seriousness of their child's illness ($r = .16$, $p<.004$) supports the predicted relationship between these variables and further supports the construct validity of the PPUS (Mishel, 1983).

Studies of related Mishel uncertainty scales (i.e., MUIS, MUIS-C) also provide support for the validity of this group of scales. For example, the Mishel Uncertainty in Illness Scale (MUIS), a similar scale that measures the individual's own level of uncertainty regarding their health condition, distinguishes between groups of individuals in the diagnostic phase of an illness, a time when uncertainty is expected to be heightened, and groups with an established diagnosis, a time when uncertainty is expected to exist at a lesser level ($F(2,250)=23.97$, $p\leq.001$) (Mishel, 1981). Uncertainty has been shown to significantly correlate with ratings of stress in hospitalized medical

patients (r = .35, p<.001) and with lack of comprehension in cancer patients on their first day of treatment (r = -.56, p<.002), confirming predictions about uncertainty and these theoretically-related constructs (Mishel, 1981).

Severity.

This study used the Parental Concerns Questionnaire (PCQ; McGrew et al., 2007) to operationalize the concept of perceived severity of an individual's ASD. The PCQ is a 13-item questionnaire that assesses the perceived severity of core diagnostic and associated psychiatric symptomatology of ASDs, including language use, sleep disturbance, aggression, and self-injurious behavior. Each symptom is identified and a descriptor of that symptom is provided. For example, for the symptom of "anxiety," a sample descriptor is "shows distress from new situations or crowds." This questionnaire was developed based on problems reported in the ASD literature, as well as on the types of problems commonly reported by families in clinical referrals. Thus, this questionnaire is not a diagnostic tool, but rather reflects issues families commonly face and define as problems. Since the literature notes a range of behavioral symptoms impacting the families of ASD individuals, including communication deficits, aggressive behaviors, self-injurious behaviors, etc., which go beyond the diagnostic criteria for specific ASD classifications, the PCQ provides a brief way in which to ascertain the parents' definition of ASD severity in terms of both diagnostic-specific deficits as well as related behavioral symptoms.

Scoring. Participants are asked to rate the 13 items in regard to the extent to which they consider a symptom to have been a problem within the previous month on the Parental Concerns Questionnaire (PCQ). The severity ratings are on a scale of 1 to 4, with (1) representing no problems, (2) representing mild problems, (3) representing

moderate problems, and (4) representing severe problems. The numeric ratings are summed to obtain a total score that could range from 13 to 42. Higher scores reflect greater perceived severity of presenting problems. Item by item analysis can be used, as well as a total PCQ score reflecting perceived severity of overall ASD symptoms. For this study, the overall score will be used as a measure of overall perceived severity of the individual's ASD.

Reliability and validity. The PCQ is reported to have good psychometric properties. Internal consistency, using Cronbach's alpha, is reported to range between 0.78 - 0.93 (McGrew et al., 2007). The validity of most of the PCQ items was established by demonstrating concordance between PCQ items and standardized assessment tools measuring the same domains, including the Child Behavior Checklist, the Child Sleep Habits Questionnaire, the Repetitive Behavior Scales – Revised, and the Autism Diagnostic Observation Schedule (McGrew et al., 2007). Of the items that did not demonstrate significant correlation with the comparative assessment tools (i.e., social interactions, aggression, mood swing), McGrew and colleagues suggest that this may be the result of sample size effect and restricted range of the ASD group (i.e., all relatively high functioning receiving no medications) (McGrew et al., 2007).

Perceived Stress.

This study used the Perceived Stress Scale (PSS; Cohen et al., 1983) to operationalize the concept of perceived stress. The PSS is a 14-item questionnaire that assesses the degree to which situations in which one's life are appraised as stressful. Participants are asked to respond to the items regarding their thoughts or feelings during the last month and indicate "how often" they have felt a certain way. This questionnaire was developed based on the argument that a psychometrically sound

global measure of perceived stress could provide valuable additional information about the relationship between stress and pathology.

Scoring. Participants were asked to rate the 14 items in regard to the how often the respondent has “felt or thought a certain way” within the previous month on the Perceived Stress Scale (PSS) using a 4-point scale ranging from 0 to 4, with (0) representing never, (1) representing almost never, (2) representing sometimes, (3) representing fairly often, and (4) representing very often. The numeric ratings are summed to obtain a total score that could range from 0 to 56. The total score is divdied by 14 (the number of items on the survey) to obtain a mean score that reflects the original scoring range. Higher scores reflect greater perceived stress.

Reliability and validity. The PSS was tested for internal consistency using three samples of college students (Cohen et al., 1983). The Cronbach alpha coefficients ranged from .84 to .86, indicating good internal consistency. Test retest coefficients was .85 at a two-day interval. The coefficient decreased to .55 for students who were tested at six-week intervals.

Validity was assessed by correlating scores on the PSS and number of life events and the impact on those events. The correlations, while statistically significant, were generally low to moderate. Low to moderate correlations in a positive direction were obtained for both physical and depressive symptomatology, indicating scores on the PSS increased with higher levels of symptomatology. These findings provided support that the PSS had adequate validity for measuring stress.

Procedures

After obtaining approval to conduct the study from Wayne State University Internal Review Board (IRB), the researcher began the data collection process. She

contacted the President of the Autism Society of Oakland County to determine how best to provide the link to SurveyMonkey to the membership. It was determined that it was best to put the link on the Autism Society's website, to publish it in the newsletter to the members, and to post the link on the Autism Society's Facebook page.

The survey was retyped into SurveyMonkey. The first page was the Research Information Sheet, which included the purpose of the study, the criteria for inclusion, the voluntary nature of participation, assurances of confidentiality, and instructions for submitting the survey. Participants had to check the agree button to continue to the survey. If at any time, the participant decides he/she did not want to continue in the study, they could discontinue and their information was deleted. After completing the survey, the members had to click the submit button. The participants were told that the researcher would make a $2.00 donation to the Autism Society of Oakland County for every completed survey that was submitted. The purpose of the donation was to encourage the members to participate.

Two weeks after the initial placement of the survey link on the website, the researcher posted a reminder notice and asked all members who met the inclusion criteria to participate. The data collection continued for an additional two weeks.

Data Analysis

The data from SurveyMonkey was downloaded into an Excel file for review after the data collection was completed. The data was transferred to IBM-SPSS ver. 21 for analysis. The first step of the analysis was a review of the data to eliminate any cases that did not met the criteria for inclusion. The cases were examined to determine the completeness of the data. If a participant left more than one scale unanswered, his/her responses were eliminated. A missing values analysis was conducted to determine the

extent of missing data. If less than 10% of the values were missing on a variable, the mean score for that variable were used to replace the missing values. If more than 10% of the values are missing, the variable may have been eliminated.

The data analysis was divided into three sections. The first section will use frequency distributions and measures of central tendency and dispersion to provide a profile of the participants. The second section will use descriptive statistics to provide baseline information about the scaled variables. The second section also included an intercorrelation matrix to describe the relationships among the variables. Inferential statistical analyses will be included in the third section of the chapter. These analyses will include stepwise multiple linear regression analysis and Baron and Kenny's mediation analyses procedures. All decisions on the statistical significance of the findings will be made using a criterion alpha level of .05. Table 2 presents the data analyses that will be used to test each hypothesis.

Table 2

Research Questions, Hypotheses, and Statistical Procedures

Research Questions and Hypotheses	Variables Under Investigation	Statistical Analysis
Q1: Can family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control? H_1: Family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control.	Criterion Variable: Family Adaptation Predictor Variables: Family Demographics • parents' ages • number of children • number of children diagnosed with ASD • socioeconomic status • Caregiver demands • Stress • Locus of control • Sense of coherence	Stepwise multiple linear regression analysis will be used to determine which of the predictor variables can be used to predict family adaptation
Q2: Will caregiver sense of control (locus of control, and sense of coherence) mediate the relationship between uncertainty and family adaptation? H_2: Caregiver sense of control will mediate the relationship between uncertainty and family adaptation.	Criterion Variable: Family adaptation: Family quality of life Predictor Variables: Uncertainty Mediating Variable: Parents' beliefs: Sense of coherence Locus of control	Mediation analysis using Baron and Kenny's (2013) four-step approach will be used to determine if the relationships between the criterion and predictor variables are mediated by parent beliefs, sense of coherence, and locus of control. The mediation analysis will use the four-step process developed by Baron and Kenny (2011): 1. Determine if the predictor variable is significantly related to the criterion variable 2. Determine if the predictor variable is significantly related to the mediating variable 3. Determine if the mediating variable is significantly related to the criterion variable 4. Determine the change in the relation between the predictor variable and the criterion variable while holding

Research Questions and Hypotheses	Variables Under Investigation	Statistical Analysis
		the mediating variable constant. If the relation between the predictor and criterion variable becomes non-significant when holding the mediating variable constant, the result is a full mediation
Q3: Will caregiver sense of control (locus of control, and sense of coherence) mediate the relationship between severity of ASD and family adaptation? H_3: Caregiver sense of control will mediate the relationship between severity of ASD and family adaptation.	<u>Criterion Variable</u>: Family adaptation: Family Quality of Life <u>Predictor Variables:</u> Perceived severity of disability <u>Mediating Variable</u>: Parents' beliefs: Sense of coherence Locus of control	Mediation analysis using Baron and Kenny's (2013) four-step approach will be used to determine if the relationships between the criterion and predictor variables are mediated by parent beliefs, sense of coherence, and locus of control. The mediation analysis will use the four-step process developed by Baron and Kenny (2011): 1. Determine if the predictor variable is significantly related to the criterion variable 2. Determine if the predictor variable is significantly related to the mediating variable 3. Determine if the mediating variable is significantly related to the criterion variable 4. Determine the change in the relation between the predictor variable and the criterion variable while holding the mediating variable constant. If the relation between the predictor and criterion variable becomes non-significant when holding the mediating variable constant, the result is a full mediation

CHAPTER 4

RESULTS OF DATA ANALYSIS

The results of the data analysis used to describe the sample and address the research questions and associated hypotheses are presented in this chapter. The chapter is divided into three sections. The first section provides a description of the sample using frequency distributions and measures of central tendency and dispersion. The statistics on the scaled variables are presented in the second section along with an intercorrelation matrix of the independent and dependent variables. The results of the inferential statistical analyses are presented in the third section of the analysis.

The purpose of this study was to explore how caretakers of children with an Autism Spectrum Disorder (ASD) are able to move through an adverse set of circumstances with which they are confronted while raising a child with considerable developmental needs and challenges, demonstrating resilience. Parents of children diagnosed with ASD who belong to the Autism Society of Oakland County were asked to participate in the study.

The link to the survey on SurveyMonkey was sent to the Autism Society of Oakland County. A total of 209 surveys were completed and submitted. After reviewing the data and eliminating surveys with extensive missing data (n = 55) or ones whose children were too old for inclusion (n = 1), a total of 153 surveys were included in the data analysis. If a survey had one or more of the scales missing, it was excluded from the study. In addition, if the parents did not meet the criteria for inclusion in the study, they were also excluded. For example, the children diagnosed with ASD had to be enrolled in an educational setting at the time of the study. If the child was not in an educational setting, the parent's responses were eliminated from the study.

A missing values analysis was used to determine the number of missing values for each of the included variables. If less than 10% of the values were missing, the mean value for the scale was used to replace the missing value. Table 3 presents results of this analysis.

Table 3

Missing Values Analysis

Variable	Number of Missing Responses	Percent
Locus of Control		
Internal	1	0.7
Chance	1	0.7
Doctors	1	0.7
Other people	1	0.7
Perceived stress	3	2.0
Perceived severity	2	1.3
Orientation to life	2	1.3
Parents' perception of uncertainty	2	1.3
Family quality of life	3	2.0

The percentages of missing responses on each of the scales ranged from 0.7% (Subscales on locus of control) to 2.0% (Perceived stress and family quality of life). As these percentage were 2.0% or less, the missing values were replaced with the mean of the subscales.

Reliability

Cronbach alpha coefficients were obtained for each of the subscales with the sample used in the study. The results of these analyses are presented in Table 4.

Table 4

Cronbach Alpha Coefficients

Scale	Alpha Coefficient
Multidimensional health locus of control	
Internal	.37
Chance	.61
Doctors	.46
Others	.35
Perceived stress	.72
Orientation to life	.29
Uncertainty	.89
Family quality of life	.95
Perceived Severity	.81

The alpha coefficients for the multidimensional health locus of control ranged from .35 for “others” to .61 for “chance.” A low alpha coefficient also was obtained for the orientation to life scale (α = .29). The alpha coefficients for the remainder of the instruments ranged from .72 to perceived stress to .95 for family quality of life, providing support that these instruments had adequate to excellent internal consistency as a measure of reliability.

Description of the Sample

The parents provided information about their personal characteristics on the survey. Their responses were summarized using frequency distributions. Table 5 presents results of this analysis.

Table 5

*Frequency Distributions – Parents' Personal Characteristics (*N = *153)*

Personal Characteristic	Number	Percent
Age		
18 to 24	1	0.7
25 to 34	31	20.3
35 to 44	69	45.0
45 to 54	43	28.1
55 to 64	9	5.9
Gender		
Female	144	94.1
Male	9	5.9
Ethnicity		
African American	1	0.7
American Indian/Alaskan Native	1	0.7
Asian/Pacific Islander	5	3.3
Caucasian	135	88.1
Hispanic	4	2.6
Middle Eastern	1	0.7
Multi-ethnic	6	3.9
Socioeconomic Status		
Lower Middle	9	6.2
Middle	26	17.9
Upper Middle	64	44.2
Upper	46	31.7
Missing 8		

The largest group of participants (n = 69, 45.0%) were between 35 and 44 years of age, with 43 (28.1%) of the parents reporting their ages were between 45 and 54 years. One (0.7%) parent indicated his/her age was between 18 and 24 years. The majority of the participants (n = 144, 94.1%) was female. Most of the participants (n = 135, 88.1%) indicated their ethnicity as Caucasian. The largest group of participants (n = 64, 44.2%) had an upper middle socioeconomic status, followed by upper status (n = 46, 31.7%. The mean family socioeconomic status was 47.38 (SD = 10.75), with a range from 20 to 66. None of the participants had educational levels and occupations

that would be considered lower socioeconomic status. Data to calculate socioeconomic status were missing for eight participants.

The participants were asked to indicate their relationship to the child with ASD. The responses were summarized using frequency distributions for presentation in Table 6.

Table 6

*Frequency Distributions – Relationship to the Child with ASD (*N = *153)*

Relationship to child with ASD	Number	Percent
Biological mother	140	91.5
Biological father	6	3.9
Stepmother	2	1.3
Foster mother	2	1.3
Adoptive mother	2	1.3
Stepfather	1	0.7

The majority of the participants (n = 140, 91.5%) reported they were the biological mother of their child diagnosed with ASD. Six (3.9%) of the participants indicated they were the biological father of the child. Two (1.3%) participants each indicated they were the stepmother, foster mother, or adoptive mother of the child diagnosed with ASD. One (0.7%) respondent reported his relationship was as the stepfather.

The parents were asked to indicate the total number of children and the number of children with ASD in their families. Frequency distributions were used to summarize their responses. Table 7 presents results of this analysis.

Table 7

*Frequency Distributions – Number of Children and Number of Children Diagnosed with ASD (*N = *153)*

Children in Family	Number	Percent
Number of Children in Family		
One	46	30.3
Two	60	39.4
Three	36	23.7
Four	7	4.6
Five	2	1.3
Eight	1	0.7
Missing 1		
Number of Children Diagnosed with ASD		
One	141	92.8
Two	11	7.2
Missing 1		

The largest group of participants (n = 60, 39.4%) reported they had two children, with 46 (30.3%) indicating they had one child. Thirty-six (23.7%) participants had three children, with 10 parents reporting they had four (n = 7, 4.6%), five (n = 2, 1.3%), and eight (n = 1, 0.7%) children. One participant did not provide a response to this question.

The majority of parents in the study (n = 141, 92.8%) had one child diagnosed with ASD, with 11 (7.2%) reporting they had two children with this diagnosis. One parent did not provide a response to this question.

The parents were asked to provide information about the child's personal characteristics. Their responses were summarized using frequency distributions for presentation in Table 8.

Table 8

*Frequency Distributions – Personal Characteristics of Children Diagnosed with ASD (*N *= 153)*

Personal Characteristic of Child with ASD	Number	Percent
Gender		
Male	127	83.6
Female	25	16.4
Missing 1		
Ethnicity		
African American	1	0.7
American Indian/Alaskan Native	0	0.0
Asian/Pacific Islander	6	3.9
Caucasian	133	86.9
Hispanic	4	2.6
Middle Eastern	1	0.7
Multi-ethnic	8	5.2
Child with ASD Lives at Home		
Yes	145	96.0
No	6	4.0
Missing 2		

The majority of the participants (n = 127, 83.6%) were male, with 25 (16.4%) parents indicating their child with ASD was female. One parent did not provide a response to this question. Most of the participants indicated their child with ASD was Caucasian (n = 133, 86.9%), followed by Asian/Pacific Islander (n = 6, 3.9%). Eight (5.2%) parents indicated their child was multi-ethnic. The largest group of children with ASD were living at home (n = 145, 96.0%), with 6 (4.0%) reporting their child with ASD was living elsewhere. Two parents did not provide a response to this question.

The parents were asked to report the age of their child with autism at time of diagnosis and at the present time. Descriptive statistics were used to summarize these ages for presentation in Table 9.

Table 9

*Descriptive Statistics – Ages of Children at Diagnosis and Presently (*N = *153)*

					Range	
Age	Number	Mean	SD	Median	Minimum	Maximum
At Time of Diagnosis	148	4.45	3.10	3.25	1.00	18.00
At Time of Study	144	10.84	5.52	10.00	1.50	25.00

Missing At time of diagnosis 5
At time of study 10

The mean age of the children at the time of their diagnosis with ASD was 4.45 (SD = 3.10) years, with a median of 3.25 years. The range in ages for age at the time of their diagnosis ranged from 1 to 18 years. Five participants did not provide a response to this question.

The participants' age at the time of the study ranged from 1.50 (18 months) to 25 years. The mean age at the time of the study was 10.84 (SD = 5.52) years, with a median of 10.00 years. Ten participants did not provide a response to this question.

The parents were asked to provide information regarding their child's diagnosis. Their responses summarized using frequency distributions. Table 10 presents results of this analysis.

Table 10

*Frequency Distributions – Diagnosis of ASD (*N = *153)*

Diagnosis of ASD	Number	Percent
Type of ASD diagnosis		
Autism	97	63.4
Asperger's Syndrome	34	22.2
PDD-NOS	22	14.4
Additional diagnoses		
ADHD	2	1.4
ADHD and Depression	1	0.7
Aphasia/Apraxia	1	0.7
Bipolar	1	0.7
Deafness	1	0.7
Epilepsy and Arthritis	1	0.7
OCD/ADHD	1	0.7
Functioning level		
High functioning/mild autism	59	38.6
Moderately high functioning/mild to moderate autism	38	24.8
Moderate functioning/moderate autism	23	15.0
Moderately low functioning/moderate to severe autism	16	10.5
Low functioning/severe autism	14	9.2
Don't know	3	2.0
Received Services before three years of age		
Yes	76	49.7
No	77	50.3
Relationship with school professionals		
Very positive	51	33.6
Positive	58	38.1
Neutral	19	12.5
Negative	7	4.6
Very negative	7	4.6
Not Applicable	10	6.6
Missing 1		

The majority of the children had been diagnosed with autism (n = 97, 63.4%), with 34 (22.2%) diagnosed with Asperger's syndrome. Twenty-two of the children in the study had a diagnosis of pervasive development disorder – not otherwise specified (PDD-NOS). Eight children had additional diagnoses, including ADHD (n = 2, 1.4%), ADHD and depression (n = 1, 0.7%), aphasia/apraxia (n = 1, 0.7%), bipolar (n = 1,

0.7%), deafness (n = 1, 0.7%), epilepsy and arthritis (n = 1, 0.7%), and OCD/ADHD (n = 1, 0.7%).

The children's functioning levels ranged from high functioning/mild autism (n = 59, 38.6%) to low functioning/sever autism (n = 14, 9.2%). Thirty-eight (24.8%) of the parents reported their children had moderately high functioning/mild to moderate autism, while 23 (15.0%) parents rated their child as having moderate functioning/ moderate autism. Sixteen (10.5%) parents indicated their child was moderately low functioning/moderate to severe autism. Three (2.0%) parents did not know their child's functioning level.

The parents were asked if their child had received services prior to three years of age. Seventy-six (49.7%) parents reported yes. The majority (n = 59, 77.63%) of parents that reported yes indicated speech therapy as the early intervention service they received for their child. Other services received included occupational therapy (n = 47, 61.84%), physical therapy (n = 15, 19.74%), and applied behavior analysis (n = 15, 19.74%). Other early intervention services received by parents for their children on a lesser scale (two or less parents reported) included: Early On social skill groups, special education preschool, tokens system approach, play therapy, floor time, and sensory integration.

When asked about their relationship with school personnel, specifically the individualized educational program (IEP) team, 51 (33.6%) parents reported they had very positive relationships, with 58 (38.1%) parents indicating their relationships with school personnel was positive. Nineteen (12.5%) parents were neutral about their relationships with school personnel and 7 (4.6%) were either negative or very negative about their relationships with school personnel. Ten (6.6%) parents indicated not

applicable as their response to this question. One parent did not provide a response to this item.

The socioeconomic status of the parents was crosstabulated by the number of parents who reported their child with ASD had received services before three years of age. The results of this analysis are presented in Table 11.

Table 11

Crosstabulations – Receive Services before Three Years of Age by Family Socioeconomic Status

	Received Services Before Three Years of Age					
	No (n = 76)		Yes (n = 77)		Total	
Socioeconomic Status	n	%	n	%	N	%
Lower Middle	3	4.2	6	8.1	9	6.2
Middle	13	18.3	13	17.6	26	17.9
Upper Middle	27	38.0	37	50.0	64	44.2
Upper	28	39.5	18	24.3	46	31.7
Total	71	100.0	74	100.0	145	100.0
χ^2 (3) = 4.68, p = .197						
Age at Diagnosis						
Three years and younger	23	30.7	51	69.9	74	50.0
Over 3 years of age	52	69.3	22	30.1	74	50.0
Total	75	100.0	73	100.0	148	100.0
χ^2 (1) = 22.73, p < .001						

Of the 74 children who had received services prior to three years of age, 37 (50.0%) were from families with upper middle class socioeconomic statuses, while 27 (38.0%) children in the families in this socioeconomic class had not received services prior to three years of age. Among the families in the upper socioeconomic status group, 18 (24.3%) had received services prior to three years of age and 28 (39.5%) had

not received these services. A chi-square test for independence was used to determine if an association existed between socioeconomic status and receiving services prior to three years of age. The results of this analysis were not statistically significant, χ^2 (3) = 4.68, p = .197, indicating no association between socioeconomic status and receiving services before three years of age.

Among the 75 children who had been diagnosed with ASD prior to or at 3 years of age, 51 (69.9%) had received services prior to 3 years. Twenty-three (30.7%) of these children had not received services prior to 3 years. In contrast, 22 (30.1%) children who had not been diagnosed with ASD prior to 3 years had received services before 3 years of age. Fifty-two children diagnosed after 3 years had not received services prior to 3 years of age. The results of the chi-square test for independence was statistically significant, χ^2 (1) = 22.73, p < .001, indicating that an association existed between receiving services prior to 3 years of age and being diagnosed before 3 years of age.

Description of the Scaled Variables

The scales completed by the participants were scored using the authors' protocols. Descriptive statistics were used to summarize the mean scores for each of the included scales and subscales. Table 12 presents results of this analysis.

Table 12

Descriptive Statistics – Scaled Variables

					Actual Range		Possible Range	
Scale	N	M	SD	Median	Minimum	Maximum	Minimum	Maximum
Locus of control								
Internal	153	3.09	.73	3.17	1.00	4.57	1.00	6.00
Chance	153	3.10	.83	3.17	1.00	4.83	1.00	6.00
Doctors	153	2.68	1.01	2.67	1.00	5.33	1.00	6.00
Other people	153	2.56	.92	2.67	1.00	5.33	1.00	6.00
Perceived stress	153	2.44	.66	2.50	1.20	4.20	1.00	5.00
Perceived severity	153	2.60	.57	2.60	1.15	4.00	1.00	4.00
Orientation to life	153	4.34	.53	4.34	3.00	6.38	1.00	7.00
Uncertainty in illness	153	3.20	.59	3.17	1.97	4.73	1.00	5.00
Family quality of life	153	3.75	.69	3.84	1.12	5.00	1.00	5.00

Four subscales, internal, chance, doctors, and other people were used to measure locus of control. The mean score for internal was 3.09 (sd = .73), with a median of 3.17. The possible range of scores was from 1.00 to 4.57, with possible scores ranging from 1.00 to 6.00. The actual scores for chance ranged from1.00 to 4.83, with a median score of 3.17. Possible scores could range from 1.00 to 6.00. The mean score for chance was 3.10 (sd = .83). Doctors had a mean score of 2.68 (sd = 1.01), with a median score of 2.67. The actual range of scores for doctors was from 1.00 to 4.83, with possible scores ranging from 1.00 to 6.00. A mean score of 2.56 (sd = .92) was obtained for the subscale, other people. The range of actual scores was from 1.00 to 5.33, with possible scores ranging from 1.00 to 6.00. Higher scores on this scale indicated greater attribution of control to that particular source.

The mean score for perceived stress was 2.44 (sd = .66), with a median of 2.50. Actual scores on this scale ranged from 1.20 to 4.20, with possible scores ranging from 1.00 to 5.00. Higher scores for perceived stress indicated greater stress.

The range of actual scores for perceived severity was from 1.15 to 4.00, with possible scores ranging from 1.00 to 4.00. The mean score for perceived severity was 2.60 (sd = .57), with a median of 2.60. Higher scores on perceived severity indicated greater perceived severity of presenting problem (i.e., ASD).

The orientation to life scale had a mean score of 4.34 (sd = .53), with a median score of 4.34. The range of actual scores was from 3.00 to 6.38, with possible scores ranging from 1.00 to 7.00. Higher scores on this scale reflect a greater sense of coherence.

The mean score for uncertainty in illness was 3.20 (sd = .59), with a median of 3.17. Actual scores ranged from 1.98 to 4.73, with possible scores ranging from 1.00 to 5.00. Higher scores on this scale indicated the amount on uncertainty a parent has about their child's illness or other health-related conditions.

Family quality of life had a mean score of 3.75 (sd = .69), with a median score of 3.84. The range of actual scores was from 1.12 to 5.00, with possible scores ranging from 1.00 to 5.00. Higher scores for family quality of life were reflective of greater satisfaction with family quality of life.

An intercorrelation matrix was used to examine the relationships among the scaled variables. Table 13 presents results of this analysis.

Table 13

Intercorrelation Matrix – Scaled Variables

	1	2	3	4	5	6	7	8	9
1	–								
2	.73**	–							
3	.58**	.58**	–						
4	.53**	.53**	.27**	–					
5	.26**	.26**	.28**	.33**	–				
6	-.14	-.09	-.09	-.16*	-.27**	–			
7	-.05	-.11	-.12	-.09	-.28**	.29**	–		
8	.05	.01	.07	.01	.23**	-.05	-.32**	–	
9	-.10	-.14	-.11	-.22**	-.38**	.24**	.38**	-.21**	–

*p ≤ .05; **p ≤ .01
Note:1 Locus of Control – Internal; 2 Locus of Control – Chance; 3 Locus of Control – Doctors; 4 Locus of Control – Other People; 5 Perceived Stress; 6 Orientation to Life (Sense of Coherence); 7 Uncertainty in Illness; 8 Perceived Severity; 9 Family Quality of Life

Statistically significant correlations were obtained between locus of control – internal and locus of control – chance (r = .73), locus of control – doctors (r = .58), locus of control – other people (r = .53), and perceived stress (r = .26). The correlations between locus of control – chance and locus of control – doctors (r = .58), locus of control – other people (r = .53), and perceived stress (r = .26) were statistically significant. Locus of control – doctors was significantly related to locus of control – other people (r = .27) and perceived stress (r = .28). Locus of control – other people was significantly related to perceived stress (r = .33), orientation to life (r = -.16), and family quality of life (r = -.22). The correlations between perceived stress and orientation to life (sense of coherence; r = -.27), uncertainty in illness (r = -.28), perceived severity (r = .23), and family quality of life (r = -.38) were statistically significant. Statistically significant correlations were found between orientation to life and uncertainty in illness (r = .29) and family quality of life (r = .24). The correlations between uncertainty in illness and perceived severity (r = -.32) and family quality of life (r = .38) were statistically

significant. The correlation between perceived severity and family quality of life (r = -.21) was statistically significant. The remaining correlations were not statistically significant.

Research Questions and Hypotheses

Four research questions and associated hypotheses were developed for the study. Inferential statistical analyses were used to address these questions, with all decisions on the statistical significance made using a criterion alpha level of .05.

Research Question 1: Can family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control?

H_1: Family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control.

A stepwise multiple linear regression analysis was used to determine if family quality of life could be predicted from the parents' ages, number of children, number of children diagnosed with ASD, socioeconomic status, locus of control (internal, chance, doctors, other), perceived stress, orientation to life, perceived severity, and uncertainty in illness. The results of this analysis are presented in Table 14.

Table 14
Stepwise Multiple Linear Regression Analysis – Family Quality of Life and Family Characteristics, Caregiver Demands, Stress, and Caregiver Sense of Control

Predictor Variables	Constant	b-Weight	β-Weight	Δ R^2	t-Value	Sig
Included Variables						
Uncertainty in illness	3.25	.38	.32	.15	4.49	<.001
Perceived stress		-.31	-.29	.07	-4.15	<.001
Age of parent		-.23	-.28	.05	-4.06	<.001
Average socioeconomic status		.02	.25	.06	3.63	<.001
Excluded Variables						
Number of children			.09		1.32	.189
Number of autistic children			-.06		-.87	.386
Locus of control – internal			-.06		-.80	.427
Locus of control – chance			-.06		-.91	.364
Locus of control – doctors			-.05		-.76	.452
Locus of control – others			-.08		-1.18	.240
Orientation to life			.12		1.71	.090
Perceived severity			-.08		-1.13	.260

Multiple R	.57
Multiple R^2	.33
F Ratio	18.18
DF	4, 148
Sig	<.001

Four predictor variables, uncertainty in illness, perceived stress, age of parent and average socioeconomic status, entered the stepwise multiple linear regression equation, accounting for 33% of the variance in family quality of life, $R^2 = .33$, $F (4, 148) = 18.18$, $p < .001$. Fifteen percent of the variance in family quality of life was explained by uncertainty in illness, $\beta = .32$, $t = 4.49$, $p < .001$. The positive relationship indicated that as scores for uncertainty in illness increased, family quality of life also increased. Perceived stress accounted for an additional 7% of the variance in family quality of life, $\beta = -.29$, $t = -4.15$, $p < .001$. The negative relationship between these variables provided support that caregivers who had less stress were more likely to have better family quality of life. Age of the parent entered the stepwise multiple linear regression equation first, accounting for 5% of the variance in family quality of life, $\beta = -.28$, $t = -4.15$, $p <$

.001. The negative relationship between the age of the parent and family quality of life indicated that younger parents tended to have better family quality of life. The average socioeconomic status of the family entered the stepwise multiple linear regression equation explaining an additional 6% of the variance in family quality of life, $\beta = .25$, $t = 3.63$, $p < .001$. The positive relationship indicated that families who had higher socioeconomic status were more likely to have a better family quality of life. The remaining variables, locus of control (internal, chance, doctors, and others), orientation to life, perceived severity, number of children and number of autistic children did not enter the stepwise multiple linear regression equation, indicating they were not statistically significant predictors of family quality of life.

Research Question 2: Will caregiver sense of control (locus of control, and orientation to life) mediate the relationship between uncertainty and family quality of life?

H_2: Caregiver sense of control will mediate the relationship between uncertainty and family quality of life.

A mediation analysis was used to determine if caregiver sense of control could be used to mediate the relationship between uncertainty and family quality of life. A mediation analysis is used to examine the effect of a third variable (mediating variable) on the relationship between a predictor and criterion variable. Because a causal relationship cannot be hypothesized between the predictor and criterion variable, a mediation analysis hypothesizes that the predictor variable is related to the mediator variable, which in turn is related to the criterion variable. Based on these relationships, the mediator variable is used to explain the relationship between the

predictor and criterion variables. Baron and Kenny's (2011) four-step mediation analysis was used to address this research question:

1. Determine if the predictor variable is significantly related to the criterion variable
2. Determine if the predictor variable is significantly related to the mediating variable
3. Determine if the mediating variable is significantly related to the criterion variable
4. Determine the change in the relation between the predictor variable and the criterion variable while holding the mediating variable constant.

If the relation between the predictor and criterion variable becomes non-significant when holding the mediating variable constant, the result is a full mediation.

A causal effect cannot be hypothesized between family quality of life (criterion variable) and perceived uncertainty (predictor variable). However, locus of control was thought to be related to perceived uncertainty and family quality of life. Examining the effects of control on the relationship between family quality of life and perceived uncertainty could provide additional explanation of this relationship.

The first mediation analysis used to test this hypothesis used family quality of life as the criterion variable and perceived uncertainty as the predictor variable. The subscale, internal, as a measure of locus of control was used as the mediating variable. Table 15 presents results of this analysis.

Table 15

Mediation Analysis – Mediating Effect of Internal Locus of Control on the Relationship between Uncertainty and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Perceived uncertainty	Family quality of life	.15	25.99	.38**
Step 2				
Perceived uncertainty	Internal locus of control	.01	.41	-.05NS

On the first step of the mediation analysis, perceived uncertainty was accounting for 15% of the variance in family quality of life, $R^2 = .15$, $\beta = .38$, $F = 25.99$, $p < .001$. The relationship between perceived uncertainty and internal locus of control was not statistically significant, $R^2 = .01$, $\beta = -.05$, $F = .41$, $p = .523$. Because of the nonsignificant finding on the second step, the mediation analysis could not be continued.

Chance, as a subscale of locus of control, was used as the mediating variable, with perceived uncertainty used as the predictor variable. Family quality of life was the criterion variable in this analysis. Table 16 presents results of this analysis.

Table 16

Mediation Analysis – Mediating Effect of Chance Locus of Control on the Relationship between Uncertainty and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Perceived uncertainty	Family quality of life	.15	25.99	.38**
Step 2				
Perceived uncertainty	Chance locus of control	.01	2.06	-.12NS

The relationship between perceived uncertainty and family quality of life, tested on the first step of the mediation analysis, was statistically significant, with uncertainty explaining 15% of the variance in family quality of life, $R^2 = .15$, $\beta = .38$, $F = 25.99$, $p < .001$. On the second step of the analysis, perceived uncertainty was not a statistically significant predictor of chance locus of control, $R^2 = .01$, $\beta = -.12$, $F = 2.06$, $p = .153$. Because of the nonsignicant result on the second step, the mediation analysis could not be continued.

A mediation analysis was used to determine if doctors as a subscale measuring locus of control was mediating the relationship between uncertainty and family quality of life. Table 17 presents results of this analysis.

Table 17

Mediation Analysis – Mediating Effect of Doctors Locus of Control on the Relationship between Uncertainty and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Perceived uncertainty	Family quality of life	.15	25.99	.38**
Step 2				
Perceived uncertainty	Doctors locus of control	.02	2.29	-.12NS

Perceived uncertainty explained 15% of the variance in family quality of life on the first step of the mediation analysis, $R^2 = .15$, $\beta = .38$, $F = 25.99$, $p < .001$. On the second step of the mediation analysis, the relationship between uncertainty and doctors, as a measure of locus of control, was not statistically significant, $R^2 = .02$, $\beta = -.12$, $F = 2.29$, $p = .133$. Based on the lack of a statistically significant finding on the second step, the mediation analysis could not be continued.

A mediation analysis was used to determine if other people, a subscale of locus of control, was mediating the relationship between uncertainty (predictor variable) and family quality of life (criterion variable). Table 18 presents results of this analysis.

Table 18

Mediation Analysis – Mediating Effect of Other People Locus of Control on the Relationship between Uncertainty and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Perceived uncertainty	Family quality of life	.15	25.99	.38**
Step 2				
Perceived uncertainty	Doctors locus of control	.01	1.21	-.09NS

On the first step of the mediation analysis, perceived uncertainty was explaining 15% of the variance in family quality of life, $R^2 = .15$, $\beta = .38$, $F = 25.99$, $p < .001$. The relationship between perceived uncertainty and doctors locus of control, tested on the second step of the mediation analysis, was not statistically significant, $R^2 = .01$, $\beta = -.09$, $F = 1.21$, $p = .273$. As a result of the nonsignificant finding on the second step, the mediation analysis could not be continued.

A mediation analysis was used to determine if sense of coherence was mediating the relationship between perceived uncertainty (predictor variable) and family quality of life (criterion variable). The results of this analysis are presented in Table 19.

Table 19

Mediation Analysis – Mediating Effect of Orientation to Life on the Relationship between Uncertainty and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Perceived uncertainty	Family quality of life	.15	25.99	.38**
Step 2				
Perceived uncertainty	Orientation to life	.08	13.58	.28**
Step 3				
Orientation to life	Family quality of life	.06	9.48	.24**
Step 4				
Orientation to life	Family quality of life	.06	9.48	.24**
Perceived uncertainty		.11	14.94	.34**
Sobel Test = 2.42, p < .001				

On step 1 of the mediation analysis, perceived uncertainty was accounting for 15% of the variance in family quality of life, $R^2 = .15$, $\beta = .38$, $F = 25.99$, $p < .001$. Eight percent of the variance in orientation to life was accounted for by perceived uncertainty, $R^2 = .08$, $\beta = .28$, $F = 13.58$, $p < .001$ on the second step of the analysis. The relationship between orientation to life and family quality of life tested on the third step of the analysis was statistically significant, $R^2 = .06$, $\beta = .24$, $F = 9.48$, $p < .001$. After holding the mediating variable constant on the fourth step of the mediation analysis, the standardized beta weight for the relationship between perceived uncertainty and family quality of life was reduced from .38 (step 1) to .34 (step 4), $R^2 = .15$, $F = 14.94$ $p < .001$.

To determine if the mediator variable, orientation to life, carried the influence of a predictor variable to a criterion variable (i.e., if the indirect effect of the predictor variable on the dependent variable through the mediator variable was significant) Sobel's test was calculated. The obtained test statistic of 2.42 was statistically significant, providing evidence that orientation to life was partially mediating the relation between family quality of life and perceived uncertainty.

Research Question 3: Will caregiver sense of control (locus of control, and orientation to life) mediate the relationship between severity of ASD and family quality of life?

H_3: Caregiver sense of control will mediate the relationship between severity of ASD and family quality of life.

A mediation analysis was used to determine if internal locus of control was mediating the relationship between severity of ASD and family quality of life. Table 20 presents results of this analysis.

Table 20

Mediation Analysis – Mediating Effect of Internal Locus of Control on the Relationship between Severity of ASD and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Severity of ASD	Family quality of life	.04	6.98	-.21**
Step 2				
Severity of ASD	Internal locus of control	.01	.40	.05NS

On the first step of the mediation analysis, severity of ASD was accounting for 4% of the variance in family quality of life, R^2 = .04, β = -.21, F = 6.98, p = .009. The relationship between perceived severity of ASD and internal locus of control was not

statistically significant, R^2 = .01, β = .05, F = .40, p = .530. As a result of the nonsignificant finding on the second step, the mediation analysis could not be continued.

The mediating effects of chance locus of control on the relationship between perceived severity of ASD and family quality of life was tested. Table 21 presents results of this analysis.

Table 21

Mediation Analysis – Mediating Effect of Chance Locus of Control on the Relationship between Severity of ASD and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Severity of ASD	Family quality of life	.04	6.98	-.21**
Step 2				
Severity of ASD	Chance locus of control	<.01	.01	.01NS

Severity of ASD was accounting for 4% of the variance in family quality of life on the first step of the mediation analysis, R^2 = .04, β = -.21, F = 6.98, p = .009. The second step of the mediation analysis tested the relationship between severity of ASD and chance locus of control. The results of this analysis were not statistically significant, R^2 < .01, β = .01, F = .01, p = .912. Because of the nonsignificant finding on the second step, the mediation analysis could not be continued.

A mediation analysis was completed to determine if doctors as a subscale of locus of control was mediating the relationship between perceived severity of ASD and family quality of life. The results of this analysis are presented in Table 22.

Table 22

Mediation Analysis – Mediating Effect of Doctors Locus of Control on the Relationship between Severity of ASD and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Severity of ASD	Family quality of life	.04	6.98	-.21**
Step 2				
Severity of ASD	Doctors locus of control	.01	.74	.07NS

On the first step of the mediation analysis, severity of ASD was accounting for 4% of the variance in family quality of life, R^2 = .04, β = -.21, F = 6.98, p = .009. One percent of the variance in doctors locus of control was explained by severity of ASD, R^2 = .01, β = .07, F = .74, p = .390. Because of the lack of statistically significant results on the second step of the analysis, the mediation analysis could not be continued.

The relationship between perceived severity of ASD and family quality of life was tested using a mediation analysis. Other people as a subscale of locus of control was used as the mediating variable in this analysis. Table 23 presents results of this analysis.

Table 23

Mediation Analysis – Mediating Effect of Other People Locus of Control on the Relationship between Severity of ASD and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Severity of ASD	Family quality of life	.04	6.98	-.21**
Step 2				
Severity of ASD	Other people locus of control	<.01	.01	.01NS

The relationship between severity of ASD and family quality of life, tested on the first step of the mediation analysis, was statistically significant, R^2 = .04, β = -.21, F =

6.98, p = .009. On the second step of the analysis, the relationship between severity of ASD and other people locus of control was not statistically significant, $R^2 < .01$, β = .01, F = .01, p = .926. Because of the nonsignificant finding on the second step of the analysis, the mediation analysis could not be continued.

A mediation analysis was used to determine if orientation to life was mediating the relationship between perceived severity of ASD and family quality of life. The results of this analysis are presented in Table 24.

Table 24

Mediation Analysis – Mediating Effect of Orientation to Life on the Relationship between Severity of ASD and Family Quality Of Life

Predictor	Criterion	R^2	*F*	Standardized *β*
Step 1				
Severity of ASD	Family quality of life	.04	6.98	-.21**
Step 2				
Severity of ASD	Orientation to life	<.01	.38	-.05NS

On the first step of the mediation analysis, severity of ASD was accounting for 4% of the variance in family quality of life, $R^2 = .04$, β = -.21, F = 6.98, p = .009. The relationship between severity of ASD and orientation to life was tested on the second step of the analysis. The results of this analysis were not statistically significant, $R^2 < .01$, β = -.05, F = .38, p = .537. Based on the lack of statistical significance on the second step of the analysis, the mediation analysis could not be continued.

Summary

The results of the data analysis used to describe the sample and address the research questions have been presented in this chapter. The sample included 153 parents of children diagnosed with ASD who were members of the Oakland County

Autism Society. These parents were between 35 and 54 years of age, female, Caucasian, and had either upper middle or upper class socioeconomic statuses. The children's ASD ranged from high functioning (mild autism) to low functioning (severe autism). The first research question used a stepwise multiple linear regression analysis to determine if parents ages, number of children, number of children diagnosed with ASD, socioeconomic status, caregiver demands, stress, and caregiver sense of control could be used to predict family quality of life. Four variables, uncertainty in illness, perceived stress, age of parent, and average socioeconomic status, entered the stepwise multiple linear regression equation, accounting for 33% of the variance in family quality of life. The second research question used mediation analysis to determine if caregiver sense of control (locus of control and orientation to life) could be used to mediate the relationship between uncertainty and family quality of life. The results of the mediation analysis using orientation to life as the mediating variable provided evidence that orientation to life was partially mediating the relationship between uncertainty and family quality of life. The mediation analyses using locus of control (internal, chance, doctors, and others) were not statistically significant. The third research question used Baron and Kenny's mediation analysis to determine if caregiver sense of control (locus of control and sense of coherence) was mediating the relationship between severity of ASD and family quality of life. The results of these analyses provided no evidence that caregiver sense of control was mediating the relationship between severity of ASD and family quality of life. A discussion of these findings and implications for practitioners and further research can be found in Chapter 5.

CHAPTER 5

DISCUSSION

The purpose of this study was to explore how caretakers of children diagnosed with an autism spectrum disorder (ASD) are able to move through adverse circumstances with which they are confronted while raising their child with considerable developmental needs and challenges, demonstrating resilience. Family resilience in this study includes family quality of life, locus of control, sense of coherence, perceived stress, uncertainty, severity, and demands.

Description of the Sample

A total of 153 parents of children with ASD participated in the study. Of this number, 144 (94.1%) were female. The age of the largest group of participants (n = 69, 45.0%) were between 35 and 44 years of age, with the second largest group falling between the ages of 45 and 54 years of age (n = 43, 28.1%). 88.1% of the participants (n = 135) indicated their ethnicity as Caucasian. The largest group of participants (n = 64, 44.2%) had an upper middle socioeconomic status, followed by upper status (n = 46, 31.7%). None of the participants had educational levels and occupations that would be considered lower socioeconomic status.

Research Questions and Hypotheses

Research Question 1: Can family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control?

H1: Family quality of life be predicted from family demographics (parents' ages, number of children, number of children diagnosed with ASD, and socioeconomic status) and caregiver demands, stress, and caregiver sense of control.

Four predictor variables, uncertainty in illness, perceived stress, age of parent and average socioeconomic status, entered the stepwise multiple linear regression equation. Uncertainty in illness was the strongest predictor and was positively related to family quality of life. Perceived stress was negatively related to family quality of life, indicating that as stress increased, family quality of life decreased. A negative relationship was found between the age of the parent and family quality of life. Younger parents were more likely to have a better quality of life. The average socioeconomic status of the family was a statistically significant predictor of family quality of life in a positive direction. This finding indicated that parents who had higher socioeconomic levels tended to have a better family quality of life. The remaining variables, locus of control (internal, chance, doctors, and others), orientation to life, perceived severity, number of children and number of autistic children did not enter the stepwise multiple linear regression equation, indicating they were not statistically significant predictors of family quality of life.

Research Question 2: Will caregiver sense of control (locus of control, and sense of coherence) mediate the relationship between uncertainty and family adaptation?

H2: Caregiver sense of control will mediate the relationship between uncertainty and family adaptation.

Baron and Kenny's mediation analysis process was used to determine if caregiver sense of control (locus of control and sense of coherence) was mediating the relationship between uncertainty and family quality of life. A partial mediation was found

for sense of coherence as a mediator between uncertainty and family quality of life. The four subscales measuring locus of control (internal, chance, doctors, and other people) were not mediating the relationship between uncertainty and family quality of life.

Research Question 3: Will caregiver sense of control (locus of control, and sense of coherence) mediate the relationship between severity of ASD and family quality of life?

H_3: Caregiver sense of control will mediate the relationship between severity of ASD and family quality of life.

Baron and Kenny's mediation analysis process was used to determine if caregiver sense of control (locus of control and sense of coherence) was mediating the relationship between severity of ASD and family quality of life. The results of these analyses provided no evidence that caregiver sense of control was mediating the relationship between severity of ASD and family quality of life.

Discussion

Hypotheses for this study were based on theory and current literature on ASD, parenting, the family adjustment and adaptation response (FAAR) model, and family quality of life research. Potentially protective and risk factors were obtained through a one-time survey completed by parents and caretakers of a child with a diagnosis of ASD via an internet link in May and June of 2014. Parents and caretakers were members of the Autism Society of Oakland County. This study employed a convenience sample, which could limit the generalizability of the results to a larger population.

Findings of the present study found two variables from parents' demographic characteristics predicted Family Quality of Life (FQOL): age (younger parents were found to have more positive quality of life) and socioeconomic status (higher SES) was

associated with more positive family quality of life. The parents in the present study had family SES that ranged from 20 to 66, with a mean of 47.38 (SD = 10.75). Possible SES scores could range from 8 to 66, with the mean for the present study 47.38 in the upper middle class category.

The parents' responses regarding their children receiving services prior to the age of 3 years was not associated with their socioeconomic levels. Receiving services prior to 3 years of age is dependent on having a diagnosis prior to that age. Some parents in both groups might not have been aware of their child's diagnosis and did not seek services. Half of the children (n = 74) had been diagnosed with ASD prior to their third birthday. Of this number, 52 (69.9%) had received services prior to 3 years of age. Among the children who had been diagnosed after 3 years of age, 22 (30.1%) had received services prior to 3 years of age. These children may have been receiving services for other diagnoses (e.g., speech and language, early childhood developmental delay, etc.).

Families with higher SES would be expected to have more available resources, and perhaps they would have fewer concerns about financial problems in addition to challenges they might face as a parent of a child with an ASD. In addition, with greater financial resources available, the family might have more therapy options available for their child with ASD. Specialized therapies may not be covered fully or may have limited coverage by medical insurance (e.g., applied behavior analysis, speech therapy, occupational therapy, etc.). Most parents who have a child with ASD live in constant hope that treatments, programs, and resources will evolve that can have a positive influence on the quality of life for their children (Wheeler, Baggett, Fox, & Blevins, 2006). Parents with a higher SES are more readily able to provide those treatments,

programs and resources than parents with a lower SES. Younger parents also were found to have a higher FQOL. This could be due to the enthusiasm and optimism often associated with youth, while older parents may have already developed a weariness that younger parents have not yet had the time or experience to develop yet.

The hypothesis that lower perceived stress led to higher FQOL was supported. The literature on perceived stress in families of children with disabilities indicated that parents of children with ASD are known to experience greater stress than parents of children with other chronic conditions (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). FQOL has been found to be negatively influenced by heightened parental stress and anxiety (Williams et al., 2003). Thus, the association between lower scores on perceived stress and higher FQOL was commensurate with what has been found in the FQOL literature on families with disabilities.

An unexpected finding from the study was that higher scores on uncertainty in illness led to higher FQOL. Sense of coherence and locus of control was hypothesized to mediate the relationship between uncertainty and FQOL. The relationship between uncertainty and FQOL was statistically significant, but the mediation failed when the four subscales of locus of control (internal, chance, doctors, others) were not significantly related to the mediators. However, sense of coherence was found to be partially mediating the relationship between uncertainty and FQOL. While parent's perceptions of illness-related uncertainty has been associated with psychological distress, continual uncertainty may serve as a catalyst for positive psychological change and personal growth in the context of FQOL (Lin, Yeh, & Mishel, 2010). Parents may have felt they had some control over their child's ASD, which was contributing to the relationship between parents' uncertainty allowing them to experience a higher FQOL. They may not

have been certain about the course of their child's condition, and their perception that they could have some control over their child's behaviors in the future was related to their FQOL. Lastly, ASD is a broad collection of complex developmental disorders, which also may explain some of the respondents' uncertainty.

A partial mediation was found for sense of coherence as a mediator between uncertainty and FQOL. The concept of sense of coherence could have a role in how parents comprehend and handle their experiences with a child's diagnosis of ASD (Antonovsky, 1987). Understanding how mastery-related beliefs could influence the family's overall quality of life is important. For example, family members who perceive behaviors associated with their child's condition as inconsistent, and their daily activities disordered as a result, may experience difficulty in developing strategies to manage stress and control demands associated with their child's disorder. When families feel the demands related to caring for their child with ASD become untenable, they may find it difficult to locate and employ appropriate resources to manage the demands. Family members who consider having a child diagnosed with ASD as devastating, without positive outcomes, may lack the motivation to confront the demands in challenging and meaningful ways. Thus, families with greater sense of coherence could be more motivated and actively involved in their child's ASD treatment by attaining appropriate services, viewing their experiences as controllable, and having better cognitive clarity regarding issues that result from demands associated with ASD.

Locus of control did not mediate the relationship between uncertainty and FQOL. Locus of control was not contributing to the statistically significant relationship between uncertainty and FQOL. While families may maintain beliefs about their personal control

over other facets of their lives, their views regarding their personal control may not be associated with the uncertainty inherent in their child's ASD outcomes and their FQOL.

While Chapter 2 reviewed the importance of LOC and SOC and how these beliefs could shape how families define and perceive their capabilities, the nature of the demands placed upon them, as well as their ability to adapt effectively was not supported in this study. While it was hypothesized that the parental beliefs of LOC and SOC would mediate the significant relationship between the severity of the child's ASD and FQOL, neither were found to be significant mediators. One explanation could be that the child's severity had a negative influence on FQOL and parents lacked the ability to control the condition. Studies within the chronic illness or disability literature have investigated the relationship between more disability-specific factors and FQOL. Wang and colleagues (2004) found that the severity of the disability was a significant predictor of both mothers' and fathers' reports of satisfaction with family quality of life (Wang et al., 2004). More research may be needed in this area to find how SOC and LOC can mediate disability severity and lead to increased FQOL.

One threat to the internal validity (mortality) and one threat to the external validity (sample bias) of the design defined by Campbell and Stanley (1963) must be considered when interpreting the findings. The differential loss of 56 participants could have had an influence on the outcomes of the study. The demographic characteristics of these parents were not known. They either did not meet the criteria for inclusion in the study or did not complete enough survey items for their submission to be considered viable. The remaining participants were generally Caucasian and had socioeconomic statuses of upper middle or upper class. These participants did not reflect a general population of parents with children diagnosed as ASD as the literature states that autism exists in all

segments of the population. These parents had the educational levels to understand their children's challenges with ASD and the financial resources to obtain innovative treatment for them.

Implications for Practitioners

As the prevalence of autism increases, it becomes increasingly more important to gain understanding on how to support both individuals with ASD, as well as their families. As the numbers of individuals diagnosed with ASD increase, so do the children with ASD in classrooms, as well as the families affected by this complex developmental disorder with no known cure. Research has demonstrated the numerous challenges that face these individuals and their families. Turnbull, Erwin, and Soodak (2006) argued that the family system must be examined as a whole, and understanding family interactions is necessary to understand a child with a disability. The present study attempted to gain a greater understanding of how parental beliefs, specifically LOC and SOC, and examined how those beliefs mediated (or failed to mediate) the relationship between caretaker demands, caretaker beliefs, and FQOL.

Beliefs held by family members can play an essential role in the relative influence that demands have on overall family adaptation (Patterson 2005). While in the present study, lower stress levels and higher uncertainty in illness contributed to more positive FQOL, it is important for mental health professionals who work with these families to be aware of the influence that additional stress can have on the quality of life of these families. In addition, professional development for mental health professionals who work in schools and in communities are needed to help gain a greater understanding of the role of FQOL and the contribution that parental beliefs can make to a family's overall QOL.

Parents in the present study typically had higher socioeconomic levels, which may have influenced the type of treatment they were receiving from their physicians and therapists. According to Patterson (1989, 2002), family resources and family coping behaviors are used to reduce the demand on caregiving. Family resources are concrete or intangible items that a family has that can be used to obtain treatment for their children. Many of the children in this study had access to innovative treatments and therapies that could help them function at a higher level. The types of treatment that children in these families receive should be made available to all families with children diagnosed with ASD to help them function better and improve overall family quality of life.

Clinical and school psychologists are knowledgeable about basic psychological concepts, but additional professional development may be needed for mental health professionals working with families to understand how these beliefs could affect parents of children diagnosed with ASD. This knowledge could be used to focus on positive resilience-based interventions that work on changing these beliefs for these families.

Limitations of the Study and Directions for Further Research

The use of a single organization in a wealthy county may have been a limitation of the study. Oakland County is among 10 highest income counties in the United States with populations over one million people. According to the 2010 census, 77.3% of Oakland County is Caucasian. The homogeneous sample used in the present study reflected the population of the county, with most of the respondents identifying as Caucasian (88.1%), female (94.1%), with the majority of them falling in the middle upper to upper SES (73.9%). Because of the homogeneity within the study, the findings may not be generalizable to all parents of children diagnosed with ASD. Replicating the study

using a more heterogeneous sample that includes parents from more diverse backgrounds could provide more information about parental beliefs and the potentially mediating relationship between demands and FQOL.

A second limitation was that there might not have been enough incentive to get fathers to participate. Fathers play important roles in the child rearing, although mothers tend to do the majority of the caretaking (Boyd, 2002). Fathers' perspective on beliefs and demands could contribute to the research and provide a broader picture of how both maternal and paternal beliefs affect the whole family and FQOL. Future research could focus on having mother-father dyads complete the survey to determine if feelings about having a child with ASD and the effects of the diagnosis on FQOL differ relative to the perspective of the parent on providing care for a child diagnosed with ASD.

Another limitation may be the mode of delivery and lack of direct incentive. A large number of respondents started the survey, but did not finish it or skipped entire sections. This could be due to lack of a direct incentive upon completion of the survey or the impersonal mode of delivery through an online program. The noncompleters may have had different SES than the ones who completed the survey. Their ways of coping and beliefs about the course of ASD might have resulted in different findings that those reported in the present study. Having the researcher attend a meeting of the organization to explain the study and answer questions regarding their participation could have motivated the participants to complete all parts of the survey. Further research on the use of online surveys for this type of research may be helpful in deciding the mode of delivery and the need for incentives for participation.

Two of the scales, Multidimensional Health Locus of Control and Perceived Stress, had low Cronbach alpha coefficients with the present sample. The alpha

coefficients reported by the scale authors for the Multidimensional Health Locus of Control scale ranged from .70 to .87, which indicated adequate internal consistency. For the present sample, the alpha coefficients ranged from .35 to .61, indicating poor internal consistency. Similar outcomes were noted for perceived stress, with the scale authors reporting an alpha coefficient of .78 compared to .29 for the present study. These differences in the reliability of the two scales may have contributed to the lack of statistically significant differences in the analyses.

A qualitative research study using focus groups could be used to determine what types of additional belief factors are contributing to FQOL in parents of adult children diagnosed with ASD. A paucity of research exists on factors associated with providing care for adult children diagnosed with ASD. As ASD is a lifelong condition, exploratory research is needed to begin understanding how parents manage care for their adult children and maintain a positive quality of life. The focus groups could involve people who are not in support groups, but are recruited from clinics, physicians, psychologists, school-based programs, or through word of mouth. This type of study could be an exploratory look into the unrecognized factors that are helping or hindering family functioning as children with ASD move into adulthood.

APPENDIX A

SURVEY AND PARENT INFORMATION SHEET

Research Information Page

***1. Behavioral Research Information Sheet**
Title of Study: Factors Affecting Quality of Life In Families of Children with Autism

Principal Investigator (PI): Jessica R. Garrett
Educational Psychology
(734) 560-8479

Purpose: You are being asked to be in a research study to explore how caretakers of children diagnosed with an Autism Spectrum Disorder (ASD) are able to move through adverse circumstances with which they are confronted while raising their child with considerable developmental needs and challenges, demonstrating resilience. You are being asked to participate because you have a child diagnosed with autism and are a member of the Autism Society of Oakland County. The estimated number of study participants to be enrolled in the study is approximately 200. Please read this form and ask any questions you may have before agreeing to be in the study.

Study Procedures: If you agree to take part in this research study, you will be asked to complete an online survey to determine the extent of your resilience in coping with having a child diagnosed with autism. The survey should take no more than 30 minutes to complete. Samples of some of the questions include:

- **My family enjoys spending time together.**
- **My family members talk openly with each other.**
- **My family has the support we need to relieve stress.**
- **My family members have friends or others who provide support.**
- **If my child's autism spectrum disorder worsens, it is my own behavior which determines how soon he/she will do better again.**
- **Most things that affect my child's autism spectrum disorder happen by chance.**
- **In the last month, how often have you felt that you were unable to control the important things in your life?**

Your identity will be protected as you will not have to provide your name or email address on the survey. You will not have to sign this research information sheet. After reading this form, you will be asked to select the choice that indicates you have read and understood the information on this form to indicate your willingness to participate in the study.

Benefits: As a participant in this research study, there will be no direct benefit for you; however, information from this study may benefit other people now or in the future.

Risks: There are no known risks at this time to participation in this study.

Study Costs: Participation in this study will be of no cost to you.

Compensation: You will not be paid for taking part in this study. However, a $2.00 donation will be made to the Autism Society of Oakland County for every survey that is completed and submitted.

Confidentiality: You will be identified in the research records by a code name or number. There will be no list that links your identity with this code.

Voluntary Participation/Withdrawal: Taking part in this study is voluntary. You have the right to choose not to take part in this study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The data that you provide may be collected and used by SurveyMonkey as per its privacy agreement. Additionally, participation in this research is for residents of the United States over the age of 18; if you are not a resident of the United States and/or under the age of 18, please do not complete this survey.

Questions: If you have any questions about this study now or in the future, you may contact Jessica Garrett at the following phone number 734-560-8479. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628.

◯ I agree to participate in the survey

◯ I do not agree to participate in the survey

Please answer the following questions about yourself and your family by indicating the answer that is most like you and your family. Some questions may ask for additional information. Please provide as much as you feel comfortable.

2. What is your age?

3. What is your gender?

- ◯ Female
- ◯ Male

4. Which racial and/or ethnic group best describes you? (Select as many that apply)

- ☐ African American/Black
- ☐ American Indian/Alaskan Native
- ☐ Asian/Asian American/Pacific Islander
- ☐ Caucasian/White
- ☐ Hispanic/Latino/Latina (e.g., Puerto Rican, Mexican, Central/South American)
- ☐ Middle Eastern

Other (please specify)

5. What is your relation to your child?

- ◯ Biological father
- ◯ Stepfather
- ◯ Foster father
- ◯ Biological mother
- ◯ Stepmother
- ◯ Foster mother

Other (please specify)

6. What is the father's highest educational level?

- ◯ Less than 7th grade
- ◯ Junior high/middle school
- ◯ Partial high school
- ◯ High school graduate
- ◯ Some college/technical school/associate's degree
- ◯ Bachelor's degree
- ◯ Graduate degree

Other (please specify)

7. What is the mother's highest educational level?

- ◯ Less than 7th grade
- ◯ Junior high/middle school
- ◯ Partial high school
- ◯ High school graduate
- ◯ Some college/technical school/associate's degree
- ◯ Bachelor's degree
- ◯ Graduate degree

Other (please specify)

8. What is the father's occupation? (Please indicate what the father does and not where he works)

9. What is the mother's occupation? (Please indicate what the mother does and not where she works)

10. How many children do you have living at home? (Include child diagnosed with ASD)

11. How many of your children have been diagnosed with autism?

12. Does your child with ASD live at home with your family?

- ◯ Yes
- ◯ No

13. Which racial and/or ethnic group best describes your ASD child? (Select as many that apply)

- ☐ African-American/Black
- ☐ American Indian/Alaskan Native
- ☐ Asian/Asian American/Pacific Islander
- ☐ Caucasian/White
- ☐ Hispanic/Latino/Latina (e.g., Puerto Rican, Mexican, Central or South American)
- ☐ Middle Eastern

Other (please specify)

14. What is the gender of your child with ASD?

- ◯ Male
- ◯ Female

15. Child's Diagnosis

- ◯ Asperger's Syndrome
- ◯ PDD-NOS
- ◯ Autism
- ◯ Don't know

Other (please specify)

16. How would you best describe your child with autism's overall functioning level at this time?

- ◯ High functioning (mild autism)
- ◯ Moderately high functioning (mild to moderate autism)
- ◯ Moderate functioning (moderate autism)
- ◯ Moderately low functioning (moderate to severe autism)
- ◯ Low functioning (severe autism)
- ◯ Don't know

17. Age of child with ASD when diagnosed

18. Age of child with ASD presently

19. Did your child receive early intervention services before the age of 3? If so, please describe what they were.

- [ ] No
- [ ] Yes

If yes, please describe early intervention services (i.e., speech and language instruction, occupational therapy, physical therapy, Applied Behavior Analysis [ABA], etc.)

20. How would you rate your present relationship with the professionals who work with your child in their school setting, specifically the IEP (Individualized Education Program) team (i.e., speech and language pathologist, school social worker, school psychologist, occupational therapist, etc.)?

- ◯ Very positive
- ◯ Positive
- ◯ Neutral - neither positive or negative
- ◯ Negative
- ◯ Very negative
- ◯ Don't know
- ◯ Not applicable - my child does not have an IEP

21. Multidimensional Health Locus of Control Scale

Each item below is a belief statement about your child's autism spectrum disorder with which you may agree or disagree. Beside each statement is a scale that ranges from strongly disagree (1) to strongly agree (6). For each item, check the circle that represents the extent to which you agree or disagree with that statement. If you have more than one child diagnosed with an ASD, please answer the following focusing on only one of your children. Since this is a measure of your personal beliefs, there are no right or wrong answers.

	1) Strongly disagree	2) Moderately disagree	3) Slightly disagree	4) Slightly agree	5) Moderately agree	6) Strongly agree
1. If my child's ASD worsens, it is my own behavior which determines how soon he/she will do better again.	○	○	○	○	○	○
2. I am directly responsible for my child's ASD getting better or worse.	○	○	○	○	○	○
3. Whatever goes wrong with my child's ASD is my own fault.	○	○	○	○	○	○
4. The main thing which affects my child's ASD is what I myself do.	○	○	○	○	○	○
5. If my child's ASD take a turn for the worse, it is because I have not been taking proper care of her/him.	○	○	○	○	○	○
6. I deserve the credit when my child's ASD improves and the blame when it gets worse.	○	○	○	○	○	○
7. Most things that affect my child's ASD happen by chance.	○	○	○	○	○	○
8. Luck plays a big part in determining how my child's ASD improves.	○	○	○	○	○	○
9. Whatever improvement occurs with my child's ASD is largely a matter of good fortune.	○	○	○	○	○	○
10. If my child's ASD worsens,it is a matter of fate.	○	○	○	○	○	○

11. If I am lucky, my child's ASD will get better.	○	○	○	○	○	○
12. As to my child's ASD, what will be will be.	○	○	○	○	○	○
13. If my child sees professionals regularly, he/she is less likely to have problems with his/her ASD.	○	○	○	○	○	○
14. Following professional's advise to the letter is the best way to keep my child's ASD from getting worse.	○	○	○	○	○	○
15. Whenever my child's ASD worsen, I should consult a trained professional.	○	○	○	○	○	○
16. Other people play a big role in whether my child's ASD improve, state the same, or get worse.	○	○	○	○	○	○
17. The type of help I receive from other people determines how soon my child's ASD improves.	○	○	○	○	○	○
18. In order for my child's ASD to improve, it is up to other peole to see that the right things happen.	○	○	○	○	○	○

22. PARENTAL CONCERNS QUESTIONNAIRE

For each behavior listed below, please select the option that describes the extent to which it has been a problem for your child WITHIN THE PAST MONTH.

	No Problem	Mild Problem	Moderate Problem	Severe Problem
1. Language use and understanding (doesn't use words, has difficulty initating conversations, etc.)	○	○	○	○
2. Compulsive behaviors (completes routines always in the same manner)	○	○	○	○
3. Anxiety (shows distress from new situations or crowds, etc.)	○	○	○	○
4. Sensory issues (reacts to lights, sounds, textures, etc.)	○	○	○	○
5. Sleep disturbance (does not fall asleep easily, wakes often, etc.)	○	○	○	○
6. Aggression (intentionally hits, bites others, etc.)	○	○	○	○
7. Hyperactivity (is constantly moving, running, jumping, etc.)	○	○	○	○
8. Attention span (has difficulty finishing a task etc.)	○	○	○	○
9. Mood swings (has unpredictable changes between emotions)	○	○	○	○
10. Eating habits (eats few foods/certain types of foods, etc.)	○	○	○	○
11. Social interactions (prefers to be alone, has few friends, etc.)	○	○	○	○
12. Self-stimulatory and repetitive behaviors (rocks, spins, flaps hands, etc.)	○	○	○	○
13. Self-injurious behaviors (bangs head, pinches, bites, hits oneself, etc.)	○	○	○	○

23. PSS-14

INSTRUCTIONS:

The questions in this scale ask you about your feelings and thoughts during THE LAST MONTH. In each case, you will be asked to indicate your response by selecting the choice that represents HOW OFTEN you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

	Never	Almost Never	Sometimes	Fairly Often	Very Often
1. In the last month, how often have you been upset because of something that happened unexpectedly?	○	○	○	○	○
2. In the last month, how often have you felt that you were unable to control the important things in your life?	○	○	○	○	○
3. In the last month, how often have you felt nervous and "stressed"?	○	○	○	○	○
4. In the last month, how often have you felt confident about your ability to handle your personal problems?	○	○	○	○	○
5. In the last month, how often have you felt that things were going your way?	○	○	○	○	○
6. In the last month, how often have you found that you could not cope with all the things you had to do?	○	○	○	○	○
7. In the last month, how often have you been able to control irritations in your life?	○	○	○	○	○
8. In the last month, how often have you felt that you were on top of things?	○	○	○	○	○
9. In the last month, how often have you been angered because of things that happened that were outside of your control?	○	○	○	○	○
10. In the last month, how	○	○	○	○	○

often have you felt
difficulties were piling up so
high that you could not
overcome them?

Orientation to Life Questionnaire

Here is a series of questions relating to various aspects of our lives. Each question has seven possible answers, with numbers 1 and 7 being the extreme answers. If the words under 1 are right for you, click 1; if the words under 7 are right for you, click 7. If you feel differently, click the number that best expresses your feelings. Please give only one answer to each question.

24. Do you have the feeling that you don't really care about what goes on around you?

◯ 1 Very seldom or never ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 very often

25. Has it happened in the past that you were surprised by the behavior of people whom you thought you knew well?

◯ 1 Never happened ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 always happened

26. Has it happened that people whom you counted on disappointed you?

◯ 1 Never happened ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 Always happened

27. Until now your life has had

◯ 1 No clear goals or purpose at all ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 Very clear goals and purpose

28. Do you have the feeling that you're being treated unfairly?

◯ 1 Very often ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 Very seldom or never

29. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?

◯ 1 Very often ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 Very seldom or never

30. Doing the things that you do every day is:

◯ 1 A source of deep pleasure and satisfaction ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 A source of pain and boredom

31. Do you have very mixed-up feelings and ideas?

◯ 1 Very often ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 Very seldom or never

32. Does it happen that you have feelings inside you would rather not feel?

○ 1 Very often ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Very seldom or never

33. Many people - even those with a strong character - sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?

○ 1 Never ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Very often

34. When something happened, have you generally found that:

○ 1 You overestimated or underestimated its importance ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 You saw things in the right proportion

35. How often do you have the feeling that there's little meaning in the things you do in your daily life?

○ 1 Very often ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Very seldom or never

36. How often do you have feelings that you're not sure you can keep under control?

○ 1 Very often ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 Very seldom or never

37. Mishel Uncertainty in Illness Scale - Parent/Child Form

INSTRUCTIONS:

Please read each statement. Take your time and think about what each statement says. Then select the choice that most closely measures how you are feeling about your child TODAY. If you agree with a statement, then you would either select "Strongly Agree" or "Agree." If you disagree with a statement, then you would either select "Strongly Disagree" or "Disagree." If you are undecided about how you feel about your child, then mark under "Undecided" for that statement. Please respond for every statement.

	5) Strongly Agree	4) Agree	3) Undecided	2) Disagree	1) Strongly Disagree
1. I don't know what is wrong with my child.	○	○	○	○	○
2. I have a lot of questions without answers.	○	○	○	○	○
3. I am unsure if my child's autism spectrum disorder is getting better or worse.	○	○	○	○	○
4. It is unclear how bad my child's symptoms will be.	○	○	○	○	○
5. The explanations they give about my child seem hazy to me.	○	○	○	○	○
6. The purpose of each treatment for my child is clear to me.	○	○	○	○	○
7. I do not know when to expect things will be done to my child.	○	○	○	○	○
8. My child's symptoms continue to change unpredictably.	○	○	○	○	○
9. I understand everything explained to me.	○	○	○	○	○
10. The professionals say things to me that could have many meanings.	○	○	○	○	○
11. I can predict how long my child's autism will last.	○	○	○	○	○
12. My child's treatment is too complex to figure out.	○	○	○	○	○
13. It is difficult to know if the treatments or medications my child is getting are helping.	○	○	○	○	○
14. There are so many different types of staff, it's unclear who is responsible for what.	○	○	○	○	○

15. Because of the unpredictability of my child's autism, I cannot plan for the future.	○	○	○	○	○
16. The course of my child's autism keeps changing. He/she has good and bad days.	○	○	○	○	○
17. It's vague to me how I will manage the care of my child after he/she leaves home.	○	○	○	○	○
18. It is not clear what is going to happen to my child.	○	○	○	○	○
19. I usually know if my child is going to have a good or bad day.	○	○	○	○	○
20. The results of my child's tests are inconsistent.	○	○	○	○	○
21. The effectiveness of the treatment is undetermined.	○	○	○	○	○
22. It is difficult to determine how long it will be before I can care for my child by myself.	○	○	○	○	○
23. I can generally predict the course of my child's autism.	○	○	○	○	○
24. Because of the treatment, what my child can and cannot do keeps changing.	○	○	○	○	○
25. I'm certain they will not find anything else wrong with my child.	○	○	○	○	○
26. They have not given my child a specific diagnosis.	○	○	○	○	○
27. My child's physical distress is predictable; I know when it is going to get better or worse.	○	○	○	○	○
28. My child's diagnosis is definite and will not change.	○	○	○	○	○
29. I can depend on professional support staff to be there when I need them.	○	○	○	○	○
30. The seriousness of my child's autism has been determined.	○	○	○	○	○
31. The professional	○	○	○	○	○

support staff use everyday language so I can understand what they are saying.

38. Family Quality of Life

This survey is about how you feel about your life together as a family. Your "family" may include many people - mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people
- who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and
- who support and care for each other ON A REGULAR BASIS.

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items below are things that hundreds of families have said are important for a good family quality of life. We want to know how satisfied you are with those things in your family. Please select the choice for the following questions that reflect your level of satisfaction with each item.

Selecting the first choice means you are very dissatisfied.

Selecting the fifth choice means you are very satisfied.

Thank you so much for sharing your opinion with us!

How satisfied am I that . . .

	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1. My family enjoys spending time together.	○	○	○	○	○
2. My family members help the children learn to be independent.	○	○	○	○	○
3. My family has the support we need to relieve stress.	○	○	○	○	○
4. My family members have friends or others who provide support.	○	○	○	○	○
5. My family members help the children with schoolwork and activities.	○	○	○	○	○

6. My family members have transportation to get to the places they need to be.	○	○	○	○	○
7. My family members talk openly with each other.	○	○	○	○	○
8. My family members teach the children how to get along with others.	○	○	○	○	○
9. My family members have some time to pursue our own interests.	○	○	○	○	○
10. Our family solves problems together.	○	○	○	○	○
11. My family members support each other to accomplish goals.	○	○	○	○	○
12. My family members show that they love and care for each other.	○	○	○	○	○
13. My family has outside help available to us to take care of special needs of all family members.	○	○	○	○	○
14. Adults in our family teach the children to make good decisions.	○	○	○	○	○
15. My family gets medical care when needed.	○	○	○	○	○
16. My family has a way to take care of our expenses.	○	○	○	○	○
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	○	○	○	○	○
18. My family is able to handle life's ups and downs.	○	○	○	○	○
19. Adults in my family have time to take care of the individual needs of every child.	○	○	○	○	○
20. My family gets dental care when needed.	○	○	○	○	○
21. My family feels safe at home, work, school, and in our neighborhood.	○	○	○	○	○
22. My family member with a disability has support to accomplish goals at school or at the workplace.	○	○	○	○	○
23. My family member with a disability has support to accomplish goals at home.	○	○	○	○	○

24. My family member with a disability has support to make friends.	○	○	○	○	○
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	○	○	○	○	○

APPENDIX B

WAYNE STATE UNIVERSITY INSTITUTIONAL REVIEW BOARD APPROVAL

WAYNE STATE UNIVERSITY

IRB Administration Office
87 East Canfield, Second Floor
Detroit, Michigan 48201
Phone: (313) 577-1628
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http://irb.wayne.edu

NOTICE OF EXPEDITED APPROVAL

To: Jessica Garrett
Theoretical & Behavior Foundations

From: Dr. Deborah Ellis or designee C. Zolondek | PB
for Chairperson, Behavioral Institutional Review Board (B3)

Date: March 21, 2014

RE: IRB #: 024414B3E
Protocol Title: Factors Affecting Quality of Life in Families of Children with Autism
Funding Source:
Protocol #: 1402012798

Expiration Date: March 20, 2015

Risk Level / Category: Research not involving greater than minimal risk

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The above-referenced protocol and items listed below (if applicable) were **APPROVED** following *Expedited Review* Category (#7)* by the Chairperson/designee *for* the Wayne State University Institutional Review Board (B3) for the period of 03/21/2014 through 03/20/2015. This approval does not replace any departmental or other approvals that may be required.

- Revised Protocol Summary Form (received in the IRB Office 3/21/2014)
- Protocol (received in the IRB Office 2/7/2014)
- A waiver of requirement for written documentation of informed consent has been granted according to 45 CFR 46 116(d). This waiver satisfies: 1) the research involves no more than minimal risk to the participants. Anonymous survey that protects participants from a potential breach of confidentiality; 2) the research involves no procedures for which written consent is normally required outside of the research context. An anonymous online survey normally does not require written consent outside of a research context; 3) the consent process is appropriate and 4) an information sheet disclosing the required and appropriate additional elements of consent disclosure will be provided to participants.
- Behavioral Research Information Sheet (dated 3/21/2014)
- Ad/Recruitment Post
- Data Collection Tool: Demographics Survey, Multidimensional Health Locus of Control Scale - Form C, Orientation to Life Questionnaire, Mishel Uncertainty in Illness Scale - Parent/Child Form, PSS, Parental Concerns Questionnaire, and Family Quality of Life

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* Federal regulations require that all research be reviewed at least annually. You *may* receive a *"Continuation Renewal Reminder"* approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval **before** the expiration date. Data collected during a period of lapsed approval is unapproved research and can never be reported or published as research data.

* All changes or amendments to the above-referenced protocol require review and approval by the IRB **BEFORE** implementation.

* Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (http://www.irb.wayne.edu/policies-human-research.php).

NOTE:

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the IRB Administration Office must be contacted immediately.
2. Forms should be downloaded from the IRB website at **each** use.

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ABSTRACT

FACTORS RELATED TO QUALITY OF LIFE IN FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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Advisor: Dr. Stephen B. Hillman

Major: Educational Psychology

Degree: Doctor of Philosophy

The purpose of this study was to explore how caretakers of children diagnosed with an autism spectrum disorder (ASD) are able to move through adverse circumstances with which they are confronted while raising their child with considerable developmental needs and challenges. Family resilience in this study includes family quality of life, locus of control, sense of coherence, perceived stress, uncertainty, severity, and demands.

The participants in this study were 153 parents of children diagnosed with ASD. The parents were members of the Autism Society of Oakland County. The participants completed a survey comprised of six scales (Parental Concerns Questionnaire, Perceived Stress Scale, Orientation to Life Questionnaire, Mishel Uncertainty in Illness Scale, Family Quality of Life, and a short demographic survey) using SurveyMonkey.

Three research questions were developed for this study. The results of the statistical analysis indicated that four variables, uncertainty in illness, perceived stress, age of parent, and average socioeconomic status accounted for 33% of the variance in family quality of life. Results of the mediation analysis used to answer the second

research question used control variables (locus of control and orientation to life) as the mediating variable. The results indicated that orientation to life was partially mediating the relationship between uncertainty and family quality of life. The third research question used the control variables (locus of control and orientation to life) as the mediating variable in the relationship between perceived severity of disability and family quality of life. The results were not statistically significant.

Because of a predominantly high socioeconomic status among the parents of children diagnosed with ASD, further study is needed using participants across the socioeconomic continuum. Additional research using instruments with better psychometric attributes for mastery, control, and stress might provide more information on parenting children with ASD and family quality of life.

AUTOBIOGRAPHICAL STATEMENT

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