COPING, LIFE SATISFACTION, AND EMPOWERMENTIN CAREGIVERS OF CHILDREN
WITH AN AUTISM SPECTRUM DISORDER

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ABSTRACT

THESIS: Coping, Life Satisfaction, and Empowerment in Caregivers of Children with an Autism Spectrum Disorder

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This study examines the relationship between coping styles, and life satisfaction, and empowerment in caregivers of children with an Autism Spectrum Disorder (ASD). Participants were 300 caregivers of children with an ASD. They were recruited through service providers for children with an ASD, Facebook Support Pages, and the snowball method. Caregivers filled out a few demographic questions, the Brief COPE, Satisfaction with Life Scale (SWLS), and the Family Empowerment Scale (FES). The first category of coping (Self Distraction, Denial, Behavioral Disengagement, Venting, Humor, Self-Blame) was negatively related to life satisfaction while the third category of coping (Emotional Support, Instrumental Support) was positively related. The family subscale of empowerment positively predicted life satisfaction.

Coping, Life Satisfaction, and Empowerment in Caregivers of Children with Autism Spectrum Disorder

Introduction

Literature Review

 Caregivers of children with an Autism Spectrum Disorder.

 Autism Spectrum Disorder (ASD) is categorized as a Neurodevelopmental Disorder and is identified by persistent deficits in communication and restricted, repetitive patterns of behavior, interests, or activities (American Psychological Association [APA], 2013). These characteristics must be present in the individual's early development period and cause significant impairment in functioning. Since the characteristics present so early, it falls to the child's parent or guardian to find services and manage these symptoms, which can lead to many difficulties for these parents. Parents of a child with a disability are pivotal for the emotional and physical well-being of their child as well as their child's development. Their level of involvement influences a child's outcome in treatment (Taub, Tighe, & Burchard, 2001), the child's overall functioning (Resendez, Quist, & Matshazi, 2000), number of problem behaviors in the child (Graves & Shelton, 2007), and child adjustment problems (Taub, Tighe, & Burchard, 2001).

 However, these parents (especially mothers) are at an increased risk for poor health and lack of well-being (Dellve et al., 2006). Caregiver burden in taking care of a child with an ASD is positively related to unmet needs relating to social relationships, mental health problems, safety of self, and communication (Cadman et al., 2012). A caregiver is anyone who has responsibility for assisting a person with a disability. In the current study it is defined as one who has primary custody of a child with an ASD.

Parents' reaction to their child receiving a diagnosis of a developmental disorder is typically some form of grieving which can either result in a resolution or a chronic state of sorrow (Cameron, Snowdon, & Orr, 1992). In a qualitative research study examining parents' narratives about their children that have been posted on the Internet, many parents were observed describing receiving their child's diagnosis as a life changing experience (Fleischman, 2004). Regarding reactions experienced by families immediately after they receive their child's diagnosis of an ASD, Hutton and Caron (2005) found that 52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame. These strong emotions in the parents regarding the diagnosis are often left unattended as the parents do not get immediate support from the doctor giving the diagnosis and immediately begin to seek out the proper services for their child. One parent described it as the lowest point in her life, "I was on the verge of a nervous breakdown. Not only was I not getting the much-needed support from peers, but I wasn't even getting support from our doctor!" (Fleischman, 2004).

Since there are so many different services and treatments for children with autism, locating the best services for an individual with ASD can be a challenge for the parents. There are a variety of services available to the families, however families are limited by how much they know how to find and how much they can afford. The increasing rate of autism has led to an increase in need for services for both children with an ASD and their families. Reported frequencies of ASD from the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (APA, 2013) are now approaching 1% of the population, with similar rates in both child and adult samples. The increase could be attributed to the change in criteria in the DSM-V, better detection, an actual increase in cases, or a combination of the factors (James, 2010).

Parents are now becoming more involved in both the diagnosis and treatment of their children. Therapy that is focusing on outcomes for the child should not be focused exclusively on the child as parent variables have a significant effect on the child's experiences and behaviors in children with an ASD (Weiss, Cappadocia, MacMullin, Viecili, & Lunsky, 2012). It is now recognized that providers of mental health services to families and children with disabilities should include facilitating the empowerment of the recipients of services along with the more traditional goals (Singh et al., 1997). Symptoms of an ASD are typically recognized during the child's second year, however they may be seen earlier than 12 months in severe cases and after two years in more mild cases (APA, 2013). This is often prior to the child beginning school, so it falls to the parents to be aware of the symptoms. In one study parents most often suspected their child had an ASD diagnosis 6 months before getting an official diagnosis (Twoy, Connolly, & Novak, 2007). ASD is often characterized by an insistence on routines, aversion to change, and sensory sensitivies (APA, 2013). This can often interfere with eating, sleeping, and many routine care activities (e.g. haircuts, or dental work), which can present daily challenges to both a child with an ASD and their family members. Events and activities that are routine for most families can end up being a source of great stress for families with children with an ASD.

Parents of a child with an ASD experience direct negative effects of the disorder that are often unaddressed. Most interventions for parents of children with autism have been focused on helping them to do better in caretaking their child, and increases in satisfaction in their own personal lives are incidental secondary consequences. Parents of children with an ASD also have a higher rate of divorce (23.5%) than parents of children without disabilities (13.8%). While the rate of divorce for parents of children without disabilities decreases after the child turns eight, this rate remains high for parents of children with an ASD and does not start to decrease until the

child turns 30 (Hartley et al., 2010). A study of family caregivers of persons with brain injuries found that caregivers were so immersed in the caring process that they neglected their own health, both physically and psychologically (Man, 2002). As a result of that self-neglect in caregivers, it is extremely important to study and understand the specific stress that parents of children with an ASD are faced with.

Stress.

Parents of children with an ASD are exposed to extremely high levels of stress. In a study comparing 51 parents of children with an ASD, 54 parents of children with Down syndrome, and 57 parents of typically developing children, Dabrowska & Pisula (2010) found that parents of children with an ASD have higher stress levels than both other parent groups. In addition, about 70% of individuals with an ASD have at least one comorbid mental disorder, which can add more stress to the caregiver. Most frequently, these comorbid disorders are ADHD, anxiety disorders, or depressive disorders (APA, 2013). Comorbid psychopathology in children with an ASD is a significant predictor of higher caregiver burden in parents (Cadman et al., 2012).

Raising a child with a developmental disability presents different challenges than that of a neruo-typical child, and is often found to be a greater source of stress. The burden on parents is particularly heavy if the child poses emotional, behavioral, and communication problems (Baker et al., 2003), all three of which are common in an individual with an ASD. Wang et al. (2013) found that mean parenting stress for mothers of children with an ASD was higher than recommended cut off levels for healthy living. These stress levels were also associated with anxiety and depression. Parenting stress is strongly related to behavior problems in the child (Baker et al., 2003). The more problem behaviors the child exhibits, the higher the level of parental stress.

Parents of children with an ASD also experience more stress than parents of children with other developmental disabilities (Wang, Michaels, & Day, 2010). Despite the higher levels of stress in parents of children with an ASD than in parents of children with other developmental disabilities, and in parents of children with no disabilities, Pottie & Ingram (2008) found that the level of ASD symptomology was not a significant predictor of parents' positive or negative daily mood.

The stress families experience as a result of having a child with an ASD is a type of unremitting chronic stress. Chronic stress is when acute stressors manifest repeatedly and concurrently. The stress then becomes part of the typical environment as opposed to an event that seldom occurs (Kaufman, 2007). Wheaton (1997, p. 53) defined chronic stress as "problems and issues that are either so regular in the enactment of daily roles and activities or are defined by the nature of daily role enactments or activities, and so behave as if they are continuous for the thee individual." Wheaton also identified ongoing role occupancy (i.e. being a parent of a child with special needs) as one of the four sources of chronic stress.

Parents of children with an ASD face chronic stress due to their life-role as a parent. Parents of children with an ASD have more caregiving burden and have more limits on community and family activities than parents of children with ADD/ADHD or parents of children without disabilities. Lesser participation in activities for the family and in the community may be due to the child's insistence on routine and schedule, or the challenges that accompany taking the child out of the familiar home environment. Parents of children with an ASD reported higher levels of concern over their child's achievement than parents of children with ADD/ADHD. They were also more concerned that their child would be the victim of bullying (Lee, Harrington, Louie, & Newschaffer, 2008). Despite this added stress, it is rare for

parents of children with mental health needs to receive mental health services and resources to help address their needs as caregivers (Gerkensmeyer, Perkins, Scott, & Wu, 2008).

Many families of children with an ASD express that they experience autism as an entity that controls their daily lives. The families expressed that they felt "robbed" of normal experiences and their lives centered unfairly on the child with autism. These families explained that their daily lives were centered on occupying and pacifying the child so that the day could be managed. Families were looking for more in life than just surviving the day, and said they found only fleeting moments where they 'felt like a family' and were satisfied (DeGrace, 2004). Many parents stated that after their child had been diagnosed, they experience a sense of trepidation, disbelief, shock, and depression. Some label the day their child was diagnosed as a day when their lives were changed forever (Fleischman, 2004).

The negative effects of stress are well documented. Greater reported stress is associated with poorer physical health and psychological heath (Edwards, Hershberger, Russell, & Markert, 2001). High levels of stress are correlated with elevated levels of psychological symptoms. This indicates that stress can result in both distress and anxiety. In addition, high levels of stress correlate with employees taking more time off work and calling in sick more often (Bergdahl, Larsson, Nilsson, Ahlstrom, & Nyberg, 2005). Parents of children with an ASD were found to be seven times more likely than control family members to quit their jobs due to problems with child care (Lee et al., 2008). In addition, chronic stress impairs both response inhibition and working memory (Mika et al., 2012). In a study of fathers of children with disabilities both parenting stress and health stress were significantly negatively related to lower satisfaction with life (Darling, Senatore, & Strachan, 2011).

Since the stress in parents of children with an ASD is so high compared to other groups, it is important to look at how they respond to that stress. Parents of children with an ASD are exposed to chronic stress from their life role as a parent of a child with special needs. Chronic stress can result in problems at work, problems with response and memory, and lower satisfaction with life. Since the stressful situation cannot be eliminated, clinicians can hope to help these parents manage and decrease the stress by helping them develop ways to deal with it. Responses to stress vary by person and over time, but patterns can often be identified and labeled as coping styles.

Coping.

Coping has to do with how a person appraises a situation and consequently responds to it. Coping includes behavioral, emotional, and cognitive responses to stress. Effective coping is how individuals are able to resolve problems, relieve emotional distress, and remain on track to achieve goals (Brown, Westbrook, & Challagalla, 2005). Identifying coping strategies will help to inform efforts to improve coping skills in individuals. Coping among family members of a child with a disability differs according to many factors including: individual factors, the process and situation within the family, and the context and conditions of the specific disability (Dellve, 2006).

Types of coping skills used vary by different contexts, situations, and individuals. The type of coping strategy that is used by a family is related to the personal assets, strengths, and cultural backgrounds of families (Man, 2002). These types of coping that will be measured in the present study include: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame (Carver, 1997). Weathersby (2007)

divided these coping methods into effective and non-effective coping strategies. Active coping, use of emotional support, use of instrumental support, positive reframing, planning, and acceptance are considered effective while denial, substance use, behavioral disengagement, and self-blame are considered non-effective.

Self-distraction as a way to cope is turning to work or other activities (e.g. reading, daydreaming, sleeping) to distract from the stressful event. Active coping is concentrating efforts and taking specific actions to try and improve the situation. Denial as a way to cope is maintaining a mindset that does not accept the stressor as reality and claims it has not happened. Substance use in relation to coping refers to using alcohol or other drugs to feel better about the stressful situation. Emotional support refers to getting comfort or understanding from another person. Instrumental support refers to getting advice or active help from another person. Behavioral disengagement suggests that the person has given up trying to cope with the situation or to do anything about it. Venting refers to expressing negative and unpleasant feelings about the situation. Positive reframing as a way to cope implies that the person is looking at the situation differently by looking for the good in it. Planning as a coping skill refers to coming up with a strategy or steps to take before taking action regarding the stressful situation. Using humor to cope is when the person makes jokes or makes fun of the situation. Acceptance is when the person believes that the stressful event is happening and makes an effort to learn to live with the situation. In regards to coping, using religion means the person has been praying, meditating, or finding comfort in their beliefs. Self-blame involves the person taking responsibility for the situation and criticizing him or herself because of it (Carver, 1997).

Brown et al. (2005) surveyed 75 workers at a certain company after a negative event and found that coping strategies can moderate the effect of negative emotions and situations on

overall performance, with effective tactics (i.e. self control) diminishing the negative effects and non-effective tactics (i.e. venting) amplifying them. The absence of effective coping adversely affects performance in work environments (Brown et al., 2005).

Considering the chronic nature of the stressors facing parents of children with an ASD due to their ongoing role occupancy as a parent, the current study seeks to examine how parents deal with this stress long term. Coping can be defined as either situational or dispositional. A measure of situational coping will describe what an individual is likely to do in one episode or specific period of time. Situational coping assumes that knowing how an individual copes with stress in general likely will reveal very little about the type of coping used in a specific stressful event or situation since coping efforts change constantly to meet the demands of a stressful situation (Penley, Tomaka, & Wiebe, 2002). A measure of dispositional coping will describe what an individual does over time. Dispositional coping assumes that people develop habitual ways of dealing with stress and these habits become coping styles (Bouchard, Guillemette, & Landry-Léger, 2004). In an effort to seek out effective strategies for parents over time, this study will compare what strategies parents typically use (their dispositional coping strategies) to their levels of satisfaction with life.

Dispositional coping describes what a person will typically do when under stress. Since parents of children with an ASD face different stressors than parents of neurotypical children, it is important to see how they respond to this stress over time. Since dispositional coping strategies can vary based on context, situation, and individual (Man, 2002), identifying the dispositional coping strategies of parents of children with an ASD can give an idea of the effect of the particular situation of having a child with an ASD on coping.

Using the COPE (a sixty item self-report scale that measures types of dispositional coping used; Carver et al., 1989) Bouchard et al. (2004) found that several types of dispositional coping (problem solving and distancing/avoidance) are related to personality traits (i.e. neuroticism, extraversion, and conscientiousness). These types of coping are also related to primary and secondary cognitive appraisals. Dispositional coping significantly predicts reasons for living and suicidal ideation. In a survey of older adults, higher use of dysfunctional coping was related to a higher suicidal ideation. However, it was also related to a higher fear of suicide and fear of social disproval, which are deterrents for suicide (Marty, Segal, & Coolidge, 2010).

There are many different dispositional coping skills one can use. These skills can be divided into problem-focused or emotion-focused types of coping (Brown, Westbrook, & Challagalla, 2005). Typically, parents of children with an ASD will use combinations of the forms of problem-focused and emotion-focused coping skills that are available to them, which makes coping a complex process (Cappe et al., 2011). Problem-focused and emotion-focused coping are not mutually exclusive categories and some coping strategies vary between categories based on the situation (Brown et al., 2005). Seeking instrumental support, planning, active coping, and suppression of competing activities are typically considered a problem-focused coping strategy while seeking social support, denial, positive reinterpretation, venting emotion, and mental/behavioral disengagement are typically considered emotion-focused (Carver et al., 1989; Woodman & Hauser-Cram, 2013).

Among parents of children with an ASD, parents who use more emotion-focused coping strategies are more likely to experience distress at work (Cappe, Wolff, Bobet, & Adrien 2011). Dabrowska & Pisula (2010) surveyed parents of children with an ASD, parents of children with Down syndrome, and parents of neurotypically developing children and found that within

parents of children with an ASD, those who used emotion-oriented coping had higher levels of

stress than those who used task-oriented coping. Those who use task-focused coping skills

(which are a subset of problem-focused coping styles) have a direct beneficial effect on their

performance (Brown, Westbrook, & Challagalla, 2005).

Parents of children with a developmental disability are most likely to use planful problem

solving coping skills and seek social support. They are least likely to use escape-avoidance and

accepting responsibility as coping skills. In addition, though there were slight differences

between groups, this rank order was found to be similar between mothers and fathers and

between adoptive and birth parents (Glidden, Billings, & Jobe, 2006). In a study of 92 mothers of

children with developmental disabilities, mothers were found to use denial as a coping strategy

most frequently and behavioral disengagement the least frequently (Woodman & Hauser-Cram,

2013). Problem-focused coping strategies have been shown to be more effective than emotion

focusing strategies. Parents of children with an ASD who employ more problem-solving

strategies are more likely to have better relationships with their child (Cappe et al., 2011).

Ben-Zur (2009) tested three coping superstrategies based on empirical classification by

Carver et al. (1989). These strategies included problem focused coping (active coping, planning,

and suppression of competing activities) emotion/support coping (instrumental and emotional

support and ventilation) and emotion/avoidance coping (mental and behavioral disengagement

and denial). Using the Hebrew version of the COPE scale (Carver et al, 1989) Ben-Zur (2009)

surveyed 480 adolescents, university students, and community residents. Problem-focused

coping has a positive relationship to positive affect while avoidance coping has a strong positive

relationship to negative affect (Ben-Zur, 2009). This suggests that people who use problem-

focused coping strategies are happier day to day than those who try to avoid or not think about

the negative situation. Interestingly, emotion/support coping has a positive correlation with both positive and negative affect. Ben-Zur (2009) suggested that these correlations could indicate a causation of either direction, but further research was needed to see if any causation exists. It could be that problem-focused coping leads to a positive affect, or that a positive affect leads to parents using problem-focused coping skills. It could also be the case that both are affected by stable personality traits. People who are generally positive may have certain traits that also lead them to use problem-focused coping skills.

The number of coping strategies reported by parents of children with an ASD decreases over time (Gray, 2006). There was also a shift over time away from using problem-focused coping towards using emotion-focused coping. Gray (2006) suggested this change could have been due to improvement in the child's behavior and the parents becoming more accustomed to the routine. As the family becomes more set in the routine, they may experience lower levels of stress and use fewer coping strategies, or at least perceive themselves as doing so. Riley & Park (2014) found that younger adults experiencing chronic stressors are more likely to employ active coping strategies, and older adults experiencing chronic stressors use less coping strategies that are problem-focused. The duration of an autism spectrum disorder diagnosis is a significant predictor of parents' daily mood (Pottie & Ingram, 2008). This correlation suggests that as time since the diagnosis increased, daily negative mood decreased, indicating that the situation of having a child with an ASD gets better instead of worse over time. Parents of children with an ASD experience chronic stress that does not remit with age, but often use fewer and less effective coping strategies as they age.

Using qualitative methodology, Luong, Yoder, and Canham (2009) found that there was a typical sequence of different types of coping parents of children with an ASD used. They

interviewed nine Southeast Asian parents (with a majority of them being mothers) of children ages 3-10 who had an ASD to determine the parents; perspectives on the effect of autism on families, their support systems, and their coping styles. They found that the first strategy used by parents was typically denial or passive coping. This strategy was followed by the use of empowerment, redirecting energy, shifting of focus, rearranging life and relationships, changing expectations, social withdrawal, spiritual coping, and acceptance. Studies examining the progression of coping skills used by parents of children with an ASD need to be replicated in other countries (such as the United States) in order to generalize the results. Lai, Goh, and Sung (2015) administered the Brief COPE (Carver et al., 1989) to 136 parents who were mostly Chinese mothers. 54% of parents had a child with an ASD while the rest of the parents had a child who did not have a diagnosis of ASD or any chronic medical condition. Coping styles were divided into categories: active avoidance coping, problem-focused coping, positive coping, and religious/denial coping. Parents of children with an ASD tended to engage in more maladaptive coping (i.e. active avoidance coping) than parents of typically developing children, which provides evidence that the situation of providing care for a child with an ASD has an effect on the type of coping used by a parent (Lai, Goh, & Sung, 2015).

Despite the increased level of stress in parents of children with an ASD, the degree of coping was found to be parallel with the degree of coping in norm groups (Twoy et al., 2007). However, the use of coping of parents of children with an ASD differed from the norm groups on several of the subscales; they are slightly less likely to use social support and spiritual support. Parents of children without developmental disorders report significantly more community support than parents of children with developmental disorders (Nachshen & Minnes, 2005). Parents of children with an ASD are more likely to use passive appraisals, which is a strategy

that focuses on inactive behaviors such as avoidance. In a study of 55 parents of children with an ASD, a majority (87%) of the participants indicated that they believed their problems would go away if they waited long enough. Parents of children with an ASD are most likely to use reframing as their primary strategy of coping. Reframing relates to how the parents can redefine the stressful events as positive, negative, or neutral (Twoy et al., 2007). Wang et al. (2013) found that the most frequently reported coping strategies among parents of children with an ASD were: acceptance, active coping, positive reinterpretation and growth, suppression of competing activities, and planning.

Since there are so many different types of coping, and individuals and families vary on which types of coping they use, it is vital to look at which coping skills are effective for parents of children with an ASD. Though many types of coping may reduce stress in the short-term, it is also important to see how the use of these skills affects the parents in the long term. One way to see how the parents are affected long term is to compare the use of dispositional coping skills to a global measure of well-being such as life satisfaction. This will help to determine which coping skills are related to higher levels of life satisfaction particularly in parents of children with an ASD.

Life satisfaction.

One measure of global well-being is life satisfaction. Life satisfaction refers to a cognitive process within an individual. It is more about how individuals judge their own lives than how they feel about them. The Satisfaction With Life Scale (Diener, Emmons, Larson, & Griffin, 1985) focuses on the positive side of an individual's experience instead of focusing on the negative emotions. It emphasizes life satisfaction by the person's own standards of evaluation. While there may be some agreement about what constitutes a 'good life,' individuals

are likely to have differing opinions. This scale reflects the importance of the individual's unique criteria and standards of success. There is no externally imposed standard on what an individual should expect from their life, and the items are global, rather than specific in their nature (Pavot & Diener, 1993).

Fuentes (2012) surveyed 71 parents raising one child who had been formally diagnosed with an ASD and lived at home with the parent examined self reported life satisfaction and found that parents of children with autism were found to have an "average" satisfaction with life. Typically individuals in an average or middle range would like to move to a higher level of life satisfaction. Greater family support and higher income were related to a higher satisfaction with life while higher parental stress levels and poorer health were related to a lower satisfaction with life (Funtes, 2012). Parents of children with an ASD often report a lack of social support, which could have an influence on their satisfaction with life. Families with higher incomes are likely to not only experience less financial burden and stress, but also be able to better meet the needs of their child with autism by being able to afford services (Fuentes, 2012). Fuentes (2012) suggested that more research be done on life satisfaction of parents of children with autism as it may also relate to the treatment that the child receives.

Caregiver burden has a substantial influence on a parent's quality of life. Parents of children with cerebral palsy (another persistent disorder that requires intensive caretaking from the parents) were found to have lower levels of quality of life and greater depressed mood than the general population. The author suggests that the higher levels of depression are due to the chronic nature of the disorder as most of the parents had been caring for the child the entire duration of the disorder (Guillamon et al., 2013).

Further research on the life satisfaction of parents of children with an ASD needs to be done as much of the research is old and may be outdated. It is imperative to see how the life satisfaction of this population has changed over time with the increase of awareness of ASDs and treatments available for children with an ASD. In addition, with the significantly higher levels of stress and caregiver burden in this population, it is vital to explore personal variables of this population so clinicians can provide much needed support and help to this group. One way clinicians can determine what type of support to give parents of children with an ASD is by which coping skills are related to higher life satisfaction and teaching those coping skills.

Coping & life satisfaction.

Different types of coping have different effects on the quality of a parent's life and presumably on the way they interpret it. Since there are so many demands and stressors in the life of a parent of a child with a disability, the way parents cope with these demands plays a strong role in overall well-being (Glidden & Natcher, 2009). Folkman and Lazarus (1984) defined effective coping strategies as those that decrease the effect of stress on well-being. Cappe et al. (2011) surveyed 160 French parents of children with an ASD to examine child and family situations, perceived stress, perceived social support, perceived control, coping strategies, and quality of life. Using the Ways of Coping Checklist (WCC-R) they discovered that use of emotion-focused coping was significantly positively related to quality of life. They found that parents of children with an ASD who consider their experience with their child as a threat or a loss had a lower quality of life. In contrast, those parents who viewed their experience with their child as a challenge instead of a loss experienced greater self-fulfillment. This may suggest that that the way parents think of their experience has an influence on quality of life and reframing could be a valuable strategy for parents of children with an ASD. Both social activities and

relationships and family activities and relationships were strongly correlated with quality of life (Cappe et al., 2011).

Since stress is negatively correlated with life satisfaction, different ways of mitigating stress (or coping strategies) should have different effects on life satisfaction. Meral, Cavkaytar, Turnbull, & Mian (2013) surveyed 11,769 mothers from Turkish families of children with intellectual disabilities and autism. These mothers reported a higher quality of life when they felt they had high emotional support. This suggests that parents of children with intellectual disabilities and an ASD would benefit from added emotional supports in the form of family, friends, and other community supports. Mothers with higher care and material support were found to have a higher quality of life. Overall, the families of children with intellectual disabilities and autism reported being slightly more satisfied than unsatisfied with their lives. Their lowest satisfaction was in the area of physical/material well-being, as raising a child with disabilities often is accompanied with financial struggles to provide for the child (Meral et al., 2013).

Coping also has an effect on daily mood. Pottie & Ingram (2008) surveyed 93 parents of children with an ASD, PDD-NOS, or Asperger's and found a significant relationship between the type of coping skill used and self-reported daily mood. They found that the use of 10 coping strategies that were significant predictors of daily mood. Higher levels of positive mood were predicted by: seeking support, positive reframing, emotional regulation, and compromise; lower levels of positive mood were predicted by escape, blaming, withdrawal, and helplessness. Interestingly, Pottie & Ingram (2008) found that higher levels of negative mood and higher levels of positive mood were both predicted by problem-focused coping. The researchers'

suggested explanation for this was that many of the challenges confronted by parents are not amenable to change, therefore a flexible and varied repertoire of coping skills is needed.

Based on the use of coping strategies, it is possible to find differences in subjective evaluations of the quality of one's life. In a study of 68 married couples with a child with developmental disabilities, differences were found in self-reported subjective well-being based on use of coping strategies. Distancing and escape-avoidance coping strategies (i.e. ways to deny or ignore the problems situation) predicted low levels of well-being while positive reappraisal predicted high levels of subjective well-being (Glidden & Natcher, 2009). For fathers, but not for mothers, of children with disabilities, a high use of accepting responsibility predicted higher levels of wellbeing. For mothers, the problem-focused strategy of confrontive coping (i.e. facing the situation) was associated with a higher level of subjective wellbeing. These results were found to be consistent after a six-year period (Glidden & Natcher, 2009). In parents with developmental disabilities, mothers' use of active and planful coping strategies were found to moderate the effect of their child's negative behaviors on depression such that those mothers were less depressed. In addition, mothers who used behavioral/mental disengagement coping strategies were found to have more depressive symptoms (Woodman & Hauser-Cram, 2013).

Coping can mediate the effect that the higher levels of stress have on satisfaction with life. Fathers of children with developmental disabilities have greater stress in daily parenting than fathers of neurotypical children. Darling et al. (2011) surveyed 85 fathers of children with disabilities and 121 fathers of children without disabilities and found that fathers of children with disabilities had significantly lower levels of coping and lower satisfaction with life. A family-centered course for Iranian parents of children with an ASD that taught coping skills and especially encouraged social supports within and between the families was provided by Samadi,

McConkey, and Kelly (2012). They found that after participation in the course there was an increase of problem-focused coping skills and improvements in health, levels of stress, and overall family functioning, all of which contribute to parental wellbeing.

Benson (2010) found a relationship between coping styles and self-reported wellbeing in mothers of children with an ASD. Due to a small sample size in his study, Benson (2010) combined the 14 subscales of the brief COPE (Carver et al., 1989) into four factors: engagement (use of instrumental support, active coping, planning, and use of emotional support), distraction (self-distraction, humor, self-blame, and venting), disengagement (substance use, behavioral disengagement, and denial), and cognitive reframing (acceptance, use of religion, and positive reframing). The distraction and disengagement subscales of coping were significant predictors of maternal depressed mood (higher use of these types of coping led to higher levels of depression). Lower levels of disengagement and higher levels of cognitive reframing both predicted higher levels of maternal well-being. Benson (2010) also found that when the child's autism symptoms or maladaptive behaviors were more severe, engagement had a positive effect on maternal well-being, but had no effect when the symptoms were less severe.

Though some studies have been done on coping and quality of or satisfaction with life, more research needs to be done in this area specifically with parents of children with an ASD. In addition, a bulk of the research focuses on quality of life or wellbeing. Though quality of life, wellbeing, and life satisfaction are similar concepts, there is an important distinction in the meanings. While an external party judges quality of life, life satisfaction is the individual's own ideals of how their life is and should be. This study focuses on the participant's own perception of how their life is going (i.e. satisfaction with life) as opposed to the quality of the participant's

life as judged by external standards (i.e. quality of life or wellbeing). Another factor that likely

has an influence on the life satisfaction of parents of children with an ASD is empowerment.

Empowerment.

Empowerment has been defined as a state as well as a process. The state of

empowerment is variable as it defines a person's current level of empowerment. The process of

empowerment is where individuals gain control over their own lives by influencing their

interpersonal and social environments (Singh et al., 1995). The most commonly cited definition

of empowerment comes from the Cornell Empowerment Group (1989, p.2) and explains

empowerment as "…an intentional, ongoing process… through which people lacking an equal

share of valued resources gain greater access and control over these resources." A number of

studies indicated that parent empowerment is related to a child's outcome in treatment (Taub,

Tighe, & Burchard, 2001), parent's confidence in dealing with the mental health system

(Bickman et al., 1998), child functioning (Resendez, Quist, & Matshazi, 2000), problem

behaviors in the child, mental health issues, psychological well-being, positive parenting

experience (Graves & Shelton, 2007), and adjustment problems (Taub, Tighe, & Burchard,

2001).

Empowerment can occur at three levels: service system, community political, and family

(Koren, DeChillo, & Friesen, 1992). The service system level of empowerment pertains to how

the parent obtains their own and their child's right to benefits, how services are used, and the

level of understanding with service providers. The community/political level of empowerment

measures the perception of the structure of services in the community, the relationships or

contacts with politicians, lobbying, assisting other families in gaining services, and an awareness

of rights (Itzhaky & Schwartz, 2010). The family level pertains to the immediate situation at

home (Koren et al., 1992). The family component can be predicted by mastery (i.e. feelings of control of the environment and the future), self-esteem, representation of individuals with disabilities, and participation in decision-making. The services component is predicted by self-esteem, representation of the disabled, and participation in decision-making. Lastly, the community component is explained by mastery, patterns of activity (i.e. level of participation in the children's activities), representation of the child, and a sense of belonging to the community (Itzhaky & Schwartz, 2010).

All three components of empowerment can be expressed in three different ways: attitudes, knowledge, and behaviors. Attitudes refer to what a parent feels and believes; knowledge refers to what a parent knows and can potentially do, and behaviors refer to what a parent actually does for their child (Koren et al., 1992).

Empowerment is extremely important in parents of children with an autism spectrum disorder as it affects the parent's involvement in and the outcomes of their child's services. Family empowerment is an indicator of a parent's ability to access and effectively utilize available services to achieve the desired outcomes for their children and their families (Singh, et al., 1997). Empowerment by definition counteracts powerlessness due to the child's condition (Man, 2002). Parents who feel disempowered may be less likely to fully participate in their child's treatment. This is important considering that parent involvement predicts child service use, which predicts the child's mental health status (Bickman, Helfinger, Northrup, Sonnichsen, & Schilling, 1998). In addition, for the child's treatment to be most effective, interventions must generalize into the home as well. Family empowerment is more strongly related to the child's outcome in treatment than hours of service the child receives (Taub, Tighe, & Burchard, 2001).

An increase in empowerment in parents of children with ASD will be beneficial to both

the parent and the child by increasing the parents' confidence in how to provide for their child.

Participation in workshops that increase empowerment also increased knowledge about mental

services and gave caregivers more confidence in their ability to deal with the mental health

system (Bickman et al., 1998). Considering that, an enhanced understanding of self-efficacy and

parent empowerment is extremely important for treatment providers (Scheel & Rieckmann,

1998). Treatment providers can encourage parent empowerment and involvement by including

the parents in the treatment and giving them control of aspects of the treatment. Caregivers who

are more empowered (i.e. perceive themselves as more competent, knowledgeable, efficacious,

and advocates of the service system) have children who function better (Resendez, Quist, &

Matshazi, 2000). Despite the extra need for advocacy in parents of children with an ASD, the

levels of empowerment for parents of children with and without developmental disorders do not

differ (Nachshen & Minnes, 2005).

Empowerment varies among caregivers based on several different factors. Both relational

and participatory help giving styles are associated with empowerment in families of children

with a disability (Dempsey & Dunst, 2004). Lack of empowerment is a critical issue for parents

of children with psychological abnormalities. In families of children with severe emotional

disturbances, empowerment was found to be significantly negatively related to whether or not

the family is in crisis, difficulty in paying bills, worry, hardiness, mental health problems,

worsening mental health, burden, and positive parenting experience. In addition, higher levels of

family empowerment predicted lower levels of problem behavior in the child (Graves & Shelton,

2007).

Family empowerment is inversely related to child adjustment problems (Taub, Tighe, & Burchard, 2001), and child behavior problems have an indirect negative effect on family empowerment (Nachshen & Minnes, 2005). Taube et al. (2001) surveyed parents and caregivers of 131 children receiving comprehensive mental health services and found that family empowerment increased over time when children were participating in services. In addition, total family empowerment, as measured by the Family Empowerment Scale Parent (Koren et al., 1992) was related to a decrease in child adjustment problems. Two of the subscales (family and service system empowerment) were significantly related to a decrease in adjustment problems while community empowerment was not. Empowerment is negatively related to parent mental health problems and child problem behavior in families of children with an ASD (Weiss et al., 2012).

Parent empowerment is extremely important to a child with an ASD as it increases the parent's involvement in services (Resendez, Quist, & Matshazi, 2000) and decreases the child's behavior problems (Graves & Shelton, 2007). However, the effect of empowerment on the parents themselves is often overlooked. While some scholars may see empowerment as one of many coping skills, others consider empowerment to be a more pervasive way of thinking and behaving. A higher level of empowerment can have an effect on how parents deal with stress (CITE) but also has implications in other areas of the parent's life. Considering empowerment separately from coping skills allows us to determine if higher levels of empowerment promote certain ways of coping with stress. Providing parents of children with an ASD with both ways of coping and increasing empowerment will give them more ways to increase their overall outcomes.

Understanding empowerment in parents of children with an ASD is vital since it has effects on so many aspects of the family's life. For the child, parent empowerment is related to a child's outcome in treatment, adjustment problems (Taub et al., 2001), child functioning (Resendez et al., 2000), and problem behaviors in the child (Graves & Shelton, 2007). Though the effects of parent empowerment on the parent themselves are often overlooked it is related to the parent's confidence in dealing with the mental health system (Bickman et al., 1998), whether or not the family is in crisis, difficulty in paying bills, worry, hardiness, mental health problems, worsening mental health, burden, and positive parenting experience (Graves & Shelton, 2007).

Coping & empowerment.

Levels of empowerment in parents of children with an ASD differ in relation to the types of coping skills used, as some coping skills seem to increase empowerment and others do not. Parents of children with autism who cope with receiving the diagnosis by joining a support group had significant increases in all three aspects of empowerment (service system, community political, and family) after six weeks of participating in the support group (Banach, Iudice, Conway, & Couse, 2010). This suggests that social support will have a positive effect on empowerment. Neely-Barnes & Dia (2008) found that increasing parents' level of empowerment and changing the way they cope were both effective ways of reducing stress in parents of children with disabilities. They found that empowerment was most closely related to problem-focused coping and that facilitating an increase in either one were effective strategies to reduce parent stress. Empowerment is related to higher use of problem-focused coping since parents are less likely to avoid situations with their child or care providers when they have confidence in their ability to handle them (Weiss et al., 2012).

Some scholars define empowerment as a form of coping (Ekwall, Sivberg & Hallberg, 2007; Luong et al., 2009) and have found it to be one of the most frequently used form by older caregivers (i.e. ages 75 and up; Ekwall et al., 2007). Luong et al. (2009) found that Southeast Asian parents of children with an ASD usually used denial or passive coping as their first form of coping and then moved to increasing empowerment as the next phase of coping. This often occurred due to parents becoming anxious about their child's condition and wanting more answers than they were receiving. Increasing empowerment allowed them to have some control over their uncertainties and reduced feelings of powerlessness when they felt others were not taking their concerns about their child seriously (Luong, et al., 2009). This suggests that coping skills that focus on acting and taking control are related to higher levels of empowerment.

Increasing empowerment could be another way for parents to cope and ultimately decrease parent stress since seeking help from human service bureaucracies tends to further aggravate parent stress (Young, Ruble, & McGrew, 2009). Thompson et al. (1997) surveyed 270 families who had children with different disabilities and were eligible for an early intervention program in Michigan. Using the Family Empowerment Scale (FES) and the Questionnaire on Resources and Stress, they found that stress was moderately negatively associated with empowerment. Turte, Correa, da Luz, and Fischer (2012) assessed empowerment as a coping strategy in young people in the workplace and found that effective coping strategies should include both empowerment and autonomy. Empowerment is more highly related to coping strategies that are considered positive or effective.

Different forms of coping effect empowerment differently. Man (2002) found that caregivers of persons with traumatic brain injuries (TBI) adopted different strategies for empowering themselves throughout their individual coping processes. Different families used

different forms of coping in order to increase their empowerment, and not every family

participant became empowered. Some coping factors that seemed to lead to empowerment

included: awareness of one's own powerless state, giving and accepting support, flexibility to

adjust life goals, strong motivation, a desire to master the situation, and clear personal

expectations. Weiss et al. (2012) suggest that parents need to be provided with both skills to

support their child's experience (empowerment) and coping strategies to deal with their own

emotions.

The present study will look at the effect of different coping skills used on levels of

empowerment. An increase in empowerment can lead to use of different coping skills, and some

coping factors seem to lead to an increase empowerment. Therefore, in this study, empowerment

will not be conceptualized as a coping skill but a separate construct that may be related to

coping.

Empowerment & life satisfaction.

Family empowerment plays a significant role in life satisfaction or quality of life in

parents of children with an ASD. In a study of 228 parents of children diagnosed with an ASD,

empowerment (as measured by the Family Empowerment Scale; Koren et al., 1992) was found

to be significantly positively related to quality of life (Weiss & Lunsky, 2011). Family

empowerment was found to be positively related to parent satisfaction in parents of children

receiving mental health services; the more empowered the parent was the more satisfied they

were with services received for their child (Resendez, Quist, & Matshazi, 2000). Treatment

models that are effective in increasing empowerment are associated with improved family

functioning, (Cunningham, Henggeler, Brondino, & Pickrel, 1999) higher mental health quality

of life in people with diabetes, (Sugiyara, Steers, Wenger, Duru, & Mangione, 2015) and higher

work satisfaction (Seibert, Silver, & Randolph, 2004). In addition, Ekwall et al. (2007) found

that for older caregivers, empowerment was one of the most frequently used coping strategies

and those with a higher quality of life considered it to be more helpful than others did.

Adults with disabilities were surveyed to determine a relationship between empowerment

and the work domain of quality of life (QOL). Empowerment was determined to exert a great

deal of influence on the QOL work domain; those who were more empowered were more likely

to be optimistic concerning their work QOL (Tschopp, Frain, & Bischop, 2009). Both

empowerment and quality of life of the parent have a positive effect on the well-being of the

child (Dellve et al., 2006).

Empowerment is an extremely important topic for parents of children with an ASD due to

the constant need for advocacy for their child. However, there has not been much research done

on the global outcomes of an increase in empowerment for this population. This study will seek

to add to the base of literature by determining if there is a relationship between family

empowerment and parents' perceived life satisfaction.

Rationale

It is vital not only to determine what types of coping skills are being used by parents of

children with an ASD, but also which ones are related to a higher satisfaction with life. In

addition, it is important to see how parent empowerment is related to parents' level of life

satisfaction. Examining the relationships of coping mechanisms and a higher level of

empowerment on a higher life satisfaction will be useful to professionals working with parents of

children with autism and developing effective interventions for this population. Understanding

the effects of coping behaviors on this population is important for both the children with an ASD

and their parents, as lower stress levels of parents will benefit the children as well.

The literature on coping mechanisms exists to show relationships of types of coping with day-to-day affect, but is lacking in the area of how different mechanisms affect long-term variables of well-being. In response, this study will examine the relationship between types of coping and life satisfaction. In addition, research on coping and empowerment among parents of children with an ASD is lacking in the United States. Resources for and social attitudes towards individuals with an ASD differ between countries, therefore stress levels and types of coping may also differ between countries. Therefore, a study in the United States on the coping mechanisms and level of empowerment of parents of children with an ASD will add to the generalizability and external validity of the already existing studies.

Parents are increasingly being included in the treatment of their children. Efforts and resources are needed to provide parents of children with an ASD with support. Parents who are not empowered are unable to procure these treatments for their children. Services for children with an ASD should aim to become more holistic and involve the family more. This type of approach could focus on a wide range of support programs that strengthen the families' resources in order to increase their ability to accept and respond to the needs of their children (Singh et al., 1995). To fully involve the parents in these services, the parents must have some feeling of empowerment. These supports and changes cannot be funded or created without research and empirical support of what strategies are useful to these parents.

Parents who are empowered will be more successful in getting treatments for their child, but research is lacking on how this will help the parents themselves. By investigating the relationships of family empowerment to satisfaction with life, this research will begin looking for positive influences that empowerment will have on the lives of parents of children with an ASD.

In addition, by finding out if different coping mechanisms are correlated with higher levels of empowerment, programs can be developed to teach these coping skills.

Research Question

The current study will examine the relationships among coping strategies, empowerment and life satisfaction in parents of children with an ASD. The research question is as follows: What is the relationship of coping skills and empowerment to life satisfaction?

Methods

Sample.

Sample size was 300 **caregivers, consisting of** parents (97%), step-parents (.3%), grandparents (1%), or other primary caregivers (1.7%) of children with an Autism Spectrum Disorder. The average age of the caregiver was 41.45 (SD=7.802). Caretaker age was coded into four categories: ages 20-39 (43.1%), 40-49 (41.3%), 50-59 (14.1%), and 60 and older (1.4%) but was still considered a continuous variable in the analysis. Both male and female caregivers were sampled. 279 of the participants (93%) were female and 21 were male (7%). Most of the participants (98.3%) identified English as their primary language. A majority of the participants (266; 89%) identified White/Caucasian., while the remainder (34; 11%) identified as Non-White. The largest minority (4%) identified as African American or Black. Parent's education level was coded into for categories: high school/some college (22.7%), a two-year degree (13.7%), a four-year degree (34.7%), and graduate school including a masters, doctorate, or professional degree (29%).

Parents were recruited through various service providers in the United States and through the snowball method. Parents recruited through service providers were encouraged to send the survey link to other parents and guardians of children with an ASD. In addition, with the permission of the facilitators of support group Facebook pages, a link to the survey was posted

on Facebook pages that serve as support groups for parents of children with Autism Spectrum

Disorder. Those participants were likewise be encouraged to share the survey link with other

parents of children with an ASD.

The children were between the ages of two and 26 ($\bar{x}$=10.07, SD=5.09). The variable of

child age was coded into four categories: ages 2-5 (23.7%), 6-10 (33.7%), 11-17 (36.7%), and 18

and older (6%), but was considered continuous for the analysis. Caregivers reported that the

child received the diagnosis of ASD between the ages of one and seventeen ($\bar{x}$=3.91, SD=2.53).

A majority of participants (71.2%) reported that their child received the diagnosis before the age

of 5. The variable of child's diagnosis age was coded into five categories: ages 1-2 (39.8%), 3-4

(31.4%), 5-6 (13.7%), 7-9 (10.4%), and 10 and over (4.7%), but was considered continuous for

the analysis.

Instruments.

Brief COPE (Carver, 1997) The Brief COPE measures which coping styles are most

frequently used by an individual. The 28 item Brief COPE has participants rate each item on a 4-

point scale ranging from one (I haven't been doing this at all) to four (I've been doing this a lot).

The scale contains statements of typical coping responses (e.g. "I've been getting help and

advice from other people"). For the full scale, see Appendix B. Two items contribute to each of

the 14 subscales each reflecting a conceptually different coping style: (1) active coping, (2)

planning, (3) positive reframing, (4) acceptance, (5) humor, (6) religion, (7) using emotional

support, (8) using instrumental support, (9) self-distraction, (10) denial, (11) venting, (12)

substance use, (13) behavioral disengagement, (14) self-blame. Interestingly, there are not strong

correlations between the subscales. Since the coping techniques are empirically separable, it is

possible to study the effects of each separately. A factor analysis demonstrated that the questions

load into different factors and are conceptually distinct categories (Carver, 1989). For instance, disengagement strategies were inversely related to more functional strategies.

The COPE Inventory was designed by Carver et. al (1989) with the purpose of identifying use of different coping responses. Carver, Scheier, & Weintraub (1989) measured the internal consistency at an acceptably high Cronbach's alpha (all the values were above .5). The COPE is used to measure dispositional coping (Carver et al., 1989).

Satisfaction with Life Scale (SWLS) (Diener et al., 1985) The SWLS is a self-report measure of global cognitive judgments of one's life satisfaction. It is a five item Likert-type scale. Participants will indicate on a 7-point scale from one (strongly disagree) to seven (strongly agree) how much they agree with each item (e.g. "in most ways life is close to my ideal"). For the full scale, see Appendix C. The scores of the SWLS can range from 5 to 35, with 20 being a neutral midpoint. Most groups fall in the range of 23-28, which represents slightly satisfied to satisfied.

The SWLS is negatively correlated with clinical measures of distress and depression (correlation with the Beck Depression inventory). In the initial testing of the scale, Diener et al. (1985) reported a coefficient alpha of .78 for the scale. The two month test-retest stability coefficient was .82. The researchers also determined that the SWLS was well suited for multiple age groups and has potential as a cross-cultural index of life satisfaction. For the sample of this study the Cronbach's Alpha was sufficiently high ($\propto$= .893).

Family Empowerment Scale (FES) (Koren et al., 1992) The FES is designed to assess empowerment in parents and other family caregivers whose children who have emotional disabilities. It is a 34-item Likert-type scale. Participants will indicate on a 5-point scale from one (not at all true) to five (very true) how true they consider items (e.g. I know what to do when

problems arise with my child). For the full scale, see Appendix D. The scores on the FES can

range from 34- 170 with higher scores showing more empowerment (Koren et al., 1992). The

scale specifies three levels of empowerment (family, the service system, and the

community/political) and three ways in which they are expressed (attitudes, knowledge, and

behaviors) (Singh et al., 1995). The family level of empowerment relates to how the parent of a

disabled child copes within the family system, including the relationships between members of

the family (e.g., I know what to do when problems arise with my child). The service system level

of empowerment pertains to how the parent obtains their own and their child's right to benefits,

how services are used, and the level of understanding with service providers (e.g., I am able to

make good decisions about what my child needs). The community/political level of

empowerment measures the perception of the structure of services in the community, the

relationships or contacts with politicians, lobbying, assisting other families in gaining services,

and an awareness of rights (e.g., I feel I can have a part in improving services for children in my

community; Itzhaky & Schwartz, 2010). Internal reliability (alpha coefficient =.88), test-retest

reliability (r= .83), and internal consistency (Cronbach's alpha = .87) are reported to be high

(Weiss & Lunsky, 2011). In the current study, the scale was adjusted to include only 28

questions in which the Cronbach's Alpha was sufficient for Community/Political ($\propto$= .861),

Service System ($\propto$= .857), and Family ($\propto$= .816). The last six questions were left out of the

survey by mistake, however the Cronbach's Alpha for the total scale was sufficiently high for the

total empowerment scale ($\propto$= .923).

Procedure.

Participants were sent the survey link through e-mail by a provider giving service to their

child or gained access to it through a Facebook support group page. The link took participants to

the Qualtrics website where they responded to the survey anonymously. Participants first saw the

Informed Consent document. At the end of that document there was a box that says "I agree" for

participants to check to indicate their consent to participate. If they did not check the box or they

clicked "I do not agree," they did not have access to the survey and were taken to the end page to

thank them for their time. If they checked the box, they received the Satisfaction with Life Scale

(Diener et al., 1985), the Brief COPE (Carver,1997), the Family Empowerment Scale (FES), and

a few demographic questions. The demographic questions appeared first, and the order of the

scales was randomized between participants. At the end, a thank you message thanked

participants for their time and asked them to pass the survey link along to other potential

participants to increase participation levels.

Analysis

Since the Brief COPE (Carver, 1997) has 14 subscales, it has sometimes been divided

into several factors (Brown, Westbrook, & Challagalla, 2005; Ben-Zur, 2009; Lai, Goh, and

Sung, 2015). A factor analysis with principal component analysis with a Varimax rotation and an

associated reliability analysis for the COPE scale was conducted. The four -factor model was the

same in both Varimax and Promax rotations, and seemed to be the most conceptually

meaningful. Of the three, four, five, and six factor analyses, only the four-factor analysis

reflected the original division of 14 subscales. The first factor included the subscales of self-

distraction, denial, behavioral disengagement, venting, humor, and self blame ($\propto$= .764) and

will be referred to as Avoidant Coping. The second factor included the subscales of active

coping, planning, and acceptance ($\propto$= .788) and will be referred to as Action Coping. The third

factor included the subscales of emotional support and instrumental support ($\propto$= .834) and will

be referred to as External Support Coping. The fourth factor included the subscales of substance

use, positive reframing, and religion ($\propto$= .591) and will be referred to as Paradigm Shift

Coping.

　　　　To replace missing data, first the prevalence of missing data for all variables in the

analytic model was examined. Although all variables in the analytic model had less than 10%

missing data, a pooled (based on five imputed samples) multiple imputation method was used to

maintain sample as well as to be parsimonious in the data with SPSS v. 23.

　　　　To answer the research questions, a general linear model (GLM) analysis was used to

investigate the effects of the predictors (i.e., demographic variables, empowerment, and coping

skills) on the caregivers' life satisfaction. GLM regression is an extension of linear multiple

regression which allows one to predict the value of a variable (i.e., life satisfaction) based on the

value of two or more other variables (demographic variables, empowerment, and coping skills).

Results.

　　　　Overall, the regression model was significant, $F(16,270)$=6.932; R^2= .304; Adjusted

R^2=.26 (see Appendix A). The model accounted for 26% of the variance in life satisfaction. The

average life satisfaction score was in the neutral to slightly dissatisfied range ($\bar{x}$= 19.906)

according to the benchmarks set by Diener and colleagues (1985). See Appendix C for a

complete list of the scoring benchmarks. In the demographic variables, white caregivers are more

likely to be satisfied with their life than non-white parents (t= 3.030, p=.002).

　　　　Regarding coping variables, COPE subscale one, Avoidant Coping, (β =-.272, t_{286} =-

4.440, p < .000) and COPE subscale three, External Support Coping, (β =. 164, t_{286} =2.606, p <

.01) were both significant predictors of life satisfaction. COPE subscale one had a negative effect

on life satisfaction while COPE subscale three had a positive effect. In the empowerment

variables, the Family subscale of the Empowerment Scale ($\beta =. 290$, $t_{286} = 3.145$, $p < .01$) was significantly positively related to life satisfaction.

Discussion

As previous studies indicated, parents of children with autism reported life satisfaction within the neutral or slightly dissatisfied range and people in this range generally would like to see their satisfaction with life increase (Fuentes, 2012). This demonstrates that this is a population in need of more research and clinical attention.

Consistent with earlier studies, Avoidant Coping skills were negatively predictive of life satisfaction (Glidden & Natcher, 2009) and are thus considered ineffective (Weathersby, 2007). The skills that are included in this subscale are Self-Distraction, Denial, Behavioral Disengagement, Venting, Humor, and Self-Blame. People who use avoidant types of coping are less happy day-to-day (Ben-Zur, 2009) and less satisfied with their life. For example a parent may be in denial about their child's diagnosis. They may refuse services and attempt to raise their child in the same way they would a neurotypical child. A parent may use self-blame as a coping strategy by believing it is their fault that their child has autism. This suggests that parents or caregivers of children with an ASD who are using these coping skills are not benefiting themselves as they may believe they are. Parents may disengage because they feel alone in their situation or that it is unmanageable, and denial was reported in one study as the first used and most used coping strategy for mothers of children with disabilities (Luong et al., 2009; Woodman & Hauser-Cram, 2013).

The External Support coping (Instrumental Support and Emotional Support) positively predicted life satisfaction. A parent of a child with autism may seek instrumental support by asking their child's therapist for advice on what to do with certain behaviors their child is

exhibiting. A parent may cope by seeking emotional support by asking for help from family and friends to deal with their emotions. This suggests, as predicted (Meral et al., 2013), that parents who see themselves as having more external supports are more satisfied with their lives. Consistent with the previous literature findings that social and family activities are related to higher quality of life (Cappe, 2011), the current study suggests that the more social support a parent has the more satisfied with their life they will be. Though there are some support groups available for parents of children with autism, they are only recently becoming available and are not widely advertised (Nachshen & Minnes, 2005). The current research suggests that parents would be more satisfied with their life if they utilized more external supports whether it be family, friends, group therapy, individual therapy, or supplemental funding from grants or other sources. This is particularly important since previous studies indicate that parents of a child with an ASD report less social and community support than parents of children with no disability or a different diagnosis (Nachshen & Minnes, 2005).

Regarding empowerment, family level was found to significantly predict life satisfaction. All three subscales such as system, service, and community levels were not associated with life satisfaction. Consistent with previous studies, empowerment is positively related to quality of life (Weiss & Lunsky, 2011). The family level of empowerment pertains to the immediate situations in the family system (e.g., I feel like my family life is under control; When problems arise with my child, I handle them pretty well). It is likely that parents are more concerned about being in control of their immediate everyday situation than they are about community and service aspects. Even though the service system and community/political levels were not significant in this model, they may be indirectly related to life satisfaction since the roles of a parent of a child with an ASD include advocacy for their child both publically and in the service

system. More research should be done to explore this relationship further. It is possible that

parents are not able to focus on levels of empowerment that deal with the systems external to

their family (macro-systems) without first feeling empowered in their own family.

Implications for Counselors

Overall Avoidant Coping was found to be negatively associated with life satisfaction

while External Support Coping and Family Empowerment were found to be positively associated

with life satisfaction. In practice, parents and caregivers of vulnerable populations are often

overlooked in favor of providing services to the person they are caretaking (Gerkensmeyer et al.,

2008). The current findings indicate that changing coping skills can improve the parent's

objective satisfaction of their own life. With the high levels of stress in parents of children with

an ASD (Lee et al., 2008) and knowledge of how to increase their satisfaction with life, more

counselors should target providing services to parents of children with ASD.

Counselors who are working towards decreasing parents' use of Avoidant Coping Skills

(Self-Distraction, Denial, Behavioral Disengagement, Venting, Humor, and Self-Blame) have

several options of strategies available to them. One strategy is to educate parents on the ASD

diagnosis. Receiving an ASD diagnosis for your child has been identified as a life changing

event (Fleischman, 2004). A significant amount of parents (10%) immediately began to blame

themselves (Hutton & Caron, 2005). Doctors often do not have the time to spend fully explaining

the diagnosis and implications and parents are left to figure it out on their own. Counselors can

alleviate self-blame and denial surrounding the diagnosis by explaining it more fully and giving

caregivers a chance to process it. Another strategy would be to help the parent develop ways to

respond to stressors surrounding their relationship with their child. If parents are more confident

that they can handle these stressors, they are less likely to disengage and avoid stressful situations.

Consistent with the literature External Support Coping Skills (Emotional Support and Instrumental Support) which are both considered effective coping (Weathersby, 2007), are associated with higher life satisfaction, these results suggest that support from a therapist would be highly beneficial to these parents. Specifically, therapists should provide psychoeducation groups for parents who are seeking instrumental support (i.e. advice on parenting child with an ASD) and provide group therapy to those who are seeking emotional support (i.e. gaining comfort and understanding from others). In addition, counselors should develop programs to educate parents about their child's diagnosis and teach them to build a support system so they don't feel alone in their situation and can share experiences with other parents of children with an ASD who will understand them.

In addition, this research demonstrates that therapies that facilitate an increase the parents' levels of family empowerment will increase satisfaction with life. The primary aspect of parent empowerment that should be addressed in therapy is gaining control over the immediate family system. Though many systems therapists may look at the family and feel that it is necessary to address the larger community systems as well, counselors may want to consider first helping the client to see what they have control over in their own family system. Helping the client to find more ways to be empowered in their own family system will provide an example for promoting community and service empowerment, which will greatly benefit the child. However, for a counselor whose primary client is the parent, this research suggests that they first focus on family empowerment. Specifically, to encourage their increase in family empowerment counselors can assist parents in developing ways to solve problems with their child, increasing

their confidence, and helping them to distinguish what they have control over and what they

don't. Since family empowerment can be predicted by feelings of control, self-esteem, local

representation of individuals with disabilities, and participation in decision-making (Itzhaky &

Schwartz, 2010), the therapist can help to facilitate clients increasing their own empowerment by

having them direct and make decisions about their own treatment.

Limitations

Recruiting participants primarily through service providers for children with an Autism

Spectrum Disorder may have biased the results since not all caregivers receive services for their

child. Services received may have an effect on stress, which is related to coping as evidenced in

the previous literature. In addition, with data being collected online, only parents who have

access to a computer and the Internet were able to participate, which limits the generalizability of

the sample. Participants recruited through service providers were given the option of a paper

copy, but none chose that option. In addition, use of the snowball method in recruiting may limit

the generalizability of the results.

There is a potential limitation in self-report bias. Parents were much less likely to report

use of coping skills that seem obviously negative such as Denial ($\bar{x}$=2.4), Substance Use ($\bar{x}$=2.7),

and Behavioral Disengagement ($\bar{x}$=2.8). Although this bias is slightly controlled for through the

nature of anonymous surveys, more observational research needs to be done on this population to

determine what types of coping skills are most frequently used. There may have also been a

social desirability bias in answering the questions on the Satisfaction With Life Scale.

Six questions were left out of the Family Empowerment Scale (Koren et al., 1992). This

was a mistake and may have had an effect on the results. However, the missing questions were

spread evenly through the subscales and the Cronbach's Alpha for the overall scale ($\propto$= .923)

and the subscales family ($\propto$= .816), Community/Political ($\propto$= .861), and Service System

($\propto$= .857) were sufficient to maintain reliability.

Conclusion

The findings of the current study demonstrated avoidant coping, external support coping

and family empowerment affect caregivers' life satisfaction negatively or positively. Given the

high stress levels of parents of children with autism and previous findings that parents of

children with autism tend to use ineffective coping skills, the current findings provide

researchers and clinicians with meaningful information in providing services to this population

by encouraging them to seek emotional and instrumental support. Further, this may provide

insight to designs for effective strategies to facilitate caregivers to increase empowerment, while

discouraging them from using Avoidant coping skills (i.e., Self Distraction, Denial, Behavioral

Disengagement, Venting, Humor, Self-Blame). More Therefore, this study's findings may make

a significant contribution to the body of literature that could draw attention to mental health

practitioners and the counseling profession to help parents increase their levels of family

empowerment and use more effective coping skills.

Appendix A

Table 1. Means of demographic variables.

Demographic Variable	Mean
Parent Age	41.38
Child Age	10.06917
Child Age at Diagnosis	3.90069

Table 2. Frequencies of demographic variables.

	Frequency	Percent (%)
Parent Race		
White	266	88.7
Non-White	33	11
Parent Primary language		
English	294.6	98.2
Other	5.4	1.8
Parent Age		
20-39	128.8	42.6
40-49	122.8	40.6
50-59	42.2	13.9
60+	4.2	1.4
Parent Education		
High School/Some College	68	22.7
2 Year Degree	41	13.7
4 Year Degree	104	34.7
Graduate School	87	29
Caregiver Relationship		
Parent	291	97
Step-Parent	1	.3
Grandparent	3	1.0
Other	5	1.7
Child Age		
2-5	71	23.7
6-10	101	33.7
11-17	110	36.7
18+	118	6.0
Child's Age at Diagnosis		
1-2	119.8	39.9
3-4	94	31.3
5-6	41.2	13.7
7-9	31	10.3
10+	14	4.7

Table 3. Average use of coping skills.

Coping Skill	Range	Mean
Active Coping	2-8	6.4061
Denial	2-8	2.412
Substance Use	2-8	2.6711
Emotional Support	2-8	5.0912
Instrumental Support	2-8	5.2804
Behavioral Disengagement	2-8	2.7857
Venting	2-8	4.0785
Positive Reframing	2-8	5.7492
Planning	2-8	6.4764
Humor	2-8	3.9327
Acceptance	2-8	6.7191
Religion	2-8	4.6216
Self Blame	2-8	4.4343
Self Distraction	2-8	4.8193

Table 4. *Factor Loadings of COPE Variables (N = 300)*

	Factor Loading-1	Factor Loading-2
Avoidant Coping		
1. Self Distraction	.395	.599
	.447	.400
2. Denial	.480	.574
3. Behavioral Disengagement	.525	.454
4. Venting	.450	.510
5. Humor	.619	.650
6. Self-Blame		
Active Coping		
7. Active Coping	.631	.629
8. Planning	.665	.715
9. Acceptance	.639	.548
External Support Coping		
10. Emotional Support	.793	.727
11. Instrumental Support	.784	.723
Paradigm Shift Coping		
12. Substance Use	-.562	-.528
13. Positive Reframing	.491	.487
14. Religion	.775	.781

Table 5. Correlations.

		Empowerment	COPE 1	COPE 2	COPE 3	COPE 4
Empowerment	Pearson Correlation	1	-.193**	.277**	.255**	.131*
	Sig. (2-Tailed)		.002	.000	.000	.033
	N	271	258	264	266	264
COPE 1	Pearson Correlation	-.193**	1	.061	.060	.191**
(Avoidant Coping)	Sig. (2-Tailed)	.002		.309	.315	.001
	N	258	286	280	282	282
COPE 2	Pearson Correlation	.277**	.061	1	.415**	.224**
(Action Coping)	Sig. (2-Tailed)	.000	.309		.000	.000
	N	264	280	291	287	287
COPE 3	Pearson Correlation	.255**	.060	.415**	1	.300**
(External Support	Sig. (2-Tailed)	.000	.315	.000		.000
Coping)	N	266	282	287	288	288
COPE 4	Pearson Correlation	.131*	.191**	.224**	.300**	1
(Paradigm Shift	Sig. (2-Tailed)	.033	.001	.000	.000	
Coping)	N	264	282	287	288	293

Note: *Significant at the p <.05 level; **Significant at the p<.01 level

Table 6. Pooled Data Parameter Estimates

	β	Standard Error	t
Ethnicity 1 (White)	.635	.208	3.060**
Ethnicity 2 (Non-white)	.255	.244	1.046
Education Level 1	-.331	.157	-2.105*
Education Level 2	.069	.175	.396
Education Level 3	.041	.137	.302
Education Level 4	0	.	.
Gender 1 (Male)	.018	.224	.060
Gender 2 (Female)	0	.	.
Parent Age	-.158	.095	-1.664
Child Age	-.073	.083	-.880
Child Age at Diagnosis	-.058	.052	-1.109
COPE 1 (Avoidant Coping)	-.272	.061	-4.440**
COPE 2 (Action Coping)	.008	.062	.127
COPE 3 (External Support Coping)	.164	.063	2.606**
COPE 4 (Paradigm Shift Coping)	.073	.060	1.204
Family Empowerment	.290	.092	3.145**
Service System Empowerment	-.111	.087	-1.273
Community/Political Empowerment	.002	.079	.029

**Significant p<.01; *Significant p<.05

Appendix B

Brief COPE

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by clicking one response for each, using the response choices listed just below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU--not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

- 1: I haven't been doing this at all
- 2: I've been doing this a little bit
- 3: I've been doing this a medium amount
- 4: I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.

27. I've been praying or meditating.
28. I've been making fun of the situation.

Scales are computed as follows (with no reversals of coding):
Self-distraction, items 1 and 19
Active coping, items 2 and 7
Denial, items 3 and 8
Substance use, items 4 and 11
Use of emotional support, items 5 and 15
Use of instrumental support, items 10 and 23
Behavioral disengagement, items 6 and 16
Venting, items 9 and 21
Positive reframing, items 12 and 17
Planning, items 14 and 25
Humor, items 18 and 28
Acceptance, items 20 and 24
Religion, items 22 and 27
Self-blame, items 13 and 26

Factors are computed as follows:
1- Avoidant Coping
Self Distraction, Denial, Behavioral Disengagement, Venting, Humor, Self-Blame
2 – Active Coping
Active coping, Planning, Acceptance
3 – External Support Coping
Emotional Support, Instrumental Support
4 – Paradigm Shift Coping
Substance use, Positive Reframing, Religion

Appendix C

Satisfaction with Life Scale

Instructions: Below are five statements that you may agree or disagree with. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7: Strongly agree
- 6: Agree
- 5: Slightly agree
- 4: Neither agree nor disagree
- 3: Slightly disagree
- 2: Disagree
- 1: Strongly disagree

1. In most ways my life is close to my ideal.
2. The conditions of my life are excellent.
3. I am satisfied with my life.
4. So far I have gotten the important things I want in life.
5. If I could live my life over, I would change almost nothing.

Scoring: Though scoring should be kept continuous (sum up scores on each item), here are some cutoffs to be used as benchmarks.

- 31-35: Extremely satisfied
- 26-30: Satisfied
- 21-25: Slightly satisfied
- 20: Neutral
- 15-19: Slightly dissatisfied
- 10-14: Dissatisfied
- 5-9: Extremely dissatisfied

Appendix D

Family Empowerment Scale

These questions ask about several areas of your life- your family, your child's services, and your community. The questions include many different activities that parents may or may not do. For questions that do not apply to you, please answer "Never". Also, we know that other people may be involved in caring for and making decisions about your child, but please answer the questions by thinking about your own situation. Feel free to write any additional comments at the end.

- 1: Not at All True
- 2: Mostly Not True
- 3: Somewhat True
- 4: Mostly True
- 5: Very True

1. I feel that I have the right to approve all services my child receives.
2. When problems arise with my child, I handle them pretty well.
3. I feel I can have a part in improving services for children in my community.
4. I feel confident in my ability to help my child grow and develop.
5. I know the steps to take when I am concerned my child is receiving poor services.
6. I make sure that professionals understand my opinions about what services my child needs.
7. I know what to do when problems arise with my child.
8. I get in touch with my legislators when important bills or issues concerning children are pending.
9. I feel my family life is under control.
10. I understand how the service system for children is organized.
11. I am able to make good decisions about what services my child needs.
12. I am able to work with agencies and professionals to decide what services my child needs.
13. I make sure I stay in regular contact with professionals who are providing services to my child.
14. I have ideas about the ideal service system for children.
15. I help other families get the services they need.
16. I am able to get information to help me better understand my child.
17. I believe that other parents and I can have an influence on services for children.
18. My opinion is just as important as professionals' opinions in deciding what services my child needs.
19. I tell professionals what I think about services being provided to my child.
20. I tell people in agencies and government how services for children can be improved.
21. I believe I can solve problems with my child when they happen.
22. I know how to get agency administrators or legislators to listen to me.
23. I know what services my child needs.
24. I know what the rights of parents and children are under the special education laws.
25. I feel that my knowledge and experience as a parent can be used to improve services for children and families.

26. When I need help with problems in my family, I am able to ask for help from others.
27. I make efforts to learn new ways to help my child grow and develop.
28. When necessary, I take the initiative in looking for services for my child and family.

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