EXPLORING THE PROTECTIVE FACTORS INVOLVED IN MAINTAINING COUPLES' RELATIONSHIPS WHEN RAISING A CHILD WITH AUTISM SPECTRUM DISORDER

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Abstract

Currently there is room for increased exploration into the protective factors that help to mitigate relationship discord and increase relationship satisfaction in couples who are raising a child or children with autism spectrum disorder (ASD). This study considered the experiences and perspective of couples who are raising a child with ASD together. The researcher employed qualitative methods to conduct semi-structured interviews with eight couples to gather a rich understanding of their perspectives, understandings, and experiences in raising a child with ASD. The researcher's analysis of the data revealed a number of themes that emerged from these semi-structured interviews. The major themes that highlight couples' resilience are Commitment, Communication, Adaptation, and Positive Outlook. Further research should be conducted to explore the needs and perspectives of couples raising children with ASD to continue to develop and implement appropriate services for this population.

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Chapter 1: Introduction

The dissolution of a relationship (marriage or common-law union) can have a dramatic impact on families, extending beyond the couple. Statistics Canada collected data under the theme of families during the 2011 *General Social Survey*.

> The target population included all persons 15 years and older living in the ten provinces of Canada, excluding full-time residents of institutions. In 2011, all respondents were interviewed by telephone. Households without telephones or with only cellular phone service were excluded. (Sinha, 2014)

Analysis from this survey indicated that about 1.2 million Canadians with children 18 years or younger were separated or divorced. Specifically, from this population 49% of these couples ended a common-law relationship and 44% ended a legal marriage. Of these couples, 38% had children together at the time of their relationship was dissolved. Additionally, 24% of couples had at least one child 18 years or younger at the time of their divorce or separation (Sinha, 2014). Approximately five million Canadians had separated or divorced within the previous 20 years (Sinha, 2014). Moreover, in 2008, the crude rate of divorce was 21.1 divorces per 10,000 people in Canada (Milan, 2013).

A meta-analytic study of family and marriage conducted by Twenge, Campbell, and Foster (2003) found that the marital satisfaction is lower among parents of infants versus non-parents, especially among mothers. They further found that “becoming a parent has the largest effect on marital satisfaction” (p. 580). Additionally, they found that parents with multiple children expressed greater marital dissatisfaction than parents with fewer children. Considering that marital satisfaction is linked to the parental experience it in important to review the impact that parental stress has on marital relationships. As identified by Hayes and Watson (2012) in their meta-analysis of parental stress, they note that parents of children with ASD experience more parenting stress when compared to parents of typically developing children or those with another disability. However, it is also important to note that this experience of parenting stress is not the sole experience for parents of children diagnosed with ASD.

The challenges associated with raising a child with ASD can become overwhelming for couples and have the potential to cause significant stress on their relationship (Freedman, Kalb, Zablotsky, & Stuart, 2012). The Statistics Canada *Health Report* (Miller, Shen, & Mâsse, 2016) indicated that children with neurodevelopmental disorders/disabilities, including those with ASD, are the largest identifiable subpopulation of children with disabilities and account for 7% to 14 % of all children in developed countries. According to the *Participation and Limitations Survey* (Statistics Canada, 2006), 61% of parents of children with disabilities reported that they sometimes, often, or always experience stress. Additionally, 66% of parents stated that they could be doing more for their child or children. In relation to couples' relationships, 30% of the Canadian population surveyed in this study stated that the impact of the child's or children's disability caused problems in their relationship. Conversely, 18% stated that having a child with a disability brought them closer together. Responses identified the impact having a child with a disability had on a previous marital relationship: 82% of parents stated that having a child with a disability caused stress/depression, 85% stated that it caused disagreements or arguments, 77% stated that it impacted their sleep, 50% stated that it contributed to financial difficulties, and 76% stated that it impacted separation or divorce (Statistics Canada, 2006).

As stated in a 2011 health report by Miller et al. (2016) based on the results from the Participation and Activity Limitation Survey (PALS) published by Statistics Canada, children with a neurodisability, including ASD, require specific services and supports that span the health, educational, and family and social services sectors throughout their lifetime. The varied research existing around the topic of relationship dissolution in couples raising children with ASD demonstrates the need to explore the link between having a child with a diagnosis of ASD and the impacts on stability and longevity of marital satisfaction over time (Hartley, et al., 2010; Sim, Cordier, Vaz, & Falkmer, 2016).

Raising a child with ASD can pose several unique challenges for parents, couples, and families. Families facing these unique challenges may experience an increase in vulnerability. This can be linked to the elevated levels of parenting demands, the increased number of stressors, and the decrease in responsiveness to the needs of one's partner during this time (Seltzer, Krauss, Orsmond, & Vestal, 2000).

The most current Canadian data that exists in relation to ASD prevalence has been recently published by the National Autism Spectrum Disorder Surveillance System (NASS) 2018 Report (Ofner et al., 2018). This surveillance report highlighted Canada's first reporting of national data and information to improve our understanding of ASD in Canada. From the data collected, it was identified that approximately 1 in 66 children and youth are diagnosed with ASD in Canada. From this, it was noted that males were four times as likely to receive a diagnosis of ASD than females. Specifically, NASS found that 1 in 42 males (23.9 per 1,000) and 1 in 165 females (6.0 per 1,000) aged 5–17 years old were diagnosed with ASD. This report highlighted the impacts that an ASD diagnosis has on the families stating, “an ASD diagnosis can involve significant emotional and financial challenges” (p. VI). Additionally, the NASS report suggested implications for those in health, education, and social services sectors stating that “ASD is an important issue due to the resources those living with ASD require for intervention and treatment and due to the on-going impact on the health and well-being of Canadian children, youth, adults and their families and communities” (Ofner et al., 2018, p. VI).

Before the NASS report was conducted researchers used American statistics to gain an understanding of the frequency of the disorder. Researchers and healthcare professionals accessed comparable data from the Centre for Disease Control and Prevention in the United States. Statistics from their 2010 report indicated that an estimated 14.7 out of 1000 American children aged 8 years old are diagnosed with ASD (Baio, 2014), and 13.4 out of 1000 American children aged 4 years old were diagnosed with ASD (Christensen et al., 2016). Additionally, there are no defined prevalence rates of ASD diagnoses for the province in which this study took place (Audas et al., 2015).

Autism research has been steadily increasing over the past decade, with a push from health authorities to increase support for individuals and their families affected by a diagnosis of ASD (Falk, Norris, & Quinn, 2014). Much of the research related to families and ASD is focused around early diagnosis and intervention strategies to help parents access the best care for their children (e.g. Corsello, 2005; Estes et al., 2015; Kern Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). Much of the research focuses on supporting the complex needs of the children who have received a diagnosis of ASD, but there is a gap in addressing parental needs, understanding, adaptation, and well-being after the diagnosis (Falk et al., 2014). There is a demonstrated need for more studies which specifically look at protective factors involved in maintaining a successful relationship post-diagnosis, or how to navigate life as a couple after a diagnosis (Baeza-Velasco, Michelon, Rattaz, Pernon, & Baghdadli 2013; Huber, Navarro, Womble, & Mumme, 2010; Sim et al., 2016).

Researcher Experiences

Due to the nature of the community, it can be difficult to reach families with children with ASD. This may be due to the complex needs of the children and families, busy schedules due to these needs, or challenges associated with accessing social spaces that meet higher demands for care. The positions held by the researcher have allowed for access to the community that may not otherwise be viable, and so it is important to underline these experiences here.

The researcher has 12 years of professional and volunteer experience in the area of ASD, which has contributed to the project as discussed below. During this 12-year period some of the researcher’s employment was seasonal, concurrent, and part-time and full-time. The researcher has worked full-time for a year with a local non-governmental organization (NGO) that worked exclusively with people with a diagnosis of ASD, their families, and other service providers. The responsibilities of this role included program development and conducting one-on-one sessions for individuals with ASD. Sessions were situated around topics related to participants’ challenges as a result of their diagnosis. Additionally, during this time the researcher conducted group support sessions for these individuals to address many issues social challenges associated with ASD.

Included in this 12 years of work experience, the researcher spent four of these years working part-time as an Applied Behavioural Analysis (ABA) therapist. During this time the researcher worked with children on specific skills, including: social interactions, problem behaviour management, and practical classroom strategies. Further, the researcher worked seasonally for four years in community programming in a small-sized city to provide recreational supports for children with ASD, ASD-related information sessions, and inclusive supports within the city's programming. Additionally, for five of the 12 years, the researcher has volunteered part-time with Special Olympics as a coach and national trainer for athletes with ASD. As a result of this invaluable experience the researcher has gained an intimate perspective on the local autism community in the province where the study was conducted.

The researcher has established an informed perspective of the local autism community through their extensive work and volunteer experience. This perspective was acquired through years of working directly in the community with various organizations, individuals, and families affected by ASD. The researcher's experiences informed their position within the study, as the researcher has an insider perspective, or insider knowledge, of the social issues related to the individuals with ASD. Within ethnographic research, insider knowledge is considered to occur when researchers are a part of the culture or community that they are studying (Hewitt-Taylor, 2002).

From the perspective of this study, this insider perspective was beneficial because the researcher was able to access the community, develop a rapport with children and families, and develop an awareness of current issues and the local climate. However, it is also important to mention some of the ethical implications of this position, such as personal bias, being a neurotypical researcher, as well as possible ethical considerations of having been a program facilitator and then a researcher; i.e., holding a *dual relationship.* To this end, the researcher was not employed by an ASD-serving organization during the research. Kagle and Giebelhausen (1994) have defined dual relationship as a secondary role that a professional may assume by coming in contact with the same client in a different professional setting, such as becoming an employer, business associate, family member, friend or other type of relationship. Thus, as a result of the various roles the researcher has had within the local autism community, the researcher may come in contact with past clients within this community. The researcher argues that these limitations were unavoidable due to the small size of the local community, as well as the even smaller population of the autism community and the limited resources available for this population. During this study there was one family that held a dual relationship with the researcher. This was a family that the researcher worked with in a prior professional position, three years prior to participant recruitment. The participants reached out to the researcher to participate in this study after receiving an email from a local NGO that worked exclusively with individuals with ASD. To manage this dual relationship, the researcher outlined their role as a researcher in this study, outlined the participants roles, the parameters of the study, and discussed their ability to drop out of the study at anytime before the data was analyzed. The researcher provided the couple with the supervisors contact information incase they had any additional questions or concerns regarding the study. There were no concerns noted by this couple throughout the research study. Ultimately, the overall benefits of having insider knowledge allowed for access to what can be considered a “hidden” population, which will serve the interests of the local autism community. Additionally, the researcher should consider underlining their role within the community as a researcher with insider knowledge.

The Current Study

Considering the prevalence of divorce and the increased relationship challenges of parents of children with special needs, the aim of the present study is to address the gap that exists in the literature regarding the experiences of couples with a child or children diagnosed with ASD. Ultimately, the goal of this study is to gain a better understanding of the protective factors that mitigate relationship discord in couples raising a child or children with ASD.

In this study, the researcher will explore the marital satisfaction of couples (defined as cohabiting parents) who have a child with a diagnosis of ASD, and the factors that help protect their relationships. Through this study, the researcher gathered an in-depth understanding of the participating couples' relationships, the struggles they face, and the protective factors which mitigate marital discord and support marital satisfaction. Specifically, the researcher explored the role that resilience plays in the success of these couples (i.e., their perceived overall satisfaction) and the specific traits that assist these couples through challenging times. To accomplish this, the researcher used qualitative methods to interview couples to gain a better understanding of their experiences and to identify factors that help them maintain a healthy and successful marriage. To explore this topic, the researcher posed the following research question:

> *RQ1:* What are the protective factors that mitigate relationship discord and increase relationship satisfaction when raising a child with a diagnosis of ASD?

Family resilience does not develop through avoidance of risk but through successful application of protective factors in adverse situations, from which the family emerges stronger (Benzies, & Mychasiuk, 2009). Black and Lobo (2008) suggested that a family's resilience is defined by the successful coping of family members when facing adversity. It is resilience that allows them to thrive and cope through support and cohesion. The aim of this study was to highlight these protective factors while examining couples raising a child with ASD. Specifically, the researcher focused on couples who have a child who has been living with a diagnosis of autism for at least five years, and who have had at least one year of experience functioning within the school system. The purpose of this criteria was to ensure that families with young children participating in the study had had the opportunity to deal with pre-school supports and encounter the possible challenges associated with the transition to the school system. It is necessary to include the second criterion because Marsh, Spagnol, Grove, and Eapen (2017) found in their systematic review of the literature (*n* = 20 studies) that children with ASD tend to be less emotionally prepared for the transition to school than their peers. They further reported that children with ASD tend to exhibit more challenges with externalizing behaviours and self-regulation, which affects their school engagement and relationship with educators. By establishing this time frame the researcher was better be able to identify the protective family factors and adjustment over time.

Theoretical Framework

Considering the current prevalence of ASD, and the uncertainty existing within the literature regarding relationship satisfaction among couples with a child with ASD, it is important to consider the concept of *resilience*, as it is quite clear that not all couples raising a child or children with ASD dissolve their relationships. The concepts of resilience and meaning reconstruction theory were used to inform the researcher's perspective during this study. Meaning Reconstruction Theory is ultimately informed by many different theories, including cognitive, attachment, and constructivist theories (Gilles & Neimeyer, 2006). Neimeyer, Prigerson, and Davies (2002) suggest that meaning reconstruction can be thought of as a psychological process of renegotiating "a coherent life narrative that accommodates painful transitions, whether normative or traumatic" (p. 248). Meaning making and reconstruction in the context of ASD refers to the potential meaning that couples may attach to the idea of raising a child with a diagnosis of ASD (Niemeyer et al. 2009). Couples often experience a plethora of feelings and emotions associated with receiving this diagnosis (Neimeyer, Burke, Mackey, & Stringer, 2009). As a result, is imperative that couples are able to successfully adapt to the diagnosis and apply a new meaning to their current circumstances. Meaning making may include the couple's positive appraisal and interpretation of their situation, focusing on the benefits or lessons that may be identified as a result of the diagnosis and the changes in future goals for their children. It is important to note that successful meaning making is associated with better adjustment and more positive outcomes for the couple (Neimeyer et al., 2009).

The study of resilience theory focuses on understanding "the processes that could account for individual positive adaptation and development, when applied in the context of adversity and disadvantage" (Crawford, Write, & Masten, 2008, p. 355). Fergus and Zimmerman (2005) also defined resilience as the process of successfully overcoming the negative effects of risk exposure, while positively navigating challenging or triggering experiences, and maintaining the ability to avoid the negative trajectories associated with these adverse or potentially harmful experiences. Resilience can be further defined as an individual's capacity to find resources that sustain well-being, the capacity of an individual's physical and social ecologies to provide these resources, and the capacity for individuals, families and communities to find culturally meaningful ways for these resources to be shared (Ungar, 2008). Resilience emphasizes the individual variations in response to risk or challenging circumstances. Resilience research asks why some individuals succumb to stress and adversity, while others successfully adapt to the same challenges (Rutter, 1987). Ultimately, resilience theory, especially related to family processes, focuses on the finding that a large amount of variation exists between individual responses to adverse environment or life experience (Patterson, 2002).

The current study utilizes resilience as a theoretical framework, which incorporates two primary components: (a) exposure to significant stressors or risks and (b) demonstration of competence and successful adaptation. Resilience is not a static concept and can be influenced by many factors at any point throughout the individual's life. It is important to consider two major processes that are involved in positive or negative individual outcomes: (a) risk factors and (b) protective factors (Braverman, 2001).

Risk factors can be defined as environmental conditions or stressors that have the potential to increase the likelihood that an individual could experience poor overall adjustment. In a study conducted by Murray (2003), exploring resilience in youth with disabilities, several categories were identified as being linked to risk factors impacting resilience. Risk factors were highlighted by the following categories: individual, school, community, and family. Within these broad categories Murray (2003) identified several specific risk factors impacting resilience. Individual risk factors included issues related to gender, race, emotional problems, stressful life events, and low IQ. The category of school included risk factors such as, poor quality of teaching instruction, unsafe school environment, negative peer relationships, and fewer opportunities for involvement in school related activities. Community risk factors focused on fewer opportunities to participate in pro-social activities, limited viable employment opportunities, fewer opportunities to create positive social bonds, and a high level of crime or violence. Lastly, examples of risk factors related to family consisted of low socioeconomic status, disorganized parenting style, and a family history of mental illness (Murray, 2003). Risk factors often relate to negative outcomes in the areas of physical health, mental health, academic achievement, and social adjustment (Braverman, 2001). Specifically, risk factors can include traumatic life events, socio-economic disadvantages, family conflict, chronic exposure to violence, as well as family mental illness, and drug abuse to name a few (Braverman, 2001).

Protective factors are characteristics of individuals or the environment that help to mitigate or reduce potentially negative effects of the risk factors (Braverman, 2001). Additionally, marriage alone has been suggested to be a critical protective factor in adult functioning (Kiecolt-Glaser & Newton, 2001). Protective factors can act in many ways to ameliorate the negative effects of risk factors. Protective factors have the ability to serve as a buffer to reduce the effects of a risk by strengthening certain internal characteristics that could combat negative outcomes. Specifically, protective factors can come in the form of positive outlook and interpretations of risk, or as social supports, communication, time together, and access to resources (Black & Lobo, 2008). Additionally, protective factors can help individuals cope with risk directly and deal with it in a more positive or constructive matter. Thus, the protective process occurs when the individual is exposed to a stressor or risk but has the capacity to adapt successfully as a result of their own personal strengths or compensatory resources (Braverman, 2001).

Bonanno (2005) stated that earlier research on resilience had typically focused on children and adolescents who were recovering from trauma. As a result, findings from studies of children and resilience had often been applied to adult functioning. He identified differences existing between resilience in children and resilience in adults, stating that adult resilience leads to an outcome trajectory that is distinct and separate from resilience in children. Additionally, when traumatic events occur in the lives of adults they often occur within the context of otherwise normal circumstances. Thus, the potentially threatening event may be brief and short-lived, and most typically functioning adults have access to a larger array of resilience promoting factors than young children. This is especially important to consider when comparing child resilience and adult resilience as it highlights the specific relevance of behavioural flexibility, including emotional regulation, required for adult resilience.

The current study is grounded in resilience theory as it relates to couples raising a child with ASD and their ability to successfully navigate challenging life experiences. Individual members within a family have the capacity to foster family resilience (protective factors) or negatively impact it (risk factors). Within the family structure, protective factors may include supportive child and parent interactions, successful maintenance of family cohesion, and a supportive environment (Benzies & Mychasiuk, 2009). Among risk factors in the context of the family unit are marital discord, parental mental illness, and anything else that has the capacity to raise the vulnerability to risk of family members. While some families are torn apart by crisis or persistent stressors, other families are able to persevere and come out from these challenging situations strengthened and resourceful (Walsh, 1996). A resilience-based framework aims to identify key interactional processes that allow individuals and families to endure and recover from the disruptive challenges they encounter (Walsh, 1996).

Chapter 2: Literature Review

To explore the experiences of couples raising children with ASD, the researcher conducted a literature review using Memorial University's research library databases combined with Google Scholar's search engine. This literature review attempted to provide an overview of the existing empirical research that focuses on the relationships of couples raising a child or children with ASD.

The researcher used Google Scholar as a preliminary search engine, initially using the search term "couples with children with autism" to do a general scope of the literature, this revealed over 22,000 potential results. In an attempt to narrow the search further the researcher than added "peer reviewed" to the search criteria and focused on items dating from 2000-2017. This narrowed the existing literature to over 5000 related articles. Further, the researcher excluded results such as newspaper articles and conference proceedings from the findings. Notably, there were many results that were not relevant to the current study. It is important to note that although the researcher narrowed the search dates to "2000–2017;" however, additional articles were used if they were frequently cited in the existing material or appeared to be a seminal piece of research. The researcher then used the material that resulted to identify other search terms, and then looked up the search terms and studies in the Memorial University library's database. The researcher identified relevant themes such as "family resilience," "protective factors," "couple resilience," "family interventions," "marital dissolution," and "divorce rates in families with special needs." From these terms the researcher was able to continue to narrow the literature search. As the search continued, new information led to further investigation of "grief and loss," "meaning-making," and "sibling outcomes." The review of the literature obtained allowed the researcher to gain a better understanding of the research topic; however, this review does not claim to be all inclusive.

It is essential to clarify that the primary intent of this study is to capture the thoughts, beliefs, opinions, and experiences, of couples raising a child with ASD. The purpose of this study is not to explore the perspectives of parents, but specifically to focus solely on the perspective of the couple. Notably, the majority of the existing literature presented below examined the perspectives of parents. Considering this, it was often difficult to keep sight of the "couple" when the predominant concentration of the literature was on "families" or "parents" raising children with ASD.

In the current study, the researcher defined a *couple* as individuals who had been cohabitating for a minimum of five years and who were co-parenting a child with ASD. Moreover, the word "divorce," which is used to represent relationship dissolution, may not directly apply to all individuals in this study. As a result, the researcher uses the terms "relationship dissolution" and "divorce" synonymously, as well as "couple satisfaction" and "marital satisfaction." Similarly, for the purposes of this thesis, the terms 'resilience,' and 'resiliency' are used interchangeably.

Overview

Parents who have a child with ASD often must adapt their parenting strategies to support the positive functioning of their child or children and the family unit as a whole. As a result, couples with a child or children with ASD require specific and comprehensive supports that consider the needs and stressors that these couples encounter (Falk et al., 2014). Therefore, this study sought to explore couples' experiences living with a child or children with a diagnosis of ASD.

Therapeutic and Family Intervention for Parents

The importance of therapeutic intervention for parents living with a child with ASD is frequently discussed within the current literature (Solomon & Chung, 2012). When a child is diagnosed with a serious life-changing condition such as ASD, the emphasis is immediately placed on early-intervention services for the child. The primary concern for parents and professionals is meeting the child's needs and providing services that will positively enhance the child's behavioural outcomes. Typically, parents place great emphasis on the child's needs, with very little focus on themselves or their relationship (Cashin, 2004). Parents of children with ASD can experience a variety of chronic and acute stressors that can negatively affect familial relationships and family functioning (Nealy et al., 2012).

Children with disabilities, including ASD, often require more parental attention and have more needs than same-age peers without disabilities (Nealy et al., 2012). This level of care often requires more time and resources to carefully plan events, routines, family activities, or family traditions, which may be impacted by the restrictions that are required to successfully navigate these situations with a child with ASD. Accommodating these restrictions can place additional stress on the family due to the extra time and demands it places on the parents. This additional stress can create tension and frustration for family members and may lead to less marital satisfaction (Burrell & Borrego, 2012). Couples raising children with ASD are often dealing with many complex and overwhelming emotions that may be difficult to navigate. It is important for couples to be able to identify these feelings and emotions because they could threaten their connection with one another (Solomon & Chung, 2012).

Couples can encounter a multitude of challenges that may impact their ability to obtain therapeutic interventions, including access to supportive/therapeutic/educational services, work life balance, and lack of child care, to name a few. When considering the area of family interventions, therapists must evaluate the unique demands that are placed on couples raising a child with ASD and help parents stay connected to each other as they work to create a new normal in their relationship (Solomon & Chung, 2012).

Additionally, Solomon and Chung (2012) stated that couples who are raising a child with ASD, and seeking therapeutic services, may have a greater knowledge base about ASD than their family therapist. Family therapists often do not have a high comfort level in dealing with families with these complex needs. This can cause problems for couples seeking services, as therapists can be reluctant to take on clients when they do not feel confident or competent in the subject area. Considering this, it may be beneficial for family therapists to have a comprehensive understanding of ASD and the needs of couples who are raising a child or children with ASD (Solomon & Chung, 2012). Since parents in some situations may have more information related to ASD, family therapists can work collaboratively with parents. On the other hand, family therapists do have a broad understanding of family systems, coping and adaptation strategies, and marriage and family therapy techniques that could improve the couple's functioning (Solomon & Chung, 2012).

Having a child with ASD affects multiple domains of family life including relationship stability and positive coping. In a study of three couples participating in a ten week in home emotionally focused therapy (ERT) intervention, researchers concluded that an in-home intervention program that would help parents strengthen their relationship and protect it against the many stressors related to raising a child with ASD (Ramisch, Timm, Hock, & Topor, 2013). During this challenging period in couples' lives, therapists have the ability to add positive family functioning and increase their overall well-being (Ramisch, 2012). Further, Ramisch suggested that it is important for both couples and therapists to focus on hope for a positive future after a diagnosis of ASD, and the potential to positively adapt to a new way of life. Therapists have the opportunity to act as a valuable resource for couples to help them access additional resources to help them adapt to the new stressors associated with a diagnosis of ASD. By developing a clearer understanding of the needs of couples raising a child with ASD, therapists would be better able to develop tailored support programs for parents. Additionally, it is the opinion of the research that family therapists can help to inform couples of the protective factors which contribute to resilience and relationship satisfaction. The following section highlights the various challenges associated with raising a child with ASD, and the possible stressors that impact the couple and family unit as a whole.

Parental Challenges, Family Stress, and Marital Distress

Couples raising a child with ASD face a variety of challenges that can be quite different from the experiences of couples with no children or with children without disabilities. Couples raising children with ASD often struggle to find adequate time for each other as much of their time is dedicated to parenting demands and responsibilities (Brobst, Clopton, & Hendrick, 2009). The stress of these challenges can be exacerbated, especially by the needs of the child, because of the significant amount of the couple's energy, efforts, and resources these needs require. In a meta-analysis by Risdal and Singer (2004), they report that the literature indicates that because of the elevation of stress on couples raising a child with ASD, they are more likely to divorce than couples raising children without disabilities. However, they further discovered that the increase in the rate of divorce exhibited was smaller than expected, rising from 3% to 6%.

All families experience stressors and encounter problems along their journey. Raising a child with ASD may come with a multitude of stressors and challenges, which could negatively impact the parent's functioning as a couple. A *stressor* can be defined as “a demand placed on the family that produces, or has the potential to produce, changes in the family system” (McCubbin & McCubbin, 1993, p. 28, as cited in Black & Lobo, 2008). This problem, demand, challenge, or loss then has the power to decrease family functioning and marital relationships (Black & Lobo, 2008). Family functioning here is defined as adaption plus cohesion within a family context (Solomon & Chung, 2012). After receiving a diagnosis of ASD, parents report expressing a number of feelings including depression, lack of competency, parenting stress, and guilt (Kuhn & Carter, 2006). Children with disabilities may need more physical care and financial support, and have greater social demands, than their same-age peers without disabilities (Burrell & Borrego, 2012). Thus, it could be hypothesized that this additional stress on the family, which could be associated with such a level of care may cumulatively lead to decreased marital satisfaction when compared to parents of neurotypical children.

Gray and Holden (1992, as cited in Hartley et al., 2010), reported that a number of factors contributed to increased family stress and marital dissatisfaction, including the uncertainty of the diagnosis, the long-term prognosis of the condition, the stressful nature of the symptoms, and the lack of public understanding and tolerance for behaviours Additionally, family stress, as reported by mothers of children with ASD, has also been related to child dependency, caregiving responsibilities, interference in daily activities, long-term child caring responsibilities, decreased social support, and decrease in personal time (Nealy et al., 2012). In their qualitative study of eight mothers with children with ASD, Nealy et. al. found that mothers often reported feeling isolated as a result of having to avoid certain social settings as a result of their child's possible behaviours. Further, children with ASD face many challenges when exploring new environments or social settings. The unpredictability of the environment or the unpredictability of the people in these environments can be triggering for the child with ASD and cause unwanted behaviours.

Keeping in mind that couples raising children with ASD report varied rates of relationship dissolution, it is critical to continue exploring this population and identify the factors within these relationships that are protective and maintain couple resilience. Much of the research is inconclusive on whether the divorce rate within this population is higher than among couples raising children without a disability. Thus, adding to the body of research that explores protective factors that mitigate relationship stress will provide useful insight for practitioners who provide services to couples raising children with ASD. The next section focuses on relationship dissolution and the impacts that raising a child with ASD may have on the couple's relationship.

Relationship Dissolution and ASD

Despite varied research evidence in relation to ASD and divorce, some studies of relationship status reveal that the quality of marital relationships have been negatively impacted by raising a child with ASD, especially when related to child problem behaviours (Benson & Kersh, 2011; Hartley et al., 2010). According to Hartley et al.

(2010), parents of children with ASD are nearly twice as likely to divorce as parents with a child without ASD (23.5% versus 13.81%). However, Freedman et al. (2012) found that divorce rates among parents with a child with ASD were similar or better than those with a child without ASD. As Freedman et al. (2012) noted, these differences may be due to sampling variances: for example, Hartley et al. (2010) studied adolescent children and parents who were married in the 1970s and 1980s, when services may not have been available during younger childhood, and divorce rates are higher for those demographics. While divorce is an indicator of relational outcomes, divorce rates often fail to capture the full extent of impact that ASD has on relationships.

The stress connected with raising a child with ASD, which may be related to behavioural issues, managing medical issues, and finding quality services and interventions, can increase tensions between parents, which may partially explain the variance in relationship dissolution. Additionally, it has been suggested that that parents of children with ASD frequently experience more stress when compared to parents of children with other disabilities. However, the possible reasons for this increase in stress tend to vary (Naseef & Freedman, 2012).

The emotional and physical demands of raising a child with ASD could impact the parents' ability to cope and may pose a threat to their psychosocial wellbeing (Higgins et al., 2005). From a sample of parents raising children with ASD, Higgins et. al (2005) indicated that parents reported lower marital happiness, family adaptability, and family cohesion when compared to a normative sample. Further, results from this study supported the need for services to foster marital and family functioning when raising a child with ASD. This view is supported by Falk et al. (2014), who suggested that supports in family therapy should be established to coincide with the specific needs of couples raising children with a diagnosis of ASD. The following section highlights the concepts of grief, loss, and meaning making, and how these factors may impact parents raising a child with ASD.

Grief and Meaning Reconstruction

It is important to consider the role that meaning reconstruction in response to greif and loss may play in the coping process that accompanies a diagnosis of ASD. From the time that a pregnancy is confirmed, many couples are filled with hopes and dreams and the expectation of a healthy baby. However, for couples whose baby is diagnosed with a lifelong condition such as ASD, profound grief may follow (Neimeyer, Prigerson, & Davies, 2002). Often with a diagnosis of ASD may come with a flood of emotions, thoughts, and questions about the child's prognosis for the future. In this sense, grieving can be defined as a process of reconstructing a worldview that has been forever challenged by this loss. Receiving a diagnosis of ASD can shatter this established world view and parents may reconstruct the meaning they have attached to their child's future. Such a reconstruction of meaning is consistent with Neimeyer, Burke, Mackey, and Stringer's (2009) discussion of grief processes, and so it is important to note here.

The reactions of parents can vary when receiving a diagnosis. According to Neimeyer et al.'s (2009) conceptualization of the principles of grief therapy, parents may attach meaning to a diagnosis outcome relatively quickly, or they may struggle with the process of adapting to a new world view. It is essential that the individuals experiencing grief find meaning in the loss they are experiencing, as successful meaning-making is linked to better adjustment and outcomes. Considering that many life events are outside of one’s control, it may be challenging to accept these sudden changes in life circumstance. However, individuals who successfully find meaning and make sense of the grief experience often exhibit lower mental distress, higher marital satisfaction, and better physical health than their counterparts (Murphy, Johnson, & Lohan, 2003).

As mentioned in the theoretical framework in this study Meaning Reconstruction Theory is ultimately informed by many different theories, including cognitive, attachment, and constructivist theories (Gilles & Neimeyer, 2006). Neimeyer, Prigerson, and Davies (2002) suggest that meaning reconstruction can be thought of as a psychological process of renegotiating “a coherent life narrative that accommodates painful transitions, whether normative or traumatic” (p. 248). Individuals who are mourning a loss often experience a roller coaster of emotions. These emotions and stages of grief vary from person to person. Typically, individuals experiencing loss express feelings such as missing and longing, and they experience episodes of intense sadness, crying, intrusive thoughts and memories, decreased energy, loss of pleasure, social withdrawal, and feelings of meaninglessness and hopelessness (Burnett, Middleton, Raphael, & Martinek, 1997; Parkes, 1996, as cited in Gillies & Neimeyer, 2006). Because of the flood of negative emotions associated with experiencing loss, the most critical process in successful adaptation is identifying the benefit in the experience. When dealing with a significant loss it is imperative that individuals attempt to engage in positive appraisals and interpretations of the situation by focusing on the benefits or lessons learned. It is important for couples who are experiencing the loss of the life they once dreamed of to find meaning in their current position. This restructuring and meaning-making can protect the couple from experiencing prolonged grief and sadness in relation to the unexpected situation. Commonly, the more challenging losses are those that fail to align with the individual's perceptions and understandings of the world. These losses fail to make sense to the individual and turn everything that once had meaning into doubt and disarray (Folkman, 2001, Thompson & Janigan, 1988, as cited in Gillies & Neimeyer, 2006).

Neimeyer, Prigerson and Davies (2002) suggested that individuals tend to organize their experiences through narrative. If this perspective is accepted, then individuals strive to recreate meaning and develop a storyline to allow them to process their loss and make sense of the new life they are living. Depending on the interpretation of the loss by the individual, this process can be a fairly smooth transition or one that is more complex and pervasive, requiring support to reconstruct meaning and successfully adapt to the loss (Neimeyer, Prigerson, & Davies, 2002). When considering grief and loss from the perspective of couples whose child has just received a diagnosis of ASD, it is important to understand the process of meaning reconstruction and how this represents the healing process. Couples may mourn the loss of the lives they had planned, the family they had constructed, and the dreams and goals they had outlined for their children. Couples may need to create new meaning that will better represent their life circumstance. Positive adaptation and meaning reconstruction will lead to more successful coping during the grieving process (Neimeyer et al., 2009). The last section focuses on family resilience and the protective factors that help couples and families successfully adapt to the challenges associated with raising a child with ASD.

Family Resilience and Protective Factors

Families build resilience not through the evasion of adverse events but through their successful use of protective factors (i.e. supports, resources, and skills) to cope with these events and become stronger in spite of them (Black & Lobo, 2008). Family resilience can also be recognized as characteristics, dimensions, and properties of families which help families to be resilient to disruption in the face of change and adaptive in the face of crisis situations (McCubbin & McCubbin, 1988). Given that families are diverse and exist in dynamic environments, it can be assumed that family resiliency varies over time, and that it is a process rather than an outcome (Black & Lobo, 2008).

Resiliency is fostered by protective factors, which have the capacity to modify or change individuals' responses to adverse events so that families may avoid possible negative outcomes (Benzies & Mychasiuk, 2009). Protective factors are not static entities; they change in relation to context, which leads to different outcomes. They help to facilitate adjustment, or the ability to maintain integrity and functioning, and to fulfill developmental tasks. When a family is being challenged, these protective factors are called upon to promote the ability to adapt, or rebound, in the presence of crisis (McCubbin & McCubbin, 1993 as cited in Black & Lobo, 2008). It is important that individuals maintain good physical and psychological well-being to adequately access these protective factors and boost resilience.

Research in the area of family resilience has suggested a number of factors and characteristics that are associated with protective advantages which foster resilience (Bayat, 2007; Black & Lobo, 2008). These may include, but are not limited to: having smaller families, thus experiencing less financial strain and experiencing lower stress

(Benzies & Mychasiuk, 2011); increased community involvement, which provides access to larger social networks and educational resources; positive life outlook; expressed spirituality; family member accord; demonstrated flexibility; communication; financial management; family time and shared recreational activities; and family routines and rituals. Evidence of family resilience such as the mobilization of resources, making positive meanings of the disability, becoming united as a family, and finding appreciation of life and other people in general, were also identified as positive factors contributing to relationship success (Bayat, 2007; Black & Lobo, 2008). Additionally, Walsh (1998) stated that making meaning of adversity, affirming strength and keeping a positive outlook, and having spirituality and a belief system all positively influence family resilience, which may aid in couples' resiliency when raising a child with a diagnosis of ASD.

The primary aim of the current study is to add to the existing literature by gaining a richer understanding of the protective factors involved in marital success for parents raising a child with ASD. The study also aims to provide recommendations for specific therapeutic interventions and future programming for parents of children with ASD. The existing literature supports the notion that couples would indeed benefit from therapeutic interventions directed at their relationship and their needs as a couple. However, due to the complexity of ASD and the lack of understanding by care providers, therapists are often hesitant to work with these families and provide supports. This research sought to shed light on the fear of treating families with children with ASD and identify programming needs for this population. This could be quite influential for implications for clinical practice as well as the social experience of the families involved.

It is important to consider that contradictory findings are often expressed within the literature. Freedman et al. (2012) cautioned that there had been very little research conducted to understand whether couples with a child or children with ASD are indeed at risk for higher rates of separation or divorce, and so results must interpreted cautiously. McCoyd, Akincigil, and Paek (2010) also noted that there is no concrete support for the hypothesis that parents of children with disabilities are at greater risk for relationship dissolution. Similarly, Reyns (2006) reported that although divorce rates of parents of children with ASD are not significantly higher, such parents do experience an overall decrease in marital satisfaction. Despite these opposing findings, it appears that the predominant position emphasizes the myth that having a child with a disability increases parents' likelihood of divorce (McCoyd et al., 2010). It is important to reference these differing findings as they provide a more comprehensive understanding of the existing research.

For the researcher it is important to consider the various viewpoints that exist when looking at the research question. The current study explores couples who are raising children with ASD and the protective factors that exist within these relationships to help them to be successful. It is important to review the existing literature to understand what exists, where there are gaps, how these gaps could be addressed, and future directions that result from the research presented.

Chapter 3: Methodology

This study utilized a qualitative research design to inform methods used. The goal of qualitative research is to describe individual accounts and lived experiences of the phenomenon under study (Giorgi, 1997). The researcher's aim is to gather a full and unique understanding of an individual's personal and lived experience through a variety of qualitative research strategies. Qualitative research begins with the acknowledgment that an underlying need exists to understand a phenomenon from the specific perspective of the lived experiences of an individual or group of individuals, as a way to understand the meanings behind it (Englander, 2012). Often, researchers have a general understanding or preconceived idea of the phenomenon being studied before conducting research in a particular area. It is important for researchers to be aware of these thoughts and ideas and not let them influence their interpretation of the data.

The purpose of this qualitative study was to understand the relationship challenges experienced by couples raising children with ASD, and the protective factors that help to mitigate stress and maintain relationship satisfaction. The experiences were unique to this population and reflected their distinct relationship needs, understandings, struggles, coping strategies, and outcomes.

Research Design

Qualitative methods refer to a broad range of research methods that produce data from people's own written or spoken word (Maykut & Morehouse, 1994). A qualitative analysis is focused on evaluating the fundamental properties of the individual(s) to allow the researcher to provide a rich and descriptive representation of the phenomenon being studied (Smith & Osborn, 2007). Qualitative approaches in psychology are typically committed to exploring, describing, and interpreting participants' individual, personal, and social experiences. It is through observation and listening to real accounts of lived experiences from participants that researchers are able to obtain a first-hand knowledge of unique perspectives (Forman, Creswell, Damschroder, Kowalski, & Krein, 2008).

Qualitative analysis, then, is much more than simply a means of data collection; it is a way for researchers to approach the empirical world (Maykut & Morehouse, 1994). After the data has been collected, analysis is conducted on the textual reports. Researchers focus on the meaning behind a piece of text instead of identifying its numerical properties (Smith & Osborn, 2007). Qualitative methods follow a flexible research design that derives concepts, insights, and understandings from data rather than processing data to access preconceived hypotheses or theories (Maykut & Morehouse, 1994).

Qualitative researchers often use non- or semi-structured interviews to acquire rich accounts on a topic of interest. When obtaining data through interviewing, researchers often use an emergent process to ensure that a genuine account of the area of interest is obtained. Examining perspectives using a qualitative process allows researchers to get to know individuals on a personal level and understand what they experience in their daily encounters with society (Smith & Osborn, 2007). It is important to note that when people's words are reduced to statistical equations, it can be challenging to represent their more nuanced and complex experiences.

It is impossible for researchers to fully eliminate their preconceptions; however, it is essential that they limit the effect of these preconceptions on the people they study. It is critical for researchers to attempt to control their own effect on the participants and to be cognizant of such effects when interpreting the data. One way to achieve this is through the process of *bracketing* (Barnard, McCosker, & Gerber, 1999). In order to address such preconceptions and possible biases this researcher made notes before the interview process began. These notes included any thoughts or any preconceptions the researcher had about the research topic. Qualitative research is employed within a broad theoretical framework; thus, researchers can never escape all of their own assumptions of the world.

Methods

Overview. This study utilized a qualitative research design to study the protective factors in couples who are raising a child with ASD. The researcher incorporated qualitative methods as a way to have an in-depth look into the various experiences held by theses couples. The aim of qualitative research is to obtain a detailed account of the individual's perceptions, experiences, and interpretations of their life situations (Smith & Osborn, 2007). The current study attempts to explore the personal experiences and ideas held by couples raising a child with ASD, and the protective factors in their relationships that help to mitigate stress and relationship discord.

Recruitment. *Purposeful sampling* was employed as a method of recruitment. Purposeful sampling is a method used in qualitative research to identify and select participants who could offer information-rich accounts pertaining to the researcher's area of study. This method is an effective way to obtain a rich source of data using limited resources (Patton, 2002).

Descriptive handouts were distributed to locations within the community, including a local NGO working with individuals with ASD, a local hospital, and the campus of a local university in a small-sized city in an Atlantic Canadian province.

Couples were invited to participate voluntarily, without remuneration. In addition to this, the NGO sent out the descriptive handout to everyone on its electronic mailing list. (The handout explained that individuals who were interested in participating in the research could contact the researcher directly as there was no direct affiliation between the research and the NGO itself.) Additionally, this researcher posted the descriptive handout on Facebook, where it was shared by anyone who felt interested.

Criteria for inclusion involved the following: couples with a child or children with a diagnosis of ASD, who had completed one year within the public or private school system. Again, the purpose of this criteria was to ensure that families participating in the study had had the opportunity to deal with pre-school supports and encounter the possible challenges associated with the transition to the school system. A couple was defined as two individuals who were living in the same residence and sharing the parenting role of raising a child with ASD. Couples did not have to be legally married, but they had to be living as a common-law family. Participants did not have to be the birth parents of the child, but they had to have been raising the child together for a minimum of five years. There were no restrictions in relation to the age, religion, ethnicity, or gender of couples.

Participants. Participants for this study consisted of eight couples who were raising a child with ASD, with one couple excluded, for a total of seven couples (*n* = 14). It is important to note that one of the couples was excluded after the interview stage. The couple was unable to answer the questions. Their primary focus was always brought back to the child, and they were unable to respond to the questions about their experience as a couple. The researcher made several attempts to redirect them back to the questions being asked; however, the couple continued with child-focused responses. As a result, their responses did not lead to any usable data. In consultation with this researcher's co-supervisors, this researcher decided to remove these data associated with this couple from the study.

Data Collection.

Participants were invited to take part in a one-and-a-half-hour interview. The study used non-directive and semi-structured interviewing methods to obtain a clear understanding of the phenomenon being studied (Giorgi, 1997). Semi-structured questioning was used here in order to allow for freedom and flexibility of individual responses (Miles & Gilbert, 2005). Interviews were conducted until saturation was reached (i.e., the point at which no new information was emerging). Specifically, saturation may be viewed as the process of data collection that occurs until redundancy occurs in the data (Morse, 2005).

A question guide was created for the interviews to be able to maintain continuity and provide a basis for analysis (Miles & Gilbert, 2005). After an extensive search of the literature, the researcher compiled a list of relevant questions to gather information about the relationships of couples raising a child with ASD. This research, along with the researcher's observational experience from years of working closely with families of children with ASD, allowed for a comprehensive list of question items (see Appendix C). Couples were asked each of the questions from the question guide, and they were encouraged to share whatever information seemed relevant to that question. At times follow up questions emerged based on the behavioural observations of the couples. The follow up questions were asked to elicit more information about the experience of the couple and based upon information that the couple had provided. Oftentimes follow up questions were asked to bring the focus of the interview back to the couple and not the child.

Before conducting the interviews, the researcher communicated via telephone, email, or Facebook Messenger with participants to explain the research process, describe the process of informed consent, and establish a sense of trust and rapport. This time allowed participants to ask any questions that they may have had or to discuss any concerns related to the research. Before each interview took place participants were asked to sign an informed consent form. They were given the opportunity to discuss any questions they had about the informed consent process before continuing on to the interview.

Depending on the needs of the participants, the interviews took place at a secure office space on a mid-sized university campus, at the homes of the participants, or via telephone. Some families expressed challenges with time and childcare and requested that the researcher come to them for the interview. For families who requested interviews be conducted in the convenience of their own home, measures were taken to insure the safety of the researcher. Specifically, this researcher provided their contact information to a supervisor, along with the time of the interview and the address of the interview location. The researcher checked in with the supervisor upon arrival and again when leaving the home. Some families lived outside of the city in various rural communities, and thus a phone interview worked best for them.

Additionally, field notes were collected as another form of data and were used to help inform the data analysis process. Field notes were taken during the interview on a spare piece of paper which was stapled to the signed informed consent sheets. After each of the interviews the researcher made additional field notes based on couples behaviours and field observations.

Data Analysis

In qualitative research informed by phenomenology, the analysis process begins with data preparation. Data were obtained from multiple sources, including tape recorded interviews and the researcher's field notes. The first step was to transcribe the data verbatim obtained from the interviews. This was completed by a professional transcriptionist, who signed a confidentiality agreement. These transcripts were then reviewed by the researcher to ensure accuracy. After transcription, the researcher communicated the transcribed notes to all the participants in order to confirm the accuracy of the transcriptions (member checking). However, only one couple chose to review the transcript; all of the other participants declined.

A *triangulation* process (see Forman et al., 2008) was then used. Member checking resulted in no couples providing feed back to the researcher. As a result the researcher used thesis supervisors in the triangulation process. Parts of the data were analyzed concurrently with the supervisors of this research. The researcher and supervisors all reviewed and coded three separate, distinct transcripts. Transcripts were coded by identifying recurrent phrases and grouped into larger themes. When the coding process was complete, the researcher and supervisors had a meeting to discuss the findings and ensure that similar themes were being identified. Once agreement was reached, the researcher coded the remaining interviews independently.

Once the researcher was immersed in the content of the interview transcripts, they worked through the *horizontalization* of the data, which is the process of assigning equal value to all description and experience (Barnard et al., 1999). During this process, the researcher reviewed the transcripts and field notes, one at a time, to identify statements within the material that described how the individuals experienced the phenomenon (see Forman et al., 2008). These statements were identified and processed by the researcher, ensuring that equal weight was given to each statement. From this, a list was configured of significant statements identified within the material. This list of statements and data were then divided into distinctive *meaning units* called categories. Meaning units are pieces of data that can stand alone outside of the context and still communicate sufficient meaning to provide understanding (Miles & Gilbert, 2005). Often, the longer the meaning unit that is created, the clearer its contextual meaning, thus allowing for greater understanding by the reader. Broad categories of meaning units were then narrowed down into four to six specific themes within three major categories.

During the data analysis phase, qualitative researchers look at the data to identify salient themes, similarities and differences, recurring ideas and language, and patterns of beliefs that can link people and settings together (Atieno, 2009). At this point, the researcher utilised the phase of *imaginative variation* (Turley, Monro, & King, 2016). In the imaginative variation phase the researcher re-evaluated the data collected and looked at each participant's description of the phenomenon in order to gain more insight on the variations and differences existing in each participant's perspectives and explanations of the situation. This allowed for the evaluation of the units of meaning to shape the overall depiction of the phenomenon; that is, while reading each transcript the researcher compiled a broad list of possible themes, phrases, and key terms based on the prevalence of these words and phrases within the transcript. This process was completed for each of the transcripts. Once each of the transcripts was reviewed and all of the data were processed and evaluated, the key terms and phrases were then condensed into categories and themes based on the frequency of these words and phrases. This allowed for a more comprehensive understanding of the phenomenon being experienced, as well as an understanding of the variations in experience that existed.

Trustworthiness

Trustworthiness refers to the validity of a qualitative research design. When addressing the idea of trustworthiness, researchers are examining the credibility, transferability, dependability, and confirmability within the research methodology (Guba, 1981). *Credibility* refers to the researcher's attempt to accurately depict the phenomenon that is being studied. In this case it is important to ensure that the researcher is actually investigating what they intended to study. The aim of this study was to explore the protective factors that interact to create positive influence on couples' relationships while parenting a child with ASD. To ensure credibility in this study, the researcher clearly defined terms and outlined objectives, identified boundaries, and utilized a resilience-based theoretical framework for the research objectives. Multiple sources of data were also used in the analysis process: the researcher's field notes, the interview transcripts, and existing theory. This triangulation process (Creswell, 1994) reinforced the validity of the findings.

Transferability is another important consideration in assessing trustworthiness. This relates to the extent to which the findings of the current study are transferable to other situations or contexts (Malterud, 2001). Transferability is difficult to achieve or maintain as the results of qualitative research are typically understood within a particular context. Thus, the present study documents the boundaries of the phenomenon being studied, provides clear representations of the sample population within the study, and thoroughly represents the connection between the research being conducted and the existing theoretical concepts.

Further, *dependability* relates to the idea that the research should be presented in such a way that if it were to be repeated it would be possible to employ the same research strategies and techniques (Shenton, 2004). This is important because it allows for other researchers to trust that the information is accurate and dependable.

Lastly, the concept of *confirmability* is important to consider when conducting qualitative research. Confirmability suggests that "researchers must take steps to demonstrate that findings emerge from the data and not their own predispositions" (Shenton, 2004). For this study, the researcher's experiences and positionality have been clearly defined, and biases were considered throughout the research process.

Ethical Considerations

In every research study, it is imperative to examine the ethical considerations involved with a research design. Participants were informed of the research objectives and goals before the start of the study, and at the end of the study they were again invited to ask questions. These questions were answered as thoroughly as possible, and any concerns were addressed before and after the research process.

It is also important for the researcher to consider the invasiveness of the research process and how this may impact on or affect the participants in the study. Participants were asked to discuss their relationship and family challenges in great detail. The informed consent document (see Appendix A) included a list of services that participants could use after the interview, and participants were reminded that they could stop the interview at any time. Participants were reminded at the end of the interview that they could contact the researcher at any time with questions. Awareness of these factors may have helped better serve the population being studied.

The researcher must also ensure that the risks to the participants do not outweigh the benefits, and that participants' rights, feelings, and emotions are protected and always a priority. To ensure these conditions were met, the study was clearer by an interdisciplinary research ethics board from the university (see Appendix B).

Chapter 4: Results

The purpose of this qualitative research was to address the following research question: What are the protective factors that mitigate marital discord and increase marital satisfaction when raising a child with a diagnosis of ASD? Data for this study was collected and organized using qualitative methods and subjected to thematic analysis. The current chapter outlines the results and data analysis from seven interviews with cohabitating couples who are parents of children with ASD. From the data obtained, four overarching themes emerged from the data in relation to the protective factors in couples' relationships. Each theme was broken down into several sub themes in order to provide a richer understanding of the phenomenon. The overarching themes identified are (a) Commitment, (b) Adaptation, (c) Communication, and (d) Positive Outlook (Figure 1).

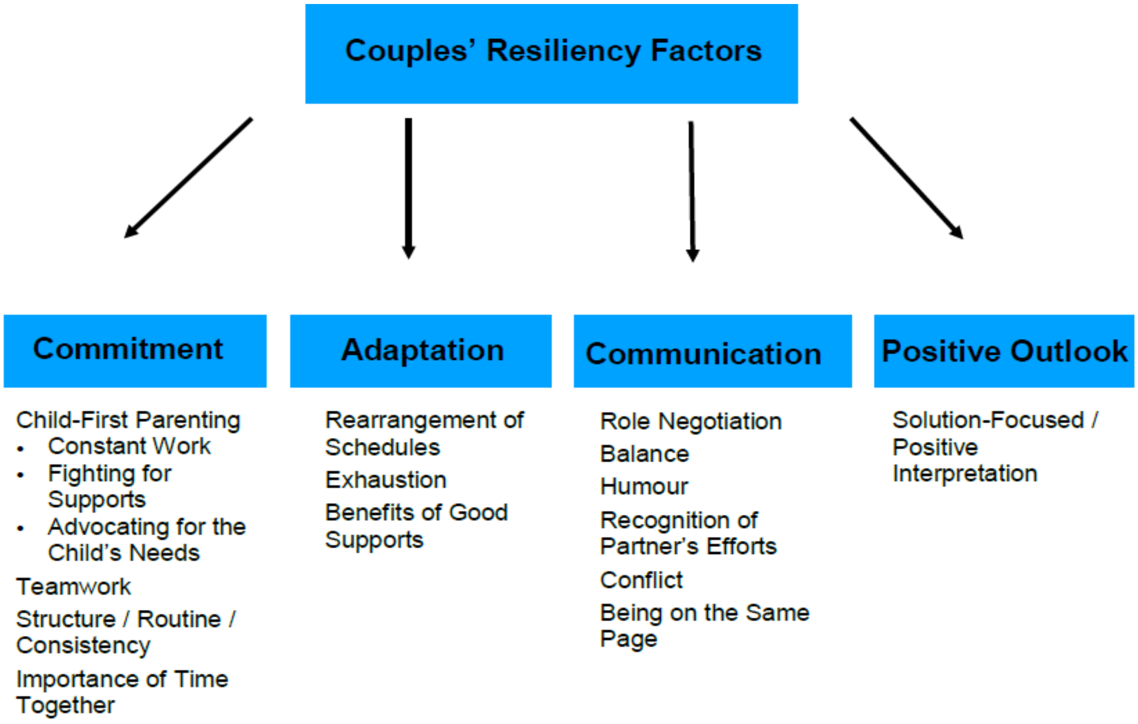

Figure 1. Overarching themes and subthemes related to protective factors in couples' relationships.

These themes outline factors that are important for positive coping, daily functioning, and running a productive household when raising a child with ASD, along with factors related to the couple's relationship. Specifically, participants reported having a stronger relationship as a result of parenting a child with ASD. Further, all couples stated that having a child with ASD had strengthened their relationship and pushed them to work harder to stay together. As a result, the themes discussed within this chapter represent the factors which contribute to the strength of their relationships.

To protect the identities of the families involved in this study, all identifiable information was anonymized throughout by utilizing pseudonyms for people and places. Families were identified by number and then assigned a letter from A to G, and all people and places associated with that family were assigned a pseudonym associated with that letter. For example, Family 1 is assigned letter A, and so all people and places involved with Family 1 are assigned pseudonyms that begin with the letter A (e.g. Adam, Anna, St. Albert's, etc.). This is further outlined in Table 1

Table 1

Pseudonyms for the Participants of This Study.

Family	Pseudonym
Family 1	The "Abbott" Family – All information coded by the letter A
Family 2	The "Bennett" Family –All information coded by the letter B

Family 3	The “Cooper” Family – All information coded by the letter C
Family 4	The “Dobbin” Family – All information coded by the letter D
Family 5	The “Elliot” Family – All information coded by the letter E
Family 6	The “Forward” Family – All information coded by the letter F
Family 7	The “George” Family – All information coded by the letter G

Commitment

Commitment in its most traditional sense focuses on the couple’s efforts to maintain their relationship together: commitment to the values of the relationship, personal marital vows, staying together, and working together to meet each other's needs on a daily basis. This is highlighted in the Dobbin family interview when Mrs. Dobbin explained that:

> We were best friends before we got married... and we are still best friends … when we married we married for life, you know for better or worse.... It’s not like okay we are having a difficult time right now so we are going to give up…. He is stuck with me and nobody else is going to take me and nobody else is going to take him.

Additionally, couples in this study commented on their dedication to maintaining their relationship, regardless of the everyday life challenges that they faced, exemplified by this statement: “We also try and do things together...we do a lot of physical activities together; we swim, we go shopping together” (Bennett Family).

All couples in this study identified the significance of commitment within their relationship. Thus, commitment was recognized as a major contributor to couples’ resilience. This section discusses in detail the different facets and values that constitute Commitment within these relationships: (a) Child-First Parenting, which includes sub-themes of Constant Work, Fighting for Supports, and Advocating for the Child’s Needs; and (b) Teamwork, which includes the sub-themes of Structure/Routine/Consistency and Importance of Time Together.

Child-First Parenting. *Child-First Parenting* can be defined as putting the child’s needs first above all else. Couples in this study said that their child’s needs come before everything else, including their own personal needs, their relationship needs, and their work obligations. The Dobbin family exemplified the child-first perspective when stating “my kids come before anyone.” Similarly, the Cooper family stated that “those kids come before anybody, anyone, and everything.”

Couples highlighted the importance of committing to the child’s needs in all domains of life. During the Abbott family interview, the couple reflected on their work with their child over the years: “We spent hours down there [the ABA workroom]; we worked with her every night.... Our priority was to make sure that every minute we were doing everything we could to help her … she was our first priority.” Situated within Child-First Parenting are the sub-themes of (a) Constant Work, (b) Advocating for the Child’s Needs, and (c) Fighting for Supports.

Constant Work. Couples identified the constant work that is required when raising a child with ASD. Mrs. Abbott explained, "[On] Christmas day, we were in there with her, Boxing Day, Easter Sunday, when we had people coming over to visit we took ourselves away from our company to go downstairs and work with her." Couples in this study indicated that there are no breaks when raising a child with ASD: it is a full-time job managing their needs, behaviours, and extra appointments. This can be seen in statements such as "I am a case manager, I did it all….It's hard work and you've got to put the work into it" (Abbott Family), "It is a full-time job" (Bennett Family), " He became like a case manager….taking care of all this" (Forward Family), "I pretty much do all of the care for the children (Mrs. Dobbin).

Fighting for Supports. All of the couples highlighted the importance of fighting for supports to enhance the functioning of their daily lives. In the current study, supports were classified as social/family supports, education supports, government supports, financial supports, outside-service supports. Out of the seven couples, six spoke of having strong supports in various areas. Only one couple stated that they did not have any supports in any of these areas. The Dobbin family highlighted the importance of supports:

> We very much believe in early intervention, [the children] have had every type of support you could possibly come up with... we have worked a lot with him, and he is doing well because of all of the supports that he is getting. (Mrs. Dobbin)

Specifically, couples stated that they are continuously seeking out supports from which their child could benefit, looking for supports within the school system, and fighting for funding and health related opportunities. This is demonstrated in the Forward family interview: "You are really on your own, to be honest if you don't fight for it you don’t get it, it is overwhelming, and it’s a full-time job.” All of the couples stated that if they did not fight for the services their child needed they would not obtain them.

> We didn’t know anything about the social services, you’ve got to figure it all out yourself... nothing is ever handed to you…. Parents have to be very strong just to handle it, because you get walked over… to be honest if you don’t fight you don’t get. (Forward family)

As a result of the everyday efforts employed by parents, Fighting for Supports is a factor in Child-First Parenting.

***Advocating for the Child’s Needs*.** Couples in this study addressed the importance of playing the role of advocate for their child. Couples reported that the only way to ensure that their child’s needs were met was by consistently advocating on their behalf. This was highlighted in the Dobbin family interview: “Don’t let them push you to the side; be there advocating and speaking up... it hasn’t come easy; it's come with a lot of tears” (Dobbin family). Additionally, many families identified the challenges associated with trying to get their child’s needs met and spoke of the effort that goes into ensuring their child gets a fair chance and opportunity to succeed: “It’s unfortunate because a lot of parents would just accept what they were told... don’t tell me he can’t do something,” and “nothing is ever handed to you.” (Abbott family).

Couples emphasized the efforts associated with advocating for their child, and creating more social awareness so that their children could participate in school-related and extracurricular activities: “I make sure that everyone involved in her life understands so that they can help her... you know so if something comes up they expect it” (Abbott family). This family also stated that they took the time to go into their child’s school and run a program for the students to better understand classmates with ASD: “It’s a program called Friend to Friend... you educate all of the students about autism.... I thought it was important because now she is not going to be bullied”.

Couples noted other challenges associated with being an advocate for their child’s needs. “You always need to advocate for your child and their needs... no one tells you things along the way... you need to be educated and seek things and supports out for yourself” (Elliot family). The comments above highlight the importance the couples placed on advocating for the needs of their child and the effort required to ensure that these needs were met.

Teamwork. Couples identified the importance of working as a team to maintain the stability and continuity of the relationship. When raising a child with ASD, couples were faced with new challenges, situations, and obstacles. As a result, they placed great value on the importance of teamwork: “A relationship is working as a team... you’re not just married, you’re best friends,” and further emphasizing, “Collaboration and teamwork, we just make it work, that’s it, you just do what you can” (Abbott family). Couples must work together in many capacities to allow for positive family functioning and organization within the home.

All of the couples in this study identified the importance of teamwork in relation to getting things done efficiently without becoming overwhelmed. This was demonstrated in the Forward family interview: “But I think we worked as a team... you know like we work together... it’s almost like a tag team, he can step in when I’m finding it tough and vice versa.” This teamwork perspective allowed the couple to manage daily tasks and maintain household chores, while providing an opportunity to strengthen their relationship.

Structure/Routine/Consistency. Couples in this study highlighted the importance of structure within day-to-day life. They explained that structure is mandatory for the maintenance of their child's behaviours and optimum functioning: "consistency has to be there all of the time" (Cooper family). Couples indicated that structure, routine, and consistency must be prioritized when raising a child with ASD. The value and importance of this factor was apparent during the Cooper family interviews: "we can't stir up the routine for this little boy, he needs to two of us to work together." The Forward family stressed the importance of sticking with the daily and weekly routines that their child was used to: "You've got to keep up with the routine," The Cooper family underlined the importance of routine in their day-to-day lives: "If we don't kind of stick to normal routines and keep everything as close to normal as possible then it throws him off and then that affects school, that affects his behaviours at home."

Couples consistently reported that communication is critical in maintaining homeostasis within the home. Additionally, couples acknowledged the importance of must adequately communicate schedules, appointments, and child's changing needs to their partners. Many of the couples in this study work on opposite schedules, and so they identified "talking on the phone" to stay connected, keeping "lists" to make sure tasks are completed, and "chatting" during their shift change to make sure everyone is up to speed on expectations and daily responsibilities.

Importance of Time Together. Considering all of the extra time and effort that is put into parenting a child with ASD, couples in this study found it difficult to make time for a relationship. Couples spoke of having very little time for themselves as a result of their busy schedules and parenting obligations: “There is very little private time: we don’t have it, really” (Bennett family). “In the younger years there wasn’t much time to spend together while raising four children, but we always made a point to have some time away” (Elliot family).

> The early days were tough to get out of the house... that was stressful. And I mean we tried to go out but [our child’s unpredictable behaviours makes you stay home more for sure.… I mean any time you have kids it’s hard to have time to yourself. (Forward family)

Regardless of the busy schedules, couples emphasized the importance of making time for themselves and their relationship:

> Making time to be together was very important. It was something to look forward to even if it was sharing a family experience…. When the kids were young we got a night here and there for dinner and a movie or a night at a hotel. This was always very important to us. (Elliot family)

The Forward family explained that with the support of their in-laws they were able to take two trips on their own or get a night off to stay at a hotel.

Adaptation

Another major theme that was identified as a protective factor in couples’ relationships was Adaptation. Having a child with ASD requires constant adaptation in many of life’s everyday events, actions, and interactions. The Elliot family highlighted this: “There is no book for raising children or for how to raise a child with ASD. You need to make up your own rules.” There are many new challenges that accompany a diagnosis of ASD that the couple must successfully navigate using the process of adaptation. Couples take on new roles and responsibilities; specifically, Mrs. Abbott said, “I am her case manager,” when reflecting upon the new roles she acquired after her child’s ASD diagnosis. The Bennett family also referenced the large number of responsibilities associated with an ASD diagnosis, which forced them to adapt to new roles. Mrs. Bennett had to take a leave of absence in order to organize the services associated with an early diagnosis (Bennett family).

In this study, the couples identified several concepts which will be discussed under the theme of Adaptation, which is defined and explored in more depth through three sub-themes: Rearrangement of Schedules, Exhaustion, and Benefits of Good Supports.

Rearrangement of Schedules. In each of the interviews, couples noted the role that adaptation played in relation to their schedules. Of the seven families interviewed, five specifically changed their schedules to ensure that one parent was always home with their child with ASD. Two families stated that one parent had to work nights while the other worked days to allow for one parent to always be home. Three families had one parent working and the other at home. The two families who did not have to negotiate their work schedules stated that they had enough supports to allow them to maintain a typical work schedule. Their significant family support allowed for both parents to maintain work outside of the home.

All of the couples who identified specifically adapting their schedules to allow for one parent to always be home stated that this was a necessity to provide the level of care their child required. For example, during the Abbott family interview Mrs. Abbott stated,

> I changed my schedule you know so when he'd come home I'd go to work... there was always someone home... our ultimate goal was her, because we didn't sit down and have dinner together that's not a priority you know that I mean. Our priority was to make sure that every minute we were doing everything we could for her.

The Bennett family said, "I had to take a leave of absence from work... and my husband had to get a new job... he had to get a job working nights."

The two couples who did not directly adapt their schedule specifically stated that they would not have been able to manage without significant family supports. The Forward family noted that for five years the father stayed home to act as the case manager; however, they also identified the abundance of support from their family:

> If we didn't have our family around it would have been much harder because you couldn't go for a walk, you couldn't get a night off, you couldn't go to a movie, you couldn't do anything... I mean we might be divorced, I mean it would have been so much more stressful if we didn't have that support… it is the kind of thing that couldn't really work without a lot of support.

The George family outlined the significant supports they had from both sets of in-laws:

> Yah, they lived up the street so she would be here in the daytime doing laundry or cleaning or whatever, and sometimes there would be a meal ready when we got home, or if there wasn't a meal ready here there was one ready up the street.

The benefits of good supports were clearly outlined by every couple, not only in reference to supporting schedules but also making life possible and adding quality to their child's care.

Exhaustion (Coping with Exhaustion). Depending on the needs of the child and the supports available for the couple, raising a child with ASD can be quite demanding. Often couples got no breaks from their children, and sleep was often interrupted. All of the couples in this study indicated that at various points throughout their relationship while raising their child with ASD they have felt extremely exhausted.

> We were up half the night... let's face it if you've got kids with special needs you are pretty brain dead most of the time; you are just trying to survive, the kids aren't asleep and they are behaving badly, you're a zombie… It's a full-time job; you're zombies; you're not thinking clearly; you're just trying to get by. (Mr. Forward)

The Dobbin family also highlighted the level of exhaustion: "I was exhausted, beyond functioning." (Dobbin family)

The Bennett family, the only couple who identified having no supports, said, "You are tired. You are tired," referring to the shifts worked and their lack of supports. Because they could not get any support they were constantly exhausted, got very little sleep, and had very little time together as a couple. When asked by the researcher if they ever got a break, they replied, "No… nothing at all." They described a conversation with a social worker when they were trying to obtain supports during the summer. Mr. Bennett worked night shift and was unable to sleep during the day while his child was out of school. Mrs. Bennett said,

> I said to the social worker, I said, listen I need it, I am working, I am not asking for a lot, I am asking for three hours in the day so that he [Mr. Bennett] can get some sleep. (Mrs. Bennett)

The couples in this study pointed out that it was very difficult to keep up with the needs of their children with ASD, the parenting demands required, and the associated exhaustion without significant supports.

Benefits of Good Supports. All of the couples in this study identified the importance of supports in relation to the positive functioning of their relationship. For the purposes of this study, *support* was identified as the support from family or friends, government services, financial assistance, or educational services. Of the couples in this study, six of the seven couples acknowledged having adequate supports in at least one of the areas listed above. Having a good system of support allowed couples to take a break from child-rearing responsibilities and spend some time together as a couple. The Forward family outlined how invaluable it had been to have a strong support system over the years:

> We had great support, we really lucked out…. I mean it would have been so much more stressful if we didn't have that support... because you couldn't go for a walk, you couldn't get a night off, you couldn't go to a movie, you couldn't do anything…. We couldn't survive without them [family support].

Because of all of the responsibilities associated with raising a child with ASD, the support from outside services helped to mitigate some of the additional stressors. The Abbott family identified supports in many areas and emphasized their importance:

> We had a lot of friends who helped us; we also had great support in the school system…. you have to have support, you got to have people to provide [information and resources], and support comes in a lot of different areas…. You

know even as much to having supports from the extracurricular activities that they are involved in... they play a big part".

Importantly, when developing this theme and examining the benefits of positive supports it was apparent that there was a negative impact on couples who did not have supports. Specifically, one couple in this study stated that they had absolutely no supports. The Bennett family expressed their lack of support, repeating throughout the interview that they had no support from schools, government, and family. Couples in this study reported that having a good system of support allows couples to get a break from child-rearing responsibilities and spend some time together as a couple. Additionally, they outlined some of the stressors that are associated with a lack of support including limited alone time ("He is always with us; we will never have a time that we have alone time"), lack of sleep ("You are tired... you are tired"), and inflexible professional obligations ("My work is not supportive at all"). Without supports couples are left to deal with all of the daily responsibilities and pressures alone.

Upon reviewing the significant role that support played in providing additional reinforcement for couples raising children with ASD, it was apparent that the one family who identified as having no supports struggled as a result.

Communication

Further, communication has been identified as a key mechanism underlying relationship satisfaction. Thus, communication occupies a crucial role in relationship dissolution, as bonds are assumed to remain strong to the extent that partners respond with sensitivity towards one another. The following section will outline the components that comprise this overarching theme of Communication, including the sub-themes of

Role Negotiation, Balance, Humour, Recognition of Partner's Efforts, Conflict, and Being on the Same Page.

Role Negotiation. Often couples find themselves overwhelmed by the extra needs, appointments, and responsibilities associated with raising a child with ASD. To mitigate stress and conflict, and maintain structure and routine, it is important for couples to establish a division of roles and responsibilities. This was perhaps most clearly highlighted during the Elliot family interview: "You support each other, and work as a team, share the roles and responsibilities; you can't take it all on on your own" (Mrs. Elliot). The George family made the same point: "We found things that she'll deal with this, and I'll deal with that." The Forward family simply expressed the need to "divide and conquer" when it came to family chores and responsibilities. Couples reported that when the roles and responsibilities are shared no one is left with the pressure to accomplish everything alone. All of the couples in this study identified the importance of negotiating roles and of sharing the oftentimes overwhelming workload.

Balance. All of the couples interviewed identified Balance as a protective factor in their relationships. Balance included not only balance in roles and responsibilities but balance in personalities, mood, and emotions. The Forward family exemplified this type of balance: "He knows when I'm getting agitated about stuff and he's a good calming influence" (Mrs. Forward), as well as "She keeps me going and I keep her going; we would have really struggled on our own" (Mr. Forward). The Elliot family addressed balance more specifically: "We balance each other out; when one is worried the other picks up the slack. We fit together; we always have." Similarly, stated, "He keeps me sane most days; he is the reasonable one; he is much calmer than I am." (Mrs. Bennett)

Each family outlined how balance looked in their relationship: “He is the calm person whereas I might hit the ceiling and come back down, he is calm…we kind of just balance each other out” (Mrs. George).

> He is not serious, like I am the serious one, I am always like okay we need to plan this or what are we going to do next year… and he always brings it back to today… he brings down my stress levels by being like that. (Mrs. Forward)

Considering the often-hectic schedules of these couples, balance at times acted as a buffer for stress and burnout.

Humour. All couples identified the value and importance of humour as a protective factor. Interestingly, humour was explicitly stated in three of the interviews as playing an important role in the couple’s relationship. Humour was present in all interviews implicitly through subtleties such as jokes directed to the researcher, inside jokes amongst the couple, laughing, or poking fun at each other. “We have the same sense of humour, and we like making fun of the same people and stuff” (George family). In reference to child rearing, the Elliot family stated, “You need to be creative and have a sense of humour; there is no book for raising children or for how to raise a child with ASD.” The Forward family demonstrated the importance of humour perhaps the most overtly of all of the couples interviewed. During the interview Mrs. Forward stated that other people have commented on the fact that she still finds her husband's jokes funny after all these years together, sharing the following story:

> I always remember one time [Mr.Forward”s] back was bad and we went to a chiropractor... he is always making these bedpan jokes and sometimes the joke goes over people’s head. I don’t really know but anyways [Mr.Forward] made this

> joke and I started to laugh, and the chiropractor commented he said (you mean you still laugh at his jokes) and I'm like (yeah I guess I do.)

Additionally, during the interview, which was conducted at the family's home, Mr. Forward made several jokes directed at the interviewer and inside jokes with his wife. Mrs. Forward said, "Sometimes he will say something, and I will anticipate that he is going to say something fully and I will start to laugh, and it's funny cause I am anticipating it." Humour was present in all of the interviews and was identified by some of the couples as a useful factor to mitigate stressful circumstances.

Recognition of Partner's Efforts. Another factor that was not mentioned directly by the couples but was identified by the researcher during the coding process, was couples' recognition of their partner's efforts. During each of the interviews, partners highlighted the roles and responsibilities of the other partner and identified their contributions, efforts, or skill sets that contributed to the overall positive functioning of their families. Mrs. Dobbin highlighted her husband's dedication to their family: "He's worked full-time every day now for 19 years." Mrs. Forward said, "He became almost like a case manager... taking care of all of this," when discussing Mr. Forward's role in managing their child's care. Mrs. Abbott stated that "my husband did a lot," when reflecting upon the work it took to set up the original supports after a diagnosis of ASD. In a subtler display of praise, couples frequently reflected support when one partner was discussing their own contributions and efforts, making comments such as "That's right, he does" or "She's good at that stuff" to signify their recognition of their efforts.

Conflict. It is also important to think about communication from the position of conflict and conflict resolution. In this study, six of the seven families stated that they rarely fight or argue, but when they do it is never very serious, meaning there is no threat to their relationship. “There was probably four or five occasions after all of these years that one or the other has been really mad with the other” (Forward family). “We haven’t got much time to fight with each other” (Abbott family). The Elliot family also suggested that they did not have the time to be fighting:

> We had a routine and a lot to do; there wasn’t much time to fight; stuff needed to be done.… we didn’t have time to have those problems or fight; we had four kids and you can’t fight in front of kids.

Only one of the couples interviewed stated that they did fight: “We argue, like we don’t physically fight but we can get into some pretty heated arguments” (Dobbin family). Interestingly, this couple also stated that they have had the same problems for a long time: “They are the same arguments that we had in our pre-marriage course; nothing has changed” (Mrs. Dobbin). Although this couple identified their capacity to fight, they did state that the status of their relationship has never been compromised.

When addressing the concept of conflict, couples noted that if there was tension they would take some time and some space before re-addressing the issue calmly with their partner. “Sometimes we would take a little time away and then we would talk about it and work it out; that’s the only option there is” (Elliot family). Similarly, “We wait until the youngsters go to bed and then we will figure it out” (Cooper family), and “We just have a little time apart and things were good again” (George family).

Being on the Same Page. Lastly, the protective factor of Being on the Same Page came up in each of the interviews. Couples stated that it was important to be in the same page in all areas including: appointments, behaviours, medicine administration, parenting strategies, routines and rules, and intervention strategies. Thus, *being on the same page* was defined as holding similar beliefs, knowledge, and understandings of expectations, and roles and responsibilities. This was critical for the successful functioning of the household. Mrs. Bennett stated, "We are just generally on the same page when it comes to most things with his treatment and everything that needs to be done, I mean in terms of school, discipline, anything like that." Since most of the couples worked different schedules, communicating the various appointments, happenings, and daily updates was very important in helping them transition smoothly.

> We kind of got to stay on the same page, and enforce the same rules and just stick to the guidelines and stick together or he is just going to go on a whirlwind... it didn't work for us to be on separate pages" (Cooper family).

Further, "We are both on the same page, that our goal right now is to make sure that there is time spent with her and that she gets everything that she needs" (Abbott family). In summary, couples underlined the importance of being on the same page in order to effectively manage their home.

Positive Outlook

When evaluating the components which comprised the theme Communication, a predominate factor was identified in each of the interviews, the couple’s natural inclination to view their situations optimistically or in a positive framework. Each of the seven couples focused on elements of good “fortune” and “luck” in reference to their life circumstances:

> We are very fortunate; if we are not going to get support that’s fine we will manage and get her through it…. there are kids out there worse than what I got...take a trip to the hospital... we counted our blessings. (Abbott family)

Further, the Forward family stated, “He’s a good boy, an angel really… you know compared to those poor children with ASD you know... we always say to each other it could have been so much worse because we have a beautiful boy.” The Bennett family also stated that they felt fortunate: “We are very lucky; he’s great, we can take him anywhere,” in reference to their child’s behaviours.

Moreover, most of the couple's, six out of the seven, directly identified their proclivity for solution-focused methods when facing life’s obstacles. “We are not the one with ASD so why would we be upset over it… we can do something about it but there are people out there who are in denial” (Abbott family).

> We both said we are going to do everything we can for him... you know it was like there were people crying and don't believe it and all that stuff but we were like right away we were like yeah let’s get help. Even though it was difficult news we didn’t ever take it bad, did we…. We accepted the responsibility as we had to get through it... he’s a good boy. (Forward family)

During the Dobbin family interview, the couple said that their children were going to be successful regardless of the challenges that they faced. Mrs. Dobbin reflected upon a conversation with her children:

> It's just a diagnosis; that doesn't mean you can't do anything; it just means you might have a little bit more difficulty than your buddy, and you have to find new ways to do things, because you have to be successful in this life.

Maintaining a positive outlook and searching for solutions when problems arose were healthy means of coping by the couples when faced with unexpected obstacles.

Conclusion

The overarching themes that have been identified in this study as protective factors within the couple's relationships are Commitment, Adaptation, Communication, and Positive Outlook. Combined, these factors contributed to the overall successful functioning of these couples' relationships and helped to mitigate stress and marital discord. This concludes the thematic results section; however, the analysis from this study revealed additional findings that did not reach saturation. These topics are worthy of consideration, and relevant for future study and so will be further outlined in the discussion section under the heading of "Non-Thematic Findings".

Chapter 5: Discussion and Implications

A stressor, demand, problem, or loss has the ability to either weaken or strengthen a family's cohesion and functioning as the family unit combats it with both action and commitment. It is through the application of protective factors that families maintain resilience (Black & Lobo, 2008). The aim of the current study was to identify the protective factors existing within a couple's relationship that foster resilience when raising a child with ASD. The results obtained indicate that four predominant and overarching protective factors are associated with couple resilience, including: Commitment, Adaptation, Communication, and Positive Outlook. This chapter will discuss these findings in further detail.

Thematic Findings

Resilience has been described as a concept that is not static, but one that can be influenced by many different factors throughout one's life (Braverman, 2001). To reiterate the definition of protective factors, Braverman (2001) suggested that protective factors can be defined as characteristics of an individual or their environment that mitigate or reduce the potentially harmful effects or risk factors or stressors. Again, when viewed from a family perspective, resilience is represented by a positive response to an adverse event in which families successfully navigate to become stronger, more confident, and more resourceful (Walsh, 1996). It is through the successful use and application of protective factors that families build resilience in the face of challenges and adversity. It is in the face of adversity that these protective factors are called upon so that individuals may successfully navigate possible negative outcomes. Further, when individuals are being challenged, these protective factors are summoned to help promote positive adaptation or appraisal in the presence of crisis (Black & Lobo, 2008).

Black and Lobo (2008) and Bayat (2007) identified possible protective factors that contribute to family resilience; although discussed earlier, this necessitates repeating here. These factors include: smaller families thus experiencing less financial strain and resulting in lower stress level (Benzies & Mychasiuk, 2011), increased community involvement which provides access to larger social networks and educational resources; appreciation for life and other people in general, mobilizing resources, expressed spirituality, family member accord, demonstrating flexibility, communication, financial management, family time and shared recreational activities, and family routines and rituals. Evidence of family resilience such as family connectedness and closeness, positive meaning-making of the disability, and spiritual and personal growth are also identified in the literature as positive factors contributing to marital success. Additionally, factors such as making meaning of adversity, affirming strength and keeping a positive outlook, and having spirituality and a belief system all positively influence family resilience (Walsh, 1998).

The current study has yielded similar findings in relation to the protective factors which foster couple resiliency. Specifically, the researcher has identified the following protective factors: Commitment, Adaptation, Communication, and Positive Outlook. Three of the four concepts are directly represented in the literature. Commitment, which is not explicitly stated, is represented by its sub-themes, Structure/Routine/Consistency and Importance of Time Together. The discussion below will explain the findings related to these protective factors.

Commitment. This protective factor highlighted the couples' commitment to raising their child together and providing him or her with every possible opportunity for personal growth through constant work, fighting for supports, and advocating for their child's needs. Couples were committed to the needs of their child before and above anything else and were committed to working together to achieve those shared goals.

Couples were also committed to each other and to the relationship. Couples highlighted their beliefs in staying together, working through issues, and working as a team to maintain the functioning of their homes. Specifically, they identified the importance of working together to maintain the structure, routine, and constancy that was mandatory for the successful organization of their child's needs and the maintenance of his or her behaviours. As stated by Walsh (1998), a well-functioning family attempts to maintain its routines even during times of chaos to maintain a sense of predictability, cohesion, and comfort.

Additionally, within the protective factor of Commitment, the couples emphasized the importance of making time for each other. Regardless of time and schedules, it was critical for the positive functioning of the relationship for the couples to set aside some time for each other; however, this time did not always involve the traditional "date night" format (e.g., going to dinner and a movie). Rather, couples indicated that spending time together referred to alternatives to dating norms, such as sitting and watching a show at the end of the day together, going for a walk, having a chat while the children were playing, sitting quietly alone together, or doing the house chores together. Because of the level of care that their child required, and depending on the amount of support they had, time together could look very different for each couple. Spending time together during family meals, chores, and errands plays an important role in maintaining stability in the family (McCubbin & McCubbin, 1988). Thus, regardless of the differences in schedules and activities, all couples identified the importance of time together.

Communication. This protective factor reflects the specific ways in which couples interacted together, negotiated their world, worked through conflict, organized their lives and schedules, and had fun together. Positive communication has been found to contribute to marital satisfaction (Hooper, Spann, McCray, & Kimberly, 2017). In this study, Communication was a broad category that highlighted the way in which couples spoke to each other, including the importance of the use of humour, recognition of the partner's efforts, balance, negotiation of roles and responsibilities, negotiation of conflict, and keeping together on thoughts, ideas, and parenting interventions (keeping on the same page).

Humour often acted as a direct buffer to stress or as a way to improve one's mood when tension was high. As stated by Cameron (1990), humour can provide individuals with a sense of proficiency that has the power to overcome feelings of powerlessness and fear. For these couples, humour provided a valuable outlet from their daily stressors. Further, in a conceptual review of the literature, Walsh (2003), as cited in Black and Lobo (2008) found that, in a healthy family, members tend to interact with each other in a way that bolsters nurturance through the process of compliments and reinforcing each other's efforts.

Couples in this study often verbalized their appreciation of their partner's efforts, and they verbally acknowledge the work their partner contributed to the family. The partner's efforts and contributions were not only noticed by the other partner but also highlighted, and praise was given. Furthermore, couples in this study stated that balance was also an important buffer to stress as it allowed them to negotiate their roles and balance each other out (i.e., when one partner was feeling tired, stressed, or overwhelmed the other would step in to balance the mood or situation).

Perhaps one of the most dominant areas of communication for these couples was the negotiation of roles and responsibilities. Couples were required to successfully navigate their new roles and responsibilities through the division of chores. Results for this study suggest that the couples divided tasks based on whose schedule allowed for the task to be completed, and on personal skills.

Conflict is also a very important factor related to couples' communication. Golby and Bretherton (1999) found that resilience in mother-child relationships are not resistant to negative emotions such as hurt or anger; however, the difference is that family members attempt to listen, understand, and respect other persons' reasons for these negative emotions. It is impossible for families to escape negative emotions, problems, or family crisis; however, it is important for families to maintain the ability to work collaboratively to solve these conflicts. The ability to collectively work together to find solutions for existing or emerging problems has been identified as a trait of resilient families (Patterson, 2002). Further, couples highlighted the importance of communicating schedules, responsibilities, appointments, and thoughts and feelings as a way to stay connected and stay on the same page with what was happening in their lives. Communicating these factors helped couples to remain up to date and contributed to the successful functioning of the home. Relatedly, couples in this study used the term "staying on the same page" to further highlight the importance of being aware of the other's thoughts, ideas, and understandings as a way to maintain cohesion and stability within the home

Adaptation. Solomon and Chung (2012) defined family functioning as a process involving adaptation and cohesion. The stress related to raising a child with ASD can therefore be conceptualized as a process that involves constant adaptation and adjustment to change on a number of levels. Specifically, the results from this study indicated three areas of adaptation: Rearranging Schedules, Exhaustion, and Benefits of Good Supports.

Many of the couples in this study had to acquire alternative employment that allowed one parent to be home with the child at all times. Couples often worked on opposite shifts to ensure that their child would receive adequate care. Not only did couples successfully negotiate conflicting schedules, but they also maintained their relationships regardless of this adapted schedule. The challenges associated with shift work hours combined with the extra parenting responsibilities often left couples feeling exhausted. Couples identified constant exhaustion as being associated with raising a child with ASD. This exhaustion was oftentimes related to the parenting responsibilities and the challenges with work schedules. The couples in this study adapted to these changes and made them work regardless of the challenges they were navigating.

Additionally, the couples stated the impact of good supports on their ability to adapt and cope with the challenges they faced while parenting a child with ASD. Having strong connections to family and social networks can be beneficial to couples because it can provide access to information, services, respite, and support (Luthar, 1999). The couples highlighted the importance of a strong network of supports in a number of areas including their network of family and friends, government services, financial assistance, and educational services. Results from this study indicate that the couples who had access to more supports experienced less exhaustion and frustration than couples without such supports. Access to a good social support system has the ability to increase positive outcomes and enhance resilience by providing a sense of connectedness (Black & Lobo, 2016). Incidentally, the one couple in this study who reported having no supports also identified the highest incidence of exhaustion and limited access to couple time, alone time, and sleep. Isolation resulting from a lack of social supports has the potential to erode resilience, especially when families are under significant stress (Luthar, 1999).

Positive Outlook. The concept of resilience relates to one's ability to successfully navigate challenges and come out strengthened and resourceful (Walsh, 1996). Thus, it is important to consider that resilience relates to the couple's interpretation and appraisal of the stressor. If couples see the stressor as an insurmountable obstacle, their ability to successfully navigate that stressor will be challenging. However, as demonstrated in this study, maintaining a positive perception and outlook acted as a protective factor in the relationship of the participating couples. These couples displayed a positive outlook when reflecting on their life circumstances and challenges. They maintained a positive perspective when discussing challenges and frequently displayed a solution-focused attitude as a means of problem solving. The positive appraisal of stressful situations and life situations allows couples to perceive the stressor as more manageable, thus allowing them to foster resilience.

When evaluating the protective factor Positive Outlook, it is interesting to reflect on couples' positive adaptation to loss. All of the couples in this study identified feelings of luck and good fortune in spite of the challenges they had encountered, and all couples demonstrated a positive outlook and used a solution-focused approach to coping with life's stressors or challenges. Additionally, all of the couples highlighted the strength of their relationships and their bonds with their children. Murphy, et al. (2003) stated that individuals who are able to attach positive meaning to the loss that they experience are more likely to experience lower levels of distress, higher marital satisfaction, and better physical health. Individuals who have difficulty accepting loss and making meaning of the way their current world looks are subject to experience prolonged grief (Neimeyer et al., 2009).

Non-Thematic Findings

It is important to note that all of the couples who participated in this study stated that their relationships were strengthened as a result of raising a child with ASD. Couples stated that having a child with ASD helped them to work harder at their relationships and become better at navigating stressors or conflict.

Interestingly, when looking at the family as a system, the well-being of one individual has the capacity to affect the well-being of another member of that family (Trivette, Dunst, & Hamby, 2010). In the current study six of the seven couples had more than one child. Of the six couples with multiple children, four had a second child with special needs. Specifically, three of these couples stated that their other child had a diagnosis of attention deficit hyperactivity disorder (ADHD). Interestingly, each couple that had two children with exceptionalities stated that at times they struggled more trying to navigate the behaviours of the child with ADHD.

Additionally, it can be challenging to be the sibling of a child with exceptionalities. Two of the couples in the current study spoke openly about the challenges experienced by the siblings of their child with ASD. Griffith, Hastings, and Petalas (2014) found that siblings of children with ASD, when rated by both mothers and fathers, had significantly higher rates of emotional problems as well a lower level of pro-social behaviour when compared to a normative sample. Conversely, in a study of psychosocial adjustment in siblings of children with ASD, conducted by Kaminsky and Dewey (2002) it was found that siblings of children with ASD were not at an increased risk for experiencing adjustment issues.

Through this study, it has been determined that the majority of available resources available to the participating couples were related to early-intervention strategies for children with ASD. Specifically, six of the seven couples noted that during the diagnosis process no support was offered to the parents or couple. The Bennett Family, upon receiving an ASD diagnosis, was offered the support of a social worker to help them cope with their emotions related to the diagnosis. This was identified as a helpful process and one that was beneficial to the family.

The results of this study suggest that receiving a diagnosis of ASD comes with an abundance of information and changes. It is a time where parents and couples need to be supported. Many of the couples in this study agreed that it would be beneficial to have resources available which specifically services the needs of the couple. Specifically, support in the way of counselling to help cope with the changes associated with the diagnosis, in understanding the challenges associated with raising a child with ASD, and in navigating the system and available supports. Additionally, couples identified challenges associated with the accessibility of resources due to lack of appropriate child care available. Access to respite or appropriate child care would mitigate this issue.

Implications

The current study highlights a number of relevant discussion points that could influence the way practitioners approach couples during the ASD diagnosis process. Specifically, out of the seven couples interviewed, only one couple was offered support during the diagnosis process.

Typically, when receiving a diagnosis of ASD the emphasis is on the child, possible interventions, and medical implications. During this process there is very little focus on the couple and their needs. All couples in this study found that the diagnosis period came with an abundance of changes, expectations, and responsibilities. There was very little guidance, instruction, or explanation provided to couples during this time. Couples in this study saw the value in having someone to provide assistance during this time to navigate this system and to provide direction, support, and information to help answer some of their questions.

Couples raising a child with ASD can experience a multitude of both chronic and acute stressors that can negatively impact their relationship satisfaction. As noted by Nealy et al. (2012) in their study of mothers, the added stress of ASD was said to cause conflict between partners which lead to relationship deterioration. Considering this, it would be beneficial for service providers including, but not limited to social workers, doctors, and therapists to consider the advantages of providing therapeutic supports for couples during this time. Additionally, having a knowledge and understanding of the protective factors that contribute to couples' resilience would benefit both couples and service providers. Couples who are going through the diagnosis process may be able to identify ways to implement these factors within their own relationships. Further, since there is often solace in support, the information presented in this study could provide couples an inside look at other couples who are successfully navigating their relationship while raising a child with ASD.

Although it is important to consider what services would most benefit the couple, it is also critical to assess the challenges associated with receiving these services. Many of the couples in this study said that even if services were available to them, they would struggle with attending because of the challenges associated with child care. As indicated in the results, five of the seven couples had had to rearrange their work schedules to accommodate the needs of their children. Therefore, it would be difficult for them to access services together as they do not have access to child care. This lack of access to appropriate child care could also create a social disconnect for the couples who are unable to get time away. Couples acknowledged that access to services, as well as access to social opportunities, can be restricted depending on the severity of their child's behaviours. Many of the couples stated that during various points throughout their child's development, their behaviours were too unpredictable to take them out in public. During this time couples were severely limited in what they could do.

Many couples expressed the importance of public knowledge, awareness, and understanding of ASD, what it is, what it can look like, and how to help. Specifically, couples emphasized the stress associated with dealing with their child's behaviours in public and how more awareness and understanding from the general public would help them to feel less judged or shamed by their parenting strategies.

While exploring the research question and evaluating the perspectives of couples raising a child with ASD, the researcher learned how easy it was to lose sight of the primary focus of this study, the “couple.” Throughout the course of the literature review, the research process, and supervisory discussions about the development of the study, the researcher and supervisors realized how easy it was to bring the focus back to the family or the child, most often the child. This was also true during the data collection phase as couples spent a large portion of the interview time focusing on their child rather than on their own relationship.

This chapter has discussed the study’s findings and their possible implications. Specifically, the chapter highlighted the most salient points identified by the couples in this study and what that could mean for other couples raising children with ASD, as well as for service providers. The following chapter will explore the possible limitations of this study as well as future directions, closing with a brief overall conclusion of this study.

Chapter 6: Limitations, Future Directions, and Conclusion

The current chapter will explore the possible limitations existing within this study as well as future directions for research in this area. The researcher will outline these limitations to provide future researchers a better understanding of the study, and to possibly help mitigate some of these issues in future research. The researcher will also provide suggestions of possible research opportunities in the future that could stem from the findings from this current study.

Limitations

It is important to consider the possible limitations within the current study. This study utilized a small sample size, and participants were recruited through limited means. Recruitment was restricted to individuals who responded to a descriptive recruitment letter that was sent out to various locales. As a result, the researcher may have missed a population of individuals who did not have associations with the local NGO or those who had limited access to internet service. It should be noted, however, that there was representation from some rural communities, though not all areas were represented. Further, although the recruitment was extended to couples of all gender identities and sexual orientations, no couples in this sample represent the LGBTQ+ community.

As outlined by Atieno (2009), human behaviour can be significantly impacted by the setting in which it occurs. Thus, it must be considered that, as a means of convenience for the participants of this study, some interviews took place over the phone, some in an office setting, and some in the homes of the participants.

Future Directions

Future researchers in the area of protective factors in couples who are parenting a child with ASD should consider interviewing a sample population of couples whose relationships have dissolved, to provide a comparison point for understanding. Additionally, it would be interesting to conduct a similar study using a quantitative methodology to assess if these findings could be extended to a wider population. As well, it would be useful to determine if these findings were statistically significant or the result of chance. As identified in "Non-Thematic Findings," researchers in the future may consider conducting studies in the areas of sibling outcomes associated with having a sibling with ASD, challenges associated with raising two children with special needs, and what services would best benefit parents raising children with ASD.

Conclusion

The current study utilized a qualitative research design and semi-structured interviews with seven couples, to address the question "What are the protective factors that mitigate relationship discord and increase relationship satisfaction when raising a child with a diagnosis of ASD?" Results from this study yielded the following suggestions for protective factors contributing to marital satisfaction when raising a child with ASD. The themes identified are as follows: Commitment, Adaptation, Communication, and Positive Outlook. These results are similar to the findings of Black and Lobo (2008) and Bayat (2007).

All seven couples, excluding one, who participated in this study stated that no supports had been offered to them, as a couple, at any point. Additionally, all couples shared the sentiment that having a child with ASD had strengthened their relationships with each other. The current study maintained its focus on the “couple,” identifying possible implications that could benefit such couples in the future, including suggestions for service providers and for other couples raising children with ASD. This study clearly outlined possible limitations, such as small sample size, and future research directions, such as exploring the perceptions of couples who have dissolved their relationships, in hopes that these observations might benefit the design of future research in this area.

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Appendix A

Informed Consent Form

Title: Exploring the Protective Factors Contributing to the Resilient Relationships of Individuals Raising a Child with Autism Spectrum Disorder

Researcher: Nikita-Rae Piercey, Memorial University, K74nrcp@mun.ca

Supervisors: Dr. Sarah Pickett & Dr. Sharon Penney, Memorial University's Faculty of Education

You are invited to take part in a research project entitled "Exploring the Protective Factors Contributing to the Resilient Relationships of Couples Raising a Child(ren) with Autism Spectrum Disorder."

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact me, the researcher, Nikita-Rae Piercey, if you have any questions about the study or would like more information before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

Introduction:

I am currently completing a Masters of Education in Counselling Psychology, at Memorial University of Newfoundland. As a part of my program I am completing a thesis under the supervision of Dr. Sarah Pickett and Dr. Sharon Penney.

Purpose of the Study:

The purpose of the current study is to investigate the positive and successful experiences, and the protective factors existing in couples' relationships, who are raising a child or children with Autism Spectrum Disorder (ASD). Specifically, I am interested in learning about the protective factors existing within the relationship that help to maintain a healthy, functioning partnership. In this study I am particularly interested in looking at the positive factors which contribute to a couple's ability to maintain their relationships when raising a child or children with ASD.

What You Will do in this Study:

In this study you will be asked to participate in an audio recorded interview process. This interview will be conducted between myself (the researcher) and you and your partner. You will be asked questions about your parenting experiences in relation to your partnership/relationship and satisfaction in the relationship. Additionally, you will be asked questions to identify specifics about the functioning of your relationship, the challenges you face, and the factors that help to support you through difficult situations. After the interviews have been transcribed you will be asked to confirm their accuracy and you will be invited to make any changes you feel are necessary (this part is optional), before returning the transcripts to myself (the researcher).

Length of Time: The average time of each interview is estimated at 1 - 1.5 hours. I will provide additional time if you are not satisfied with the amount of detail you provided.

Withdrawal from the Study:

You are free to withdraw from this study and there will be no negative consequences now or in the future.

You may choose to withdraw by contacting me via phone or email (Nikita Piercey at (709) 727-0482 or k74nrcp@mun.ca). However, once the data has been transcribed, analyzed, and written into the thesis, then I will no longer be able to separate your data. The deadline for this will be four weeks after you receive your original transcript back for review.

If you choose to withdraw from the study your audio recorded interview will be deleted and any transcripts will be deleted and paper copies shredded.

Possible Risks:

You will be asked to discuss the functioning of your relationships. In other words, how you work as a couple and any challenges that you may face individually or together. As a result of the intimate nature of the conversation, you may feel embarrassed, or uncomfortable. You will not be pressured to continue if you do not want to, and what you choose to share is decided by you. You are not obligated to answer any question that you do not want to.

If you experience distress as a result of the content of this study, you will be provided with contact information to seek support or mental health services in your area. If you experience distress it is also advised to make contact with your family or primary care physician. Here is a list of additional resources which you may benefit from if you experience distress:

- Mental Health Crisis Line, 24 hour Toll Free 1-888-737-4668
- Association of Psychology Newfoundland and Labrador (APNL) (709)739-5405
- Canadian Counselling and Psychotherapy Association (CCPA) 1-877-765-5565
- Newfoundland and Labrador Association of Social Workers (NLASW) (709)753-0200
- 24 hour Walk-in Crisis Services, Psychiatric Emergency, Health Science Centre
- 24 hour Walk-in Psychiatric Assessment Unit, Waterford Hospital, Waterford Bridge Road, St. John's, NL

Confidentiality:

The ethical duty of confidentiality includes safeguarding your identities, personal information, and data from unauthorized access, use, or disclosure.

Transcriptions will be stored on a password-protected computer. The only individuals that will have access to the data are myself and my supervisors. Any physical data (i.e. paper, notes) will be stored in a locked filing cabinet. Record maintenance of the data will follow Memorial University's research storage policies.

No identifiable quotes will be used in the publication of the research. Any quotes with identifiable information, such as city or province, will be anonymized (i.e., "Newfoundland and Labrador" will be changed to an "Atlantic Canadian province"). Pseudonyms will also be used in place of real names.

For further clarity and understanding of Memoiral's protocol please reference: http://www.mun.ca/research/ethics/humans/icehr/informed-consent/wording-suggestions.php

Anonymity:

Anonymity refers to protecting your identifying characteristics, such as name or description of physical appearance.

All of your identifying information will remain anonymous in this study.

Every reasonable effort will be made to ensure your anonymity. You will not be identified in publications.

Recording of Data:

Interview sessions will be audio recorded in order to facilitate the transcription of data for analysis purposes, and written notes will be taken at the same time. If you are not comfortable being recorded, only notes will be written down. If you are not comfortable with notes being taken during the session I will ask you if you are comfortable if I take notes after the interview from memory.

Use, Access, Ownership, and Storage of Data:

Only myself (the researcher) and my co-supervisors will have access to the data at any given time. Data collected during the study will be held following standard procedures and policies of Memorial University of Newfoundland before being destroyed. Hard copies will be kept in a locked filing cabinet following the same procedures.

Hard copy data will be kept on a password-protected USB stick. All electronic data files will be password-protected and stored on password-protected devices. Additional data will be stored in a filing cabinet under lock and key, only myself (the researcher) and my co-supervisors will have access to these materials.

Data will be kept for a minimum of five years, as required by Memorial University's policy on Integrity in Scholarly Research.

Sharing of Results with Participants:

You will have access to the completed project (thesis dissertation) via the Memorial University site: http://collections.mun.ca/cdm/search/collection/theses.

When the project is complete you will be informed via email and provided with a synopsis of the findings as well as a copy of the final report.

Questions:

You are welcome to ask questions before, during, or after your participation in this research. If you would like more information about this study, please contact:

Nikita-Rae Piercey
E: k74nrcp@mun.ca
T: (709) 727-0482

Dr. Sarah Pickett
E: spickett@mun.ca
T: (709) 864-4380

Dr. Sharon Penney
E: scpenney@mun.ca
T: (709) 864-7556

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research, such as the way you have been treated or your rights as a participant, you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 709-864-2861.

Consent:

Your signature on this form means that:

- You have read the information about the research.

- You have been able to ask questions about this study.

- You are satisfied with the answers to all your questions.

- You understand what the study is about and what you will be doing.

- You understand that you are free to withdraw participation (Until four weeks after you receive your original transcript back for review) in the study without having to give a reason, and that doing so will not affect you now or in the future.

Withdrawal:

- You understand that if you choose to end participation **during** data collection, any data collected from you up to that **point will be destroyed**.

Circle YES or NO for the following:

I agree to be audio recorded Yes No

I agree to the use of direct quotations Yes No

I allow data collected from me to be analyzed in NVivo (which is analysis software commonly used in data collection research) YES NO

By signing this form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

Your Signature Confirms:

I have read what this study is about and understood the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

I agree to participate in the research project understanding the risks and contributions of my participation, that my participation is voluntary, and that I may end my participation.

A copy of this Informed Consent Form has been given to me for my records.

______________________________ ______________________________

Signature of Participant Date

Researcher's Signature:

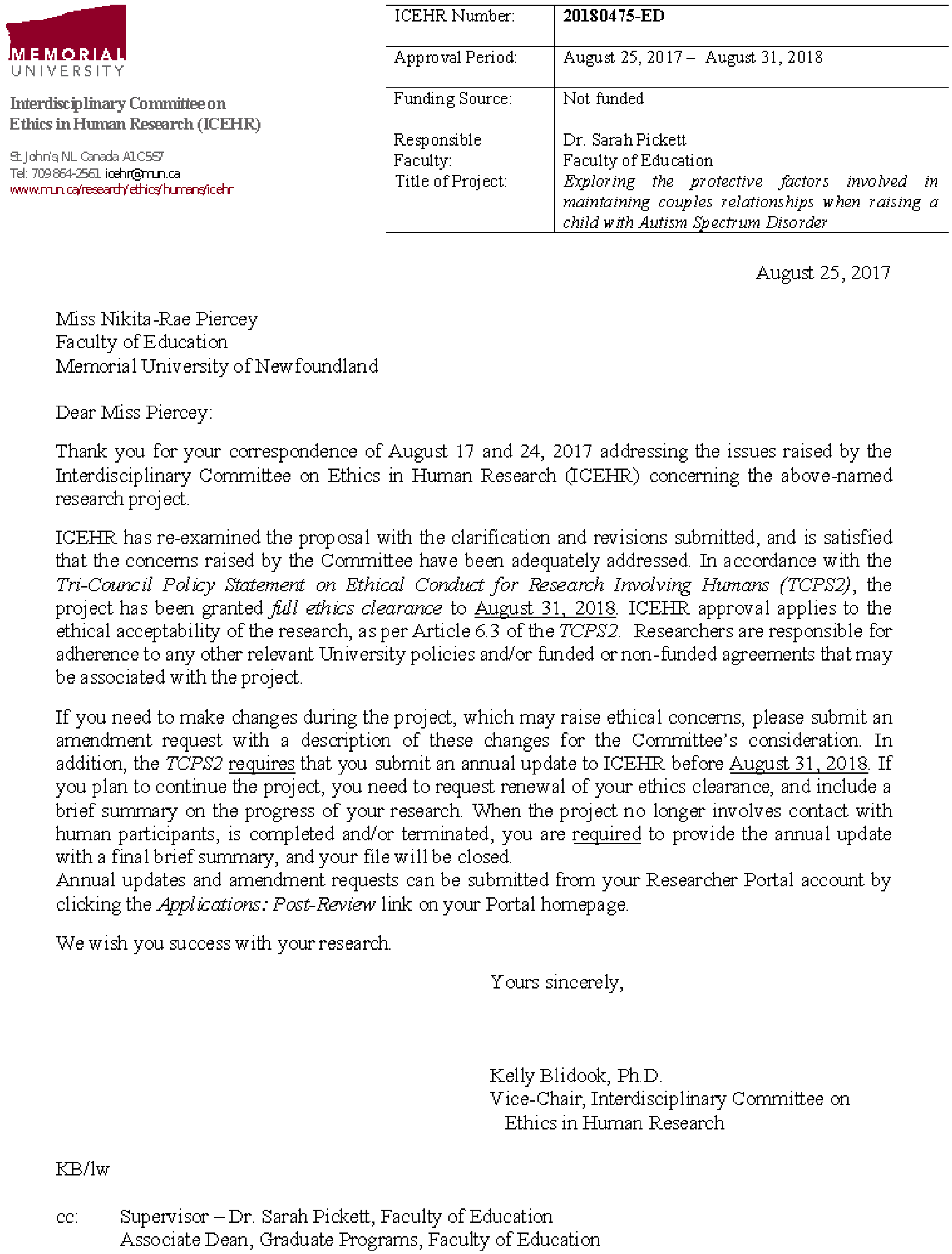
I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

______________________________ ______________________________

Signature of Principal Investigator Date

Appendix B

Ethics Clearance



MEMORIAL UNIVERSITY

Interdisciplinary Committee on
Ethics in Human Research (ICEHR)

St. John's, NL Canada A1C 5S7
Tel: 709 864-2561 icehr@mun.ca
www.mun.ca/research/ethics/humans/icehr

ICEHR Number:	**20180475-ED**
Approval Period:	August 25, 2017 – August 31, 2018
Funding Source:	Not funded
Responsible Faculty:	Dr. Sarah Pickett Faculty of Education
Title of Project:	*Exploring the protective factors involved in maintaining couples relationships when raising a child with Autism Spectrum Disorder*

August 25, 2017

Miss Nikita-Rae Piercey
Faculty of Education
Memorial University of Newfoundland

Dear Miss Piercey:

Thank you for your correspondence of August 17 and 24, 2017 addressing the issues raised by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) concerning the above-named research project.

ICEHR has re-examined the proposal with the clarification and revisions submitted, and is satisfied that the concerns raised by the Committee have been adequately addressed. In accordance with the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2)*, the project has been granted *full ethics clearance* to August 31, 2018. ICEHR approval applies to the ethical acceptability of the research, as per Article 6.3 of the *TCPS2*. Researchers are responsible for adherence to any other relevant University policies and/or funded or non-funded agreements that may be associated with the project.

If you need to make changes during the project, which may raise ethical concerns, please submit an amendment request with a description of these changes for the Committee's consideration. In addition, the *TCPS2* requires that you submit an annual update to ICEHR before August 31, 2018. If you plan to continue the project, you need to request renewal of your ethics clearance, and include a brief summary on the progress of your research. When the project no longer involves contact with human participants, is completed and/or terminated, you are required to provide the annual update with a final brief summary, and your file will be closed.
Annual updates and amendment requests can be submitted from your Researcher Portal account by clicking the *Applications: Post-Review* link on your Portal homepage.

We wish you success with your research.

Yours sincerely,

Kelly Blidook, Ph.D.
Vice-Chair, Interdisciplinary Committee on
Ethics in Human Research

KB/lw

cc: Supervisor – Dr. Sarah Pickett, Faculty of Education
Associate Dean, Graduate Programs, Faculty of Education

Appendix C

List of Potential Semi-Structured Interview Questions

The semi-structured interview inherently allows for an emergent/dynamic process of engagement between the interviewer and interviewee. For this reason the questions have been organized into three primary categories with sample subquestions. An emergent and dynamic interview process allows for flexibility within and between interviews to reshape and craft the subquestion in a manner that most closely address the primary categories and/or the subcategories. As such, subquestions may be added and/or refined based on responses provided by the participants over the course of data collection.

Section 1

Participant perspectives/outlooks/views/interpretations of their situations and circumstance. General questions will also be asked to learn more about the family dynamic and family structure.

How many children do you have?

How long have you been together?

Did you both want/plan to have children?

How did you cope with the diagnosis of ASD?

Has your financial position been stressed as a result of a diagnosis of ASD?

What do you think has made you successful parents / What factors do you think you possess that help to maintain your relationship?

Do you worry at times about the status of your relationship? What thoughts or concerns do you have about the future? What situations have you found to be most stressful and how were these issues resolved? How did you navigate these new stressors?

How has raising a child with an exceptionality been different from your other children? Explain what you have learned from this process and experience.

What have you found to be your biggest stressors? (common everyday/unexpected) Do you think you are optimistic people or pessimistic individuals? How would you rate your child(ren)'s behaviours – mild, moderate, severe? Did you have any pre-existing mental health issues before becoming parents?

Section 2 Individuals/couples social support system and family networks, and connection to resources.

What supports have been in place for you as parents or as a couple? Have any of these been helpful? What do you think would be helpful?

How would you describe how the diagnosis of ASD affected you? The family? Are you religious or have any spiritual affiliations? How would describe your social supports and support of family and friends? Do you think you could do it on your own? What would it look like to do it on your own?

Section 3 Collaborative family interactions/communication styles/ family time spent together/ couple time/ quality of time/ as well as thoughts/beliefs/opinions on importance of these factors.

How do you typically go about problem solving as a couple? Describe your parenting style? What is your style of communication? How do you usually resolve conflicts? What situations have you found to be most stressful and how were these issues resolved? What have you found to be your biggest stressors? What activities do you like to do together?

What does time alone look like for you?