

LIVING WITH A SIBLING WHO HAS AUTISM SPECTRUM DISORDER

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts (M.A.) in Applied Psychology

Faculty of Graduate Studies
Laurentian University
Sudbury, Ontario

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THESIS DEFENCE COMMITTEE/COMITÉ DE SOUTENANCE DE THÈSE
Laurentian Université/Université Laurentienne
Faculty of Graduate Studies/Faculté des études supérieures

Title of Thesis Titre de la thèse	LIVING WITH A SIBLING WHO HAS AUTISM SPECTRUM DISORDER		
Name of Candidate Nom du candidat	Carvalho, Marilia		
Degree Diplôme	Master of Arts		
Department/Program Département/Programme	Psychology	Date of Defence Date de la soutenance	September 13, 2017

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Abstract

The document presented herein is a manuscript-based thesis, entitled: Living with a Sibling who has Autism Spectrum Disorder (ASD). This thesis consists of an exploratory investigation to learn more about the experiences of individuals who have a sibling with ASD. The data obtained is discussed in two papers. The first paper focuses on the discussion of future caregiving which involves the transference of care to siblings (with typical development) when parents are no longer able to provide care. The scope of the second paper solely focuses on data obtained from interviews using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). Siblings highlighted particular aspects of future caregiving that harboured concerns, resulting in the discussion of four relevant themes. The second paper was guided by the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988, 1989; Patterson & Garwick, 1994) to explore the type of stressors that were experienced and whether adequate supports were being utilized. To understand experiences specific to demands and supports, a mixed-methods approach was employed. Informed by the FAAR, interview transcripts were analyzed using Thematic Analysis (Braun & Clarke, 2006), revealing four themes. Descriptive statistics were also provided based on data obtained from two questionnaires: The Sibling Inventory of Behaviour Scale (SIBS) and The Sibling Daily Hassles and Uplifts Scale (SDHUS). Results concluded that siblings are constantly in the process of finding new resources and developing new capabilities to manage demands across the life span. Clinical implications for each paper are discussed further.

Keywords: The following keywords could be used to describe this thesis document entitled: Living with a Sibling who has Autism Spectrum Disorder: Autism Spectrum Disorder, Siblings, FAAR, Stressors, Supports, Future Caregiving

Acknowledgments

I would like to express my gratitude first and foremost to the siblings who participated in this study. They shared some of their greatest memories and obstacles with me in an honest manner. I am truly thankful for their trust in me and the directives of my thesis work. I was inspired by their resilience and perspectives and I learned so much from their stories.

I would also like to thank my supervisor Dr. Shelley L. Watson and my committee members, Dr. Diana Coholic and Dr. Sylvie Larocque. Each one of you took time from your busy schedules to carefully read through all my chapters. Dr. Watson, thank you for your patience and encouragement after each revision. It was a long journey but I felt that I had become a stronger writer with your guidance. In addition, the feedback provided by my committee members was invaluable and I am grateful for their support. Throughout this writing process I know that I worked with a team of individuals with immense expertise and passion for the field of developmental disabilities. Thus, I am happy to have shared my thesis experience with them.

To my family, I would like to say thank you for your unrelenting support. There were many times when I felt that giving up was my only option and your words of encouragement were the reason I kept going. My family has inspired my passion for family research as I have learned first-hand that there is no stronger bond than the ones shared with parents and siblings. I would also like to thank my peers for their support and the laughs that we shared together. My time at Laurentian University was my first experience away from home yet you all provided me with a new sense of home, which I greatly appreciated.

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Chapter 1: Introduction

The quality of family life cannot be fully understood until all members are considered. Together, families have unique patterns of functioning that differ in degrees of emotional closeness, styles of communication and expectations, particularly when faced with challenges or obstacles (Cridland, Jones, Stoyles, Caputi & Magee, 2016). Specifically, the presence of a disability can be an unexpected event causing an adverse effect on the behaviours, thoughts and feelings of the entire family unit (Unal & Baran, 2011). Disability can become an influential factor that changes how they function as a system together (Moyson & Roeyers, 2012). For example, with increased demands of care, parents often expect siblings of the child with ASD to assume greater duties associated with caregiving. Additionally, siblings may receive less parental attention as a result (Chan & Goh, 2014). The responsibilities, stress levels, attitudes, and interactions may change between sibling dyads, creating unique dynamics and expectations in the relationship. Therefore, the experiences of non-diagnosed siblings are also potentially impacted (Burbidge & Minnes, 2014).

Hence, the complexities of relationships between brothers and sisters potentially differ when one sibling has a developmental disability, such as Autism Spectrum Disorder (ASD). In order to better understand these sibling experiences, it is vital to ask siblings without a disability to report the difficulties in having a brother or sister with ASD, but also, the positive aspects of their shared experiences. Still, there is an existent paucity within family studies regarding sibling relationships when an individual has ASD (Volling & Blandon, 2005). Thus, the present study provides an investigation of sibling experiences when a brother or sister has ASD, from the perspective of the non-diagnosed sibling.

This literature review provides a greater context about family and sibling dynamics, and introduces existing literature that examined sibling relationships influenced by ASD. First, this literature review provides an overview of ASD. Second, general family and sibling research is explored in order to appreciate differences and similarities between families of individuals with and without ASD. Third, families and siblings of individuals with other disabilities are examined closely in the literature in order to determine whether varying diagnoses create different challenges and/or opportunities for families and siblings. Last, the literature review focuses on families of individuals with ASD and the target population, siblings of individuals with ASD, which provides foundational research findings to inform the proposed study.

1.1 Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder that is pervasive in nature (Tsao, Davenport & Schmiede, 2012). Although behaviours and deficits vary along the spectrum, individuals with ASD typically experience some degree of impairment in reciprocal social communication. This impairment can interfere with the creation and maintenance of relationships with others (Zablotsky, Bradshaw & Stuart, 2013). In addition, language deficits are prevalent, ranging from language delays, overall literal language to complete absent language (American Psychiatric Association, 2013). Other challenging behaviours can include atypical eye contact and robotic or slower motor movement (American Psychiatric Association, 2013). Taken together, these deficits create immense difficulty in the initiation of joint attention with others (Green, 2013).

The latest revision of the Diagnostic and Statistical Manual (American Psychiatric Association, 2013) reported that 1% of the overall population is diagnosed with ASD, thereby impacting many families. Within the context of understanding sibling experiences, the social

repertoires are limited, which can make communication with brothers and sisters of typical development challenging. As such, the quality of engagement and reciprocity can differentiate in sibling relationships in which a brother or sister has ASD, in comparison to sibling pairs in which no disability is present.

1.2 Research on Families of Children with Typical Development

Relationships within a familial unit provide an essential social learning context for young children (Blandon, 2005). These early interactions can have enduring positive or negative influences on a child's emotional and cognitive functioning (Blandon, 2005; Favez et al., 2012). Conversely, unhealthy relationships with parents and siblings, characterized by high conflict and low warmth, are linked to psychopathology in children (Raikes & Thompson, 2006). For example, relationships between husband and wife impact children even if they are not directly involved. Specifically, marital dissatisfaction and conflict negatively affect the child's ability to emotionally regulate (Favez et al., 2012). Cummings and Davies (2010) explain that children often learn maladaptive behaviours to shield themselves from the negativity of the parental conflict. In cases when disability is evident, families strive to balance new demands with capabilities in order to fully adapt to new challenges. The process that families undergo when faced with a crisis, such as learning about a child's disability, is discussed in the following section.

1.3 The Family Adjustment and Adaptation Response (FAAR) Model

The Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1994), as seen in Figure 1, provides a framework to conceptualize the experiences of families of children with a disability.

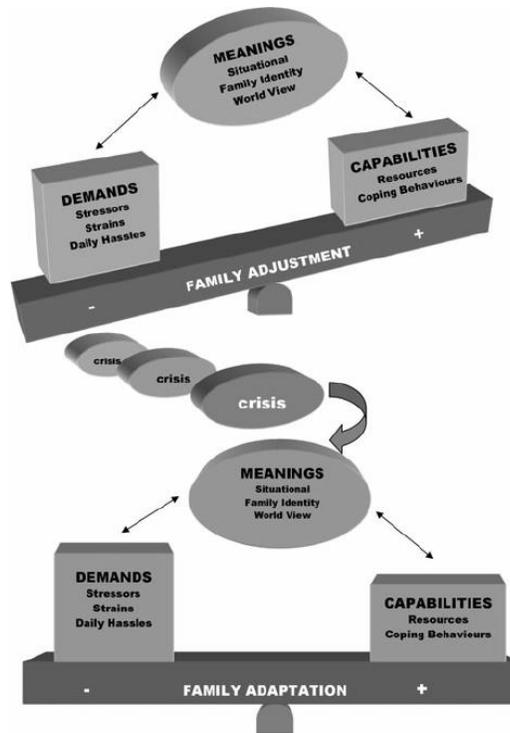


Figure 1: The Family Adjustment and Adaptation Response Model
(Patterson & Garwick, 1994)

This model explains how individuals adjust and adapt to stressful events or situations that occur (Patterson, 1994). As situations change, families experience repetitive cycles involving adjustment, crisis and adaptation (Patterson, 1994). Essentially, this pattern occurs as families face challenges in relation to demands that can arise as a result of a child’s disability and meeting needs (e.g., symptom management, respite) sufficiently. For example, once families adjust to having a child with a particular disability, it can be a financial struggle to obtain appropriate medical services or behavioural interventions. In turn, the family may adapt to a specific intervention program that is available, implement therapeutic techniques at home or modify their work schedules to spend more time at home.

There are multiple factors, such as a crisis, that can upset the balance of adjustment and adaptation. Patterson (1994) explains that the ways in which families appraise their situations

moderates the level of stress that they feel. Appraisal derives from two forms of establishing meanings: situational and global (i.e., family identity, worldview). Situational meanings include the appraisals of specific circumstances. For example, a parent may have to enrol a child in special education programs if the child has a disability that impairs academic functioning, or parents may have to reschedule work meetings around medical appointments. Global meanings beliefs about life and family in general. One example is how families feel about disability; do they perceive it as a punishment or as an opportunity to serve a special purpose? Consequently, the meanings that are assigned to these particular situations can monitor how much stress is experienced. These meanings influence the impact of stressors on the family depending on the meaning (positive or negative) assigned to a particular situation.

Furthermore, appraisal can moderate a family's level of distress because it controls how a family perceives a particular event and evaluates whether it can be positive or negative. For example, a family of a child with typical development may consider parental involvement in multiple extracurricular activities to be highly stressful and overwhelming. Conversely, a family who has adjusted and adapted accordingly to these demands will not feel overwhelmed by such a schedule. The framework of this model can be applied to many families. For example, in a study examining the lives of siblings of adolescents with cystic fibrosis, daily medical routines became normalized in these families (Larocque, 2006). These families did not perceive their medical obligations to be exceptionalities in their lives. Rather, non-diagnosed siblings (of individuals with cystic fibrosis) stated that their families were like "any other family" (Larocque, 2006), demonstrating a healthy balance between demands and capabilities.

Therefore, families are active agents in attempting to create and maintain a harmonious balance between their capabilities and the demands to establish adaptation (Patterson, 1988).

These demands can range in severity from life-changing “stressors” that cause significant changes in their lives, to strains (which place pressure on families to change systems that are not working) or daily hassles (Patterson, 1988). The FAAR model explains that adequate resources can restore and maintain balance in the lives of families after demands have been met (Patterson, 1994). Resources can come from within the familial unit (e.g., unity among members or marital satisfaction), within family members themselves (i.e., their own coping mechanisms and perceptions) and the greater community outside of the family (e.g., other support systems, availability of intervention programs and/or medical teams).

In sum, this model illustrates how families cope with challenges, but also how they embrace their lifestyles. When families have resources, their adaptability is high, resulting in lower stress levels. On the contrary, if resources are scarce and coping mechanisms have not yet been adopted, families can be overwhelmed by various stressors, strains and/or daily hassles. However, it is essential to remember that stress levels in families derive from demands or challenges of child’s disability, rather than the child him/herself.

1.4 Families of Individuals with Autism Spectrum Disorder

As aforementioned, a large range of social, behavioural and emotional difficulties characterize ASD (American Psychiatric Association, 2013). As a result, these traits in individuals with ASD present various challenges for families (Chan & Goh, 2014; Seymour, Wood, Giallo & Jellett, 2013). For example, while parenting responsibilities decrease in families with children with typical development, these responsibilities increase in families with daughters or sons with ASD (Chan & Goh, 2014). One stressful task that is experienced as the child ages is the long-term planning process that must be arranged in order to care for the child with ASD in adulthood and old age (Chan & Goh, 2014). Studies have shown that siblings of a child with

ASD are becoming increasingly expected (by parents) to assume primary caregiving roles when parents are no longer capable of such care. Until then, parents are primarily faced with caregiving challenges. Unfortunately, parents often become at risk for stress that can deteriorate into depression or anxiety (Seymour et al., 2013). In addition, mothers are often required to supervise and assist children with ASD to a greater and constant extent (Orsmond & Seltzer, 2007). The necessity of increased supervision can strain parent-child relationships as children with typical development experience differential attention from parents (Chan & Goh, 2014).

In addition to constant supervision, Cidav and colleagues (2012) reported that mothers of children with ASD earned significantly less in the workplace (due to restricted work hours) and were most likely to be unemployed compared to mothers of children with other health challenges. In another study, Doussard-Roosevelt and colleagues (2003) found that mothers experienced interactions of lower quality with their child compared to mothers of children with typical development. Furthermore, these mothers were also at a greater risk of poor mental health (Doussard-Roosevelt, Joe, Bazhenova & Porges, 2003).

In contrast, families also experience high levels of resiliency. In line with the FAAR model, the attribution of positive meanings to a child's diagnosis encourages the establishment of a closer familial unit. In the same vein, families who attribute positive meanings to their experiences are repeatedly successful at overcoming multiple challenges (Bayat, 2007). In a sample of families with children with ASD, about 62 percent of families agreed that the family had become closer as a result of the diagnosis (Bayat, 2007). Furthermore, parents believed that sibling relationships became strengthened as brothers and sisters without ASD frequently devoted time to care and protect their siblings with ASD (Bayat, 2007). However, it is important

to note that maternal reports about sibling interaction frequently show discordance with the personal accounts of siblings (Moysen and Roeyers, 2012).

Parental beliefs about disability have a significant influence on how a brother or sister perceives his or her sibling with ASD, which in turn influences the quality of the relationship (Sage & Jegatheesan, 2010). In a study comparing sibling relationships, two families of different cultural backgrounds, Asian American and European American, had a child with ASD. The European American family educated their son (without ASD) about the behaviours and accommodations associated with the disability. In their family, ASD was viewed as an opportunity to educate others about ASD. The environment of openness and pride about disability was reflected in the sibling's docile and accepting behaviours of his brother with ASD. On the contrary, the sibling of the Asian American family was not told about ASD for two years after his brother was born (due to the parents' feelings of shame). The sibling without ASD ultimately refused to interact with his brother (with ASD) and had to be forced by his mother to engage with his brother because he did not understand his behaviours (Sage & Jegatheesan, 2010). Thus, the way in which families prepare themselves and other children for the arrival of a child with ASD varies, can cause effects within families of diverse cultures.

1.5 The Comparison of Autism Spectrum Disorder to Other Disabilities in Families

Studies (e.g. Bouras & Jacobson, 2002; Ross & Cuskelly, 2008) have found that a child's disability can have a negative effect on the lives of all nuclear family members. For example, financial hardship is an issue commonly faced by families, as children with disabilities have a higher likelihood of living in homes with lower incomes (Parish, Rose, Grinstein-Weiss, Richman & Andrews, 2008). Additional support programs, special education and/or interventions also require a greater level of income from caregivers, resulting in higher levels of

stress (Saunders et al., 2015). Other challenges for families may include the process of determining an official diagnosis for their child. The establishment of a diagnosis serves multiple purposes, including having greater access to services and funding which may assist families with daily life activities (Watson, 2008). In families with children who have Fetal Alcohol Syndrome Disorder (FASD), seeking a diagnosis is particularly stressful (Watson, Hayes, Coon & Radford-Paz, 2013). Although families of children with ASD receive an initial diagnosis, they may not be adequately diagnosed because a dual diagnosis of ID is not always given when it should be thereby restricting additional funding for families (Saunders et al., 2015). The reason being, multiple diagnoses, such as ASD with ID increases the probability of receiving home and community services. Thus, families are left at a significant disadvantage when additional disabilities are not discovered. The lack of an additional diagnosis has many implications as the combination of ASD and ID are often linked to the highest level of financial and employment burden for parents compared to families with children who only have ASD or ID (Saunders et al., 2015).

In terms of parenting stress, studies have shown that mothers of children with Down Syndrome (DS) had much healthier adaptation than mothers of children with ASD. They also had greater coping mechanisms that allowed them to experience less parenting stress when compared to the ASD population (Griffith, Hastings, Nash & Hill, 2010). Differences in parenting stress may also be attributed to the reduced level of behavioural problems that characterize DS compared to the more problematic behaviours of ASD (Griffith et al., 2010). Hence, the severity of the illness or disability plays a pertinent role in determining how the sibling perceives the relationship and the degree of adaptation to the situation (Larocque, 2006). Similarly, severity is also an important factor in cases where ASD is present, due to the wide

range of symptoms (of varying severity) that can influence the relationship. Although multiple difficulties are reported in the examination of families of children with other disabilities, raising a child with ASD has been found to have a greater emotional burden than children with another disability (Hastings, 2008). In particular, families of individuals with ASD often have strained sibling and parental relationships (Rao & Beidel, 2009).

Due to the interrelation of individuals in the family unit, ASD can affect the emotional and behavioural functioning of the non-diagnosed sibling. Effects can occur directly, through sibling interaction or behaviours (Moyson & Roeyers, 2012), or indirectly as a function of parental stress (Cummings & Davies, 1994). Previous studies have reported that mothers who experience high levels of stress or depression may exhibit decreased parenting abilities (Cummings & Davies, 1994). Such a diminished ability can have a negative impact on the individual with ASD, but also on siblings (with typical development), who may receive less attention as a result (Chan & Goh, 2014; Cridland et al., 2016). Thus, with noted implications from strained parent-child relationships, a closer look is warranted into the experiences of the “forgotten” siblings (Chan & Goh, 2014).

1.6 Research on Siblings with Typical Development

The examination of sibling relationships is a fairly recent phenomenon in family research. Until the early 1980s, mothers were often the focal point of familial research. However, as mothers began working outside the home to create a dual-income, siblings became primary influences on each other (Stoneman, 2005). Accordingly, there have been an increasing number of studies that have begun to explore the dynamics of sibling relationships. Specifically, past studies have posed that siblings have a long-lasting effect on their relationship with each other, and on individual development (McHale et al., 1986).

Various studies (e.g., Begum & Blacher, 2011; Findler & Vardi, 2009; Floyd et al., 2009; Heller & Arnold, 2010; Stoneman, 2005) have demonstrated that sibling relationships play an important role in an individual's life. These relationships are the most enduring connections, easily surpassing 65 years in length (Conway & Meyer, 2008). Research within a similar vein find that Euro-American children spend a majority of leisure time with siblings in comparison to parental figures and peers (Feinberg, Solmeyer & McHale, 2012). One study found that 77 percent of typically developing adolescent siblings consider their brother or sister to be the most important person in their life (Derkman, Scholte, Van der Veld, & Engels, 2010). These findings also suggest that siblings become influential role models and are providers of companionship, intimacy and nurturance. As expected, siblings also frequently rely on each other when parents perish.

The amount and intensity of prolonged contact between siblings can also have an effect on development (Furman & Buhrmester, 1985). Noller (2005) suggests that the developmental trajectory of a child can also be understood through sibling relationships because these relationships provide a model for effective cooperation, mutual sharing and conflict management. Consequently, these emotional bonds foster the development of social competence, overall adjustment, and peer acceptance (Feinberg et al., 2011). Essentially, the relationship becomes a "training ground" for cognitive and social development (Howe & Recchia, 2014). Older siblings also have a tendency to be role models and caregivers for younger brothers or/and sisters. These responsibilities are magnified in cultures that revere familial responsibilities (Lobato et al., 2009), such as older siblings claiming responsibility for younger brothers and/or sisters. In turn, siblings become socialization agents (Howe & Recchia, 2014) in they effectively learn skills and social repertoire (e.g., requesting items, giving a toy or greeting another

individual) from each other that transgress into other domains, such as school and romantic relationships (Feinberg et al., 2011). Volling and Blandon (2005) echoed similar findings and explained that sibling relationships harbour emotional closeness and warmth, which develops prosocial behaviours and social understanding. Positive sibling relationships may also serve as buffers from effects of adverse life events (Volling & Blandon, 2005). Despite the occurrences of stressful life events, individuals with affectionate and caring sibling relationships are less likely to develop internalizing symptoms, such as anxiety or depression (Gass, Jenkins & Dunn, 2007).

The effects of sibling relationships are still evident in adulthood (e.g., intimacy and perspective-taking), even after frequency of sibling contact is reduced (i.e., as children become older and establish independence; Waldinger et al., 2007). Thus, it is vital to understand sibling experiences that are impacted by unique factors, such as disability, as it influences individual development across the lifespan.

1.7 Siblings of Individuals with Autism Spectrum Disorder

The complexities of sibling relationships are increased when a brother or sister has ASD. These complexities may be bidirectional, in which each individual affects their brother or sister (Brewton, Nowell, Lasala & Goin-Kochel, 2012). For example, siblings with typical development have been found to have a positive effect on the social competency of their brothers or sisters with ASD, especially in earlier life stages (Brewton et al., 2012; Tsao, Davenport & Schmiede, 2012). However, negative findings in regards to this bidirectional relationship have a higher prevalence in the current literature.

The concept of similarity from social psychology (Lazarsfeld & Merton, 1954) offers an explanation as to why these sibling dyads may experience greater difficulties. This concept suggests that individuals who are generally alike (e.g., similar interests and/or capabilities) feel a

higher attraction and likability to each other (Riggio, 2000). When applied to sibling relationships, similarity motivates supportive behaviour and empathy (Erikson & Gerstel, 2002; Riggio, 2000). However, siblings of individuals with ASD report less favourable attitudes toward their brother or sister's role in the family compared to siblings who had brothers or sisters with other developmental disabilities (Begum & Blacher, 2011). These negative attitudes held by siblings of a brother or sister with a disability could derive from a lack of understanding about ASD. As such, siblings with typical development may not have the necessary skills, or techniques to manage behavioural difficulties that are symptoms of the disability. In addition, individuals who have a brother or sister with ASD may also have a higher risk of psychological problems compared to siblings of individuals with other disabilities (Petalas et al., 2009). Specifically, externalizing (e.g., aggression and hyperactivity) and internalizing (e.g., anxiety, withdrawal or somatic complaints) problems have been found in siblings of individuals with ASD (Smith & Perry, 2004; Verte, Roeyers, & Buysse, 2003) further emphasizing the need for tailored supports. Thus, these individuals may require early interventions (Tudor & Lerner, 2015).

In a study examining the relationships between sibling dyads in adulthood, it was also found that siblings of children with ASD had less reciprocal contact, lower levels of positive affect in the relationship, and felt a high level of pessimism when asked about the sibling's (with ASD) future (Petalas et al., 2009). Unfortunately, this same study also found that strained sibling relationships negatively impacted relationships with parents. As can be predicted, children with ASD require more attention and supervision than siblings with typical development (Chan & Goh, 2014), increasing the difficulty for parents to provide partial attention to all children. Due

to additional needs, the child with a disability is often provided additional attention, which is not completely understood by the child with typical development.

On the contrary, Pilowsky and colleagues (2004) found insufficient evidence to support high risk factors of negative cognitive and psychological outcomes of individuals with siblings who have ASD. Similarly, in a Canadian study conducted on siblings of individuals with ASD, findings demonstrated that siblings with typical development were not at a greater risk of adjustment issues or loneliness compared to sibling dyads in which no disability is present (Kaminsky & Dewey, 2002). Furthermore, the same study demonstrated that these siblings did not have deficits in social competence as previous studies suggested (e.g., Gold, 1993; Rodrigue et al., 1993). In another study conducted by Kaminsky and Dewey (2002), siblings reported a high level of admiration and affection for their brother or sister (with ASD). They also revealed that they argued less with their sibling with ASD compared to brothers or sisters with typical development and did not experience differential treatment from parents (Kaminsky & Dewey, 2001). Siblings with typical development also reported having fun with their brothers and/or sisters with ASD and described them to be good-natured (Mascha & Boucher, 2006). Although there are limited studies citing positive effects, it is important to note that the frequency of negative findings may be attributed to the fact that few studies have focused on positive aspects evident in these relationships.

The literature review presented provides a comprehensive background about family and sibling functioning and includes a discussion about the effects of having a brother or sister with ASD on the non-diagnosed sibling. As the literature yields mixed findings, it is imperative to obtain a clearer understanding about the lived experiences of individuals who have a sibling with ASD. As the familial unit ages and extended family networks diminish, the sibling relationship

typically becomes the longest lasting relationship in an individual's life (Gass et al., 2007; Green, 2013). Further, the longevity of such a bond plays a vital role as it influences an individual at every stage across the lifespan. Therefore, it is crucial to understand the influences that siblings can have on each other, and how these influences differ with the presence of ASD.

1.8 Purpose of the Research

The proposed research aimed to understand sibling relationships in which an individual is diagnosed with ASD. This exploratory study captured the essence of sibling relationships by understanding the experiences through the subjective lens of the sibling without ASD. Within the scope of sibling dynamics, positive aspects within these relationships was also examined. As a result, this study differentiates from past studies that fixate on the negative effects of having a sibling with ASD, thereby producing an incomplete picture of these relationships.

1.8.1 Research Question. The current study strives to answer the following question:

1. What is it like living with a sibling with ASD?: The main objective of the proposed study is to gain insight into the experiences of siblings with a brother or sister with ASD. In addition, the study will be designed to understand the daily hassles and uplifts within these multifaceted familial dynamics, as informed by the FAAR model (Patterson & Garrick, 1994).

1.8.2 Rationale. The current study seeks to address paucities evident within family literature. Siblings are dyads that are commonly overlooked in the examination of familial dynamics and overall functioning. While some studies have conveyed that ASD is the disability that causes the most challenges in families (e.g., Petalas et al., 2009) other studies report conflicting findings when comparing ASD to other disabilities and normative populations. As demonstrated in a study by Watson and colleagues (2013), challenges and uplifts experienced by families vary by disability. In a comparison of parenting stress, it was found that parents of

children with FASD experienced difficulties in managing behavioural challenges that were of a delinquent and harmful nature (Watson et al., 2013) while families of children with ASD expressed greater concerns over the child's anxiety and tantrums (Watson et al., 2013). With these findings in consideration, it would be beneficial to learn more about the triumphs or tribulations experienced by siblings (with typical development) that are specific to ASD.

Studies should also explore the positive experiences of individuals who have siblings with ASD in order to appreciate unique familial dynamics. It is mistakenly assumed that positive experiences exclusively occur between siblings with typical development. Past ~~Many~~ studies have simply compared siblings of individuals with ASD to siblings with brothers or sisters with typical development (e.g., Begum & Blacher, 2011; Findler & Vardi, 2009; Petalas et al., 2009; Singhi, Malhi & Pershad, 2002; Stoneman, 2005), resulting in a poor representation of the ASD population. It is more accurate to learn about siblings who have a brother or sister with ASD, without comparing them to typical or normalized sibling experiences. Siblings may need greater supports to adjust and adapt however it cannot be assumed that these bonds have less relationship quality than sibling dyads without disabilities.

Another limitation that the current study aimed to address includes the lack of first-hand perspectives of siblings with typical development within the literature. Often, siblings are overlooked or misrepresented because the family matriarch is asked to complete questionnaires and interviews on their behalf (Begum & Blacher, 2011; Lobato et al., 2011; Moyson & Roeyers, 2012; Petalas et al., 2009). As a result, the perspective of the sibling with typical development is not accurately captured. Furthermore, research has shown that there is often a discrepancy between self-reports of parents and children (Moyson & Roeyers, 2012). Thus, a study focusing

on the direct perspective of siblings, such as the current project, will contribute inform and extend family research.

The final rationale for the current study involves the consideration of advanced health care and longevity of life for individuals with ASD. Matured siblings with disabilities, such as ASD, are being admitted into long-term care at reduced rates (Burke et al., 2012). Accordingly, families are deciding to prepare siblings for caregiving roles. These long-term plans have become increasingly common among families, which has motivated a movement towards deinstitutionalization of individuals with mental disorders (such as ASD) due to reduced demand (Ebrahimi, 2010; Hamelin, Frijters, Griffiths, Condillac & Owen, 2011). Deinstitutionalization has recently become evident across many countries in Europe. For example, in Norway and Sweden, residential institutions have been discontinued due to strong declines in demand for these institutional settings (Beadle-Brown et al., 2007; Mansell, 2006).

The movement towards individualized transition planning has also been adopted in Canada, wherein a recent policy shift of deinstitutionalization came into effect. The shift focuses on the individual's strengths to formulate interventions that can be followed at home or within the community (Hamelin et al., 2011). Following this movement, the Ontario government terminated all institutional facilities, prompting the transition of individuals with disabilities into the community (Hamelin et al., 2011). Consequently, siblings are being considered as subsequent carers to a greater degree as these institutions have been eliminated as prospective options when parents are no longer able to provide care.

In the same vein, siblings of individuals with ASD have assumed greater caregiving responsibilities (Burke et al., 2012; Heller & Arnold, 2010). The onus of such care on siblings is a fairly new phenomenon in the domain of sibling relationships, thus information is required in

understanding how siblings manage these new responsibilities. Another important question to consider is how long-term care is initially decided and what qualities of sibling relationships lead to caregiving roles in adulthood. Although siblings are assumed to be future caregivers, research has shown that they are often not involved in planning future care (Heller & Arnold, 2010). The exclusion of siblings (with typical development) can be problematic as involvement of multiple family members is beneficial in the establishment of a care plan for the future (Heller & Caldwell, 2006). Heller and Caldwell (2006) argue that without planning and tailored supports, individuals with disabilities such as ASD, have a greater likelihood of being placed in unsuitable settings. Additionally, they are faced with inadequate financial and legal safeguards when parents are no longer able to be primary caregivers (Freedman, Krauss & Seltzer, 1997).

However, the planning process can have an emotional and distressing effect on individuals with siblings who have ASD. For example, Griffiths and Unger (1994) found that despite being involved in discussions about future planning, a majority of siblings were still unsure about what their role as a caregiver entailed and continued to feel uncertain about parental expectations. Thus, with these studies in consideration, it is vital to understand how caregiving responsibilities ultimately affect siblings (with typical development) and how they can be supported throughout their tribulations and concerns.

1.9 Methodology

The scope of the current study focuses on the range of experiences related to having a brother or sister with ASD. In order to encapsulate such experiences, a mixed methods approach, informed by the FAAR model (Patterson, 1988), was employed. The incorporation of both qualitative and quantitative measures warrant a rich, thick description of experiences through the subjective lens of siblings with typical development (Merriam, 2002). The first component of the

study consisted of the administration of questionnaires to participating siblings. The Sibling Inventory of Behaviour Scale (SIBS; Schaefer & Edgerton, 1981; Hetherington, Henderson & Reiss, 1999) and The Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2005) are both reliable and valid measures that can quantify problematic challenges or uplifts experienced by siblings. In addition, a basic interpretive approach (Merriam, 2002) was employed within qualitative, semi-structured interviews that were analyzed using Interpretative Phenomenological Analysis (Smith, Flowers & Larkin, 2009) or Thematic Analysis (Braun & Clarke, 2006). Both methods of analysis are discussed further in the Qualitative Interviews section.

The use of a mixed methods approach within data collection lends strength and rigour to the study. The combination of qualitative and quantitative data enhances results as narratives add meaning to descriptive statistics obtained from quantitative measures (Creswell, 2014). A mixed methods approach also facilitates the ability to explore a more multifaceted research question because it is not restricted to one approach (Johnson & Onweugbuzie, 2009). Consequently, this method of data collection led to the exploration of two pervasive concerns evident within sibling experiences: future caregiving, and the balance between demands and capabilities. Each manuscript (presented in Chapters 2 and 3) had a related, but differing research objective, thus each employed its own respective method of qualitative analysis. Similarly, while the first paper focuses solely on qualitative data, the second paper integrates both quantitative and qualitative findings. The methods employed in each paper and respective results are discussed further in each manuscript, accordingly. Ethics approval for this study was granted by the Laurentian University Research Ethics Board (see Appendix A).

1.9.1 Participants. The current study was an expansion of a larger project that investigated the experiences of families of children with multiple disabilities, including ASD or Fetal Alcohol Spectrum Disorder (FASD). Further information regarding the study can be found elsewhere (see Watson, Coons & Hayes, 2013). Respondent driven sampling was utilized whereby individuals known to the researcher (as a function of the larger study) were contacted and asked to participate. Convenience or snowball sampling was another method that was employed, through the use of postings on the media platform, Facebook. Word of mouth was also used, where potential participants who were interested in sharing their stories contacted the researcher. At this time, questionnaires were also mailed to siblings or a link to online questionnaires was provided (dependent on the preference of the participant). If participants preferred online questionnaires, they completed the full survey on the REDCap, an online platform used for the design and collection of data. Before interviews commenced, consent was attained from participants. If questionnaires were completed online, the participant had to indicate their consent on an online form prior to beginning the survey.

A majority of participants were assessed through disability-related support organizations, notably sibling support groups. Emails were sent to leaders of ASD stakeholders and they were asked to distribute study flyers (see Appendix B) to individuals who attended their programs or support groups. Initially, there was no cut-off age given for participants in order to maximize recruitment. As such, 23 participants, ranging from 5 to 53 years in age were enrolled in the study. However, once data collection was completed, it would found that a majority of siblings were in adulthood. Therefore, it was determined amongst the research team that the inclusion of participants under 16 years of age would provide an uneven depiction of sibling experiences. As a result, any siblings who were younger than 16 years old were excluded from the data analysis

resulting in a refined total of 17 participants. Therefore, the data collected from 17 participants were analysed. The demographic characteristics of the sample, without excluded participants, can be found in Table 1.

Table 1

Participant Demographic Characteristics

Demographic Characteristics	
Characteristics of participants (<i>n</i>)	23
Gender (% female)	84.2
Average age	25.9
Age range	5-53
Relation to child with disability	
Biological (<i>n</i>)	15
Step-sibling (<i>n</i>)	2
Other additional siblings ^a (<i>n</i>)	11
With typical development ^b (<i>n</i>)	9
Other disability	2
Characteristics of siblings with ASD (<i>n</i>)	25
Gender (% male)	85.7
Average age	24.5
Age range	5-56

Note: ^a = number of participants who had more than one sibling, ^b= number of participants who had other siblings with disabilities, in addition to a brother or sister with ASD.

1.9.2 Questionnaires. Both questionnaires, discussed below, were selected based on their complementary nature to the research question which aims to capture positive and negative aspects of sibling relationships. Questionnaires were administered to the sibling with typical development to obtain experiences from the perspective of the non-diagnosed sibling. Responses from both questionnaires resulted in ordinal data thereby influencing the decision to use descriptive statistics (i.e., frequencies, means, and standard deviations). Further details about the results that were obtained can be found in Chapter 3.

Sibling Inventory of Behaviour Scale (SIBS; Schaefer & Edgerton, 1981; Hetherington, Henderson & Reiss, 1990): The SIBS is one of the earliest questionnaires that was developed for the purpose of assessing the quality of sibling relationships, specifically positive and negative involvement (Volling & Blandon, 2005). The items were first developed by using the reports of mothers and fathers in families with a child with a disability (Volling & Blandon, 2005). As a result, the SIBS devised 28 items that capture siblings' behaviours towards their brother or sisters, and how they believe they are perceived by their brother or sister. The SIBS consists of four 4-item scales that assess empathy and concern ($\alpha=.81$), kindness ($\alpha=.74$), leadership and involvement ($\alpha=.80$), and acceptance ($\alpha=.78$). There are also four 3-item scales that assess anger ($\alpha=.75$), unkindness and teasing ($\alpha=.79$), avoidance ($\alpha=.64$) and embarrassment ($\alpha=.89$). The questionnaire continued to be revised in 1992, when Hetherington and Clingempeel (1992) modified the questions, resulting in six sibling relationship scales: involvement/companionship, empathy/concern, rivalry, avoidance, aggression and teaching/directedness. In 1999, the SIBS was revised once more to reduce the number of questionnaire items (Hetherington, Henderson & Reiss, 1999). Studies that examined the latest version of the SIBS convey that all scales have acceptable Cronbach alphas: empathy ($\alpha=.88$), rivalry ($\alpha=.77$), aggression ($\alpha=.80$), avoidance

($\alpha=.85$), companionship/involvement ($\alpha=.88$). Thus, the SIBS continues to possess a long history of use and valid psychometric testing (Volling & Blandon, 2005). The complete SIBS questionnaire can be found in Appendix D.

The Sibling Daily Hassles and Uplifts Scale (Giallo and Gavidia-Payne, 2005): The SDHUS was adapted from the Daily Life Stressors Scale (DLSS) for children (Kearney et al., 1993). The child version of the DLSS demonstrated a significant correlation with the Children's Depression Inventory (.72) and the Anxiety Scale for Children (.60; Kearney et al., 1993). Most recently, the measure was modified by Giallo and Gavidia-Payne (2006). The SDHUS is a self-report questionnaire for siblings in which they rate the frequency and intensity of 43 hassles (e.g. *"My brother or sister with a disability does strange things"*, *"I don't feel "normal" because people are staring or looking at us"*) and 24 uplifts (e.g. *"I know and understand a lot about disability"*, *"They make me feel special because I know how to manage my brother or sister with a disability"*) on a 5-point scale. Stress is associated with hassles while positive affect is derived from uplifts. Notwithstanding modification to questionnaire items, the SDHUS continues to yield high internal consistency ranging from $\alpha=0.88$ to $\alpha=0.93$ (Giallo & Gavidia-Payne, 2006). The complete SDHUS questionnaire can be found in Appendix E.

1.9.3 Qualitative Interviews. Following a basic interpretative approach (Merriam, 2002), in-depth semi-structured interviews were conducted with siblings who did not have ASD themselves. This approach is commonly used in qualitative research to examine how individuals interpret their experiences and understand their circumstances or world (Chapman & Smith, 2002). By analyzing these personal accounts qualitatively, the perceptions and opinions of this particular population can be understood rather than generalized or based upon secondary information from informants (e.g., parents; Chapman & Smith, 2002). As a result, qualitative

interviews contributes new knowledge to existing paucities about sibling relationships within family research.

Due to the expanding nature of the larger project, some interviews and questionnaires were administered by two other researchers, including the lead researcher and a graduate student. Of the 19 siblings who participated in interviews, I completed 14 of the interviews and administered the questionnaires. Most interviews were conducted over the phone or via Skype, based on the preference of each participant. The duration of each interview typically ranged from 25 minutes to an hour, depending on the extent of information volunteered by siblings. If the participant was a child, he or she was given the choice to be interviewed alone or with parents present. Participants were also contacted again via email or telephone if any inquiries arose during the analysis of their transcripts.

Semi-structured interviews were selected for the purpose of data collection because it enables researchers to find subjective information that will answer the main research question, “what is it like to live with a sibling with ASD?” The interview guide consisted of 19 questions (refer to Appendix C for the complete interview guide) that were primarily used as a guide to initiate and prompt conversation. Greater discussion was fostered through this flexible interview style as opposed to a stringent question and answer format. In order to ensure that participants were not influenced by the researcher to respond in any particular way (e.g., either negatively or positively), no close-ended questions were asked. An example of an open-ended question that was asked included, “How would you describe your sibling?” To obtain further detail, prompts, such as “Can you give me an example?” were given when necessary. Finally, all interviews were audio-recorded, with permission from the participant, to facilitate the transcription process

(Shaw, 2010; Smith & Eatough, 2007). Finally, all interviews were transcribed verbatim upon completion. Transcripts were then read multiple times to increase familiarization with the data.

As aforementioned, this thesis consists of two studies. Each study-research question utilized a different method of qualitative analysis to complement the different research objectives, respectively. Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) was utilized for the first study-research question due to its broader scope of focus on the real meanings or essence of subjective experiences (Merriam, 2002; Shaw, 2010; Smith & Eatough, 2007). With this approach, researchers can enter into the subjective world of the participant and explore more deeply into the lived experiences of siblings that may not be extensively captured in questionnaires or observations. IPA is a data-driven, inductive approach, thus, interpretations were made directly from the analysis of interviews, rather than existing theory (Shaw, 2010). Alternatively, the second study-research question employs the perspective of a predetermined framework, the FAAR, to specifically understand how siblings manage demands and access supports. Accordingly, the second manuscript discusses results obtained from Thematic Analysis (Braun & Clarke, 2006). Further detail regarding the respective method of analysis for both studies is explained within each manuscript.

1.10 Reflexivity

Within the realm of qualitative research, the researcher constantly engages with the participant to understand their language, experiences and the stories that they tell. Subsequently, this understanding allows one to learn further about humankind (Shaw, 2010). However, as the researcher is the main instrument in qualitative research, reflexivity herein plays a crucial role (Patton, 2002). Thus, transparency is warranted as it reveals decisions that were made throughout the progression of the study (Engward & Davis, 2015). With transparency, readers can judge

whether potential causes of conflict are evident (Engward & Davis, 2015). Through the awareness of a reflexive stance, the quality of qualitative research is enhanced, thereby establishing credibility (Patton, 1999, 2002). Therefore, the paragraphs that follow include a discussion about my personal and professional background, and how it may have influenced the interpretations made throughout the progression of my research. The disclosures made herein reflect the assumptions and biases that I previously held and theoretical beliefs that have motivated me to create research questions about sibling relationships in which a brother or sister has ASD.

My interest in the field of developmental disabilities lies within my personal experiences. My cousin was born with developmental delay and behavioural characteristics that were highly misunderstood at the time. I witnessed my aunt and uncle struggle for years to confirm a diagnosis. There were countless diagnostic exams, various attempts at symptom management, inexhaustible doctor visits, but no answers were given. This frustrating process continued for years until an appointment with a psychologist provided insight into the challenges that were being experienced. Finally, an answer was provided to the great unknown: ASD. With an official diagnosis, understanding and triumphs followed. It became clear that knowledge of the disability not only brought tranquility to a prolonged mystery, but a platform from which to seek solutions, including supports such as respite and resources for behavioural management. Naturally, I wanted to learn more about a disorder that had impacted the members of my family so significantly. Consequently, I chose to explore ASD as part of my undergraduate degree and continued to conduct research within the field in a graduate program.

As a function of my thesis, I was provided an opportunity to learn more about the positive aspects of sibling experiences in order to attain a balanced investigation of these

relationships. Prior to interviewing participants, I familiarized myself with the existing literature and found that having a sibling with ASD was analogous to negative experiences in previous studies. Upon closer evaluation, I realized that positive experiences and first-hand perspectives of siblings (with typical development) were often not considered. Being aware of the incomplete picture provided within the literature, I strove to capture a balanced understanding of sibling experiences. For example, I was also taken aback by the complexity of these sibling relationships. In particular, participants described significant tribulations in their life as a result of their siblings' ASD. However, when discussions concentrated on the future, siblings quickly designated themselves as subsequent caregivers when parents could no longer provide care. I admired the resiliency of these siblings, as experienced a lack of resources and supports, yet persevered in order to provide care for their siblings. Entering each interview without the assumption that sibling experiences were good nor bad allowed me to develop neutral lens. This neutrality made it possible to understand all sibling perspectives, regardless of the story they told and the meanings that they attributed to their experiences.

During my master's degree, I was also fortunate to have completed my clinical placement at the Hospital for Sick Children within the Good 2 Go Transition Program. I interacted with patients who had complex health issues that consisted of developmental disabilities and other medical complications. I learned about supports such as financial assistance and transportation services that were available to families. Despite being familiar with the field of developmental disabilities, I was unaware of such services before beginning my placement. This lack of knowledge concerned me, as I wondered whether families knew about these resources. Once all interviews were completed, it became clear that significant gap existed between the availability and accessibility of services for families of individuals with ASD. As a researcher and training

clinician, I felt an impetus to learn more about these supports and then translate my research findings to clinical settings.

As mentioned previously, transparency within qualitative research is granted by the researcher's full disclosure, including the theoretical orientation that he or she chooses to follow. I believe that the biopsychosocial approach is a holistic way to understand human development and disability (Castro & Pinto, 2013). Through the evaluation of biological (e.g., genetic), psychological (e.g., personality, behaviour) and social (cultural, socioeconomic, family) factors, the biopsychosocial model acts as a framework to understand an individual's current level of functioning (Castro & Pinto, 2013). Thus, this approach encourages the researcher to understand how a complex interaction of factors can affect the individual with a disability. As a result, I was cognizant of a multitude of different factors (such as the individual's environment, family dynamics and social networks) mentioned throughout interviews, which helped me understand the experiences of siblings (who have a brother or sister with ASD) in a comprehensive manner.

1.10.1 The Researcher-Participant Relationship. Within qualitative research, a study can be considered a collaboration between the researcher and the participant. However, the type and extent of information that participants choose to reveal during an interview is highly dependent on the quality of their relationship with the researcher (Newton, 2017). Prior to beginning my thesis work, I had previous experience with interview administration. Although it was solely for assessment rather than research purposes, I gained skills in building rapport and maintaining a neutral stance. While a majority of these interviews were not conducted in-person, they were completed via Skype or telephone. Thus, I had to be aware of my facial expressions and the tone of my voice when listening to the stories of participants and providing responses. I believe that the careful management of these expressions and establishing rapport minimized the

risk of response bias, particularly social desirability bias. All siblings provided rich accounts of negative and positive events, which lessened my concern of participants attempting to present themselves in a favourable light.

In qualitative research, individuals may also have complex motives for choosing to participate, such as relieving themselves of distressing memories (Collins, Shattell & Thomas, 2005). This notion appeared evident in my research project. During the interviews, the emotional content provided by many participants was high, particularly during the discussion of future care (which is introduced in Chapter 2). An implication that arose was that I felt the need to offer help or validate the responses of participants. Being unable to provide any therapeutic support led to feelings of helplessness on my behalf, in many interviews. These feelings were especially apparent in cases where participants described maltreatment of their sibling with ASD.

In addition, I also worried about influencing participants' responses or projecting my own feelings and values onto the interpretation of interviews. For example, I felt that I understood the sacrifices that participants were willing to make for their siblings. However, as an individual from a European culture that places expectations on offspring to become caregivers, I had to ensure that my own values were not colouring my interpretations of interviews. To ensure that I understood the stories of participants, I summarized their responses and repeated it back to them. Subsequently, I received a confirmatory response or a correction. This strategy ensured that I left each interview with an accurate depiction of participants' accounts, rather than my perception of their experiences. To monitor my own conduct within interviews, I was also aware of whether I was too encouraging of particular responses or stories and made notes within my audit trail, accordingly.

Throughout my study I learned about the importance of sibling inclusion within the creation and implementation of supports and resources for families. The experiences shared by siblings emphasized multiple gaps within service availability and accessibility. Though I believe that professionals should be informed about existing struggles within these populations, I was also unaware of these issues before speaking to siblings in a research capacity. My main struggle during this project included hearing about the acute and chronic problems experienced by siblings and their families, yet being unable to offer helpful and practical solutions. As a result, my thesis work has inspired me to pursue a clinical position within the field of developmental disabilities, particularly ASD. As an endeavouring clinician, I believe that the voices of those in need should guide our directives and goals. As a training clinician, I will use the stories that have been shared with me throughout this project to inform my practice in the future.

1.11 Conclusion

Current literature about siblings with ASD has yielded conflicting results. In order to develop a balanced investigation of sibling interactions, this study adopts an exploratory stance to learn about the triumphs and tribulations that experienced by this population. Insight into these sibling dyads allows researchers to learn about which factors moderate or mediate stress experienced in the relationships, or which factors potentially provide greater opportunities and uplifts experienced between siblings. By exploring the perspectives of siblings, researchers can understand how families function as whole units and related issues such as future planning and service availability and accessibility. Thus, results obtained from this proposed study can convey information about the developmental trajectory of sibling dyads. The attainment of these results may explain why siblings with typical development choose to accept or reject caretaking responsibilities of a brother or sister with a disability in the future. In summary, the study

ultimately seeks to extend and replicate past studies and address gaps in the literature in order to contribute to the growing literature about sibling relationships.

1.12 Overview of Subsequent Chapters

This manuscript based thesis adopts an exploratory stance to examine the lived experiences of siblings (with typical development) who have a brother or sister with ASD. The investigation captures both positive (e.g., uplifts) and negative (e.g., hassles) aspects of experiences discussed by participants. Thus, readers are provided with a comprehensive picture of sibling experiences. Both manuscripts also consist of qualitative data that were analyzed using a basic interpretive approach (Merriam, 2002).

The first paper entitled, “What Now?” Concerns and Worries of the Next Generation of Caregivers: An Analysis of Future Caregiving When a Sibling has ASD, utilizes qualitative data from semi-structured interviews to focus on a prominent concern expressed by all participants: Future caregiving. Using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009), four themes that represent concerns regarding provisions of future were captured. Results indicate that siblings are cognizant of the likelihood of providing subsequent care when parents are no longer able. Thus, the themes established within this paper are reflective of the next generation of caregivers as they begin to think about and actively plan for this particular transition. Specifically, they refer to felt expressions of uncertainty and fear due to the ambiguity surrounding the future in general. Additionally, the aging of current caregivers is also discussed as it commonly prompted participants to anticipate their brother or sister’s discontinuance of care. Siblings also explored their thoughts regarding expectations of care and the sacrifices that may be made for their brother or sister with ASD. Implications related to interventions and future planning by siblings is discussed further.

The second paper entitled, “We Were All in Survival Mode”: The Balance between Demands and Capabilities When a Sibling has Autism Spectrum Disorder, explores the stressors and supports that are experienced by individuals who have a brother or sister with ASD. This paper employs a mixed-methods approach using semi-structured interviews analyzed with Thematic Analysis (Braun & Clarke, 2006), and the administration of two questionnaires: The Sibling Inventory of Behaviour Scale (SIBS) and The Sibling Daily Hassles and Uplifts Scale (SDHUS). Within this paper, analysis was strongly informed by the FAAR (Patterson, 1988; Patterson & Garwick, 1994) model, as it depicts how siblings can oscillate from stages of adjustment and adaptation in various life stages. Four particular themes, reflective of the FAAR model and sibling experiences, are discussed in further detail: Demands (Stressors, Strains and Daily Hassles), Informal and Formal Supports, Advocacy for Siblings with ASD, and Adjustment and Adaptation. Findings strongly indicate that the availability of resources and supports across the lifespan can play a crucial role in helping siblings adapt and thrive through varied demands and daily stressors. Further implications regarding the availability and accessibility of disability-related resources and services.

Following both papers, subsequent chapters of this thesis provide a final discussion of both studies with concluding remarks. Lastly, recommendations for future studies within sibling research and clinical implications are provided, ensued by an explanation of how knowledge garnered from this project will be translated into practice.

**“What Now?” Concerns and Worries of the Next Generation of Caregivers:
An Analysis of Future Caregiving when a Sibling has Autism Spectrum Disorder**

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Abstract

With the advent of deinstitutionalization in Canada, siblings are becoming subsequent caregivers of brothers and sisters with Autism Spectrum Disorder (ASD), yet the transference of care remains unexplored in the family literature. Compared to children with typical development, parents of children who have ASD report higher levels of burnout as caregivers. However, parents do not typically involve children in the process of planning for future care, thus, siblings may be unprepared for anticipated challenges associated with caregiving. The current study explored the experiences of siblings of individuals with ASD. Interpretative Phenomenological Analysis of interview transcripts revealed that following the role of parents, as subsequent caregivers, was a prominent concern amongst participants. Results demonstrated that siblings felt highly uncertain about challenges associated with future caregiving. They also questioned whether they could maintain the same expectations of care as parents. Lastly, siblings expressed the importance of being able to achieve a balance between managing caregiving responsibilities and one's own lifestyle.

Keywords: Caregivers, Adult Siblings, Autism Spectrum Disorder, Deinstitutionalization

“What Now?” Concerns and Worries of the Next Generation of Caregivers:

An Analysis of Future Caregiving when a Sibling has Autism Spectrum Disorder

All members within a family system are interconnected as they influence each other's behaviours, values, attitudes (Begum & Blacher, 2011) and individual development is heavily affected by various interacting subsystems, such as parents and siblings. Although parent-child relationships and children's peer relationships have been studied extensively, the focus on sibling relationships is relatively novel within the context of disability (Chan & Goh, 2014; Dew, Llewellyn & Balandin, 2004; Volling & Blandon, 2006). The few studies conducted (e.g. Bouras & Jacobson, 2002; Hastings, 2007) have found that a child's disability, such as Autism Spectrum Disorder (ASD) can be an influential factor on the lives of all family members. Consequently, the examination of sibling relationships is crucial for the overall understanding of family dynamics, in which a brother or sister has ASD.

Sibling Relationships

In addition to siblings providing a long-lasting peer relationship, they also hold protective roles in the lives of their brothers and sisters, especially during stressful life events (Gass, Jenkins & Dunn, 2007). Essentially, they act as a potential buffer that can moderate the relationship between marital discord and negative child symptomatology (i.e., aggression, depression, anxiety; Gass et al., 2007). However, research about sibling relationships in which a brother or sister has ASD has yet to reach a consensus regarding positive or negative effects on the sibling with typical development.

Researchers (e.g., Bouras & Jacobson, 2002; Ross & Cuskelly, 2006) have demonstrated that individuals who have siblings with ASD (compared to siblings of individuals with typical development and other disabilities) have more internalizing and externalizing disorders

(Rodrigue, Geffken & Morgan, 1993), issues with social and behavioural adjustment (Hastings, 2003; Orsmond & Seltzer, 2007), difficulties in the management of autistic behaviours, negative emotions that warrant distress (e.g., guilt; Opperman & Alant, 2003), and experience differential treatment from parents (Cridland, Jones, Stoyles, Caputi & Magee, 2016). The wellbeing of mothers has also been shown to play a role in sibling adjustment, as maternal depression often correlates with higher ratings of problem behaviours (Quintero & McIntyre, 2010) and increased depression in siblings of children with ASD (Orsmond & Seltzer, 2009). When compared to a normative sample, siblings of individuals with ASD also exhibit fewer prosocial behaviours (Hastings, 2003).

Furthermore, a case study conducted by Benderix and Sivberg (2007) noted multiple stressful life conditions faced by these siblings on a daily basis. These conditions included: feeling obligated to protect their brother or sister with ASD, feeling sorry for their sibling, having hopes and wishes that their family may have some relief with the brother or sister (with ASD) in a group home, feeling anxious and unsafe as a result of impulsive and uncontrolled physical violence on the part of the sibling with ASD, and having their relationships with friends negatively affected.

Compared to individuals of siblings with Down Syndrome (DS), siblings of adults with ASD reported less contact, lower levels of positive affect in the relationship, expressed more pessimistic thoughts about their sibling's future, and reported that their relationships with parents had been impacted (Orsmond & Seltzer, 2007). Other reports described these sibling relationships to be characterized by lower levels of prosocial behaviours, intimacy and nurturance (Kaminsky & Dewey, 2001). Previous research has also suggested that negative

effects may have persisted in the sibling relationship into adulthood (e.g., Orsmond & Seltzer, 2007).

Contrary to these negative findings, other researchers found that increased risks for emotional difficulties are not present in individuals who have siblings with ASD. For example, Kaminsky and Dewey (2002) compared siblings of individuals with ASD with siblings of children with DS and siblings of typically developing children. Results demonstrated that the ASD sample did not have a greater risk of adjustment difficulties nor loneliness. Furthermore, deficits in social competence were not found, as suggested by previous researchers (e.g., Gold, 1993; Rodrigue et al., 1993). Positive differences were also noted when siblings of individuals with ASD were compared to the normative sample. For example, siblings of children with ASD reported greater admiration of their brother/sister with ASD and described their relationship as having lower levels of competition and quarrelling. They also reported higher levels of affection (Kaminsky & Dewey, 2001). In the same vein of positive findings, further studies have found that siblings of individuals with ASD also have increased emotional maturity (Gray, 1998) and better patience and tolerance to manage challenging behaviours of ASD (Moyson & Roeyers, 2011).

Sibling Caregiving

The family literature yields mixed findings about the effects of having a sibling with ASD. However, it is quite clear that siblings still undertake significant responsibilities, such as supervision and care, that are not typically reported in populations in which no disability is present (Benederix & Sivberg, 2007; Dellve, Cernerud & Hallberg, 2000).

Advanced and improved medical care has prolonged the longevity of life for individuals with developmental disabilities, resulting in a larger number of older parents providing care

throughout their lifespan (Ebrahimi, 2010). Hence, these individuals are outliving parents at a rapidly growing rate (Burke, Taylor, Urbano & Hodapp, 2012), increasing the risk of being left without a caregiver (Braddock et al., 2009). Such a potential risk elicits great concern in parents as they contemplate whether there will be a suitable person to become a subsequent caregiver and provide the same level of care (Llewellyn, Gething, Kendig & Cant, 2003).

Due to an unprecedented need to find future caregivers for individuals with ASD (Burke et al., 2012; Heller & Arnold, 2010; Holl & Morano, 2014), siblings are increasingly being faced with new responsibilities and challenges associated with permanent caregiving (Burke, Fish & Lawton, 2015). Past studies have examined predictors of siblings' expectations to provide care, such as demographic variables, maternal wellbeing (Zablotsky, Bradshaw & Stuart, 2013), and level of severity of the individual with ASD (Krauss, Seltzer, Gordon & Friedman, 1996). Generally, given the presence of a disability in a family unit, the roles and responsibilities vary for the sibling of typical development. A pattern of role functioning known as "Parentification" can occur, particularly for older siblings (Seligman & Darling, 2007). "Parentification" can include taking on greater roles and responsibilities at school, such as advocacy and protection of siblings with ASD from peers, as well as at home with increased household chores. These responsibilities typically increase as individuals grow older, and when their brother or sister with ASD enrolls in secondary school (Cridland, et al., 2016).

Although it is natural for siblings in adolescence to assume greater care responsibilities, the range and degree of care involved by siblings may have a negative effect on the family system, as it restricts healthy adolescent individuation from the family unit. Additionally, a multitude of factors can impact whether an individual will decide to be a full-time caregiver. Due

to the variability of such factors, it is important to examine sibling experiences qualitatively as each experience varies by individual.

Recently, provisions of care have gradually shifted from institutional settings to family-centred care, which was initiated in response to the process of deinstitutionalization (Ebrahimi, 2010; Hamelin, Frijters, Griffiths, Condillac & Owen, 2011). Specifically, in Canada, a recent policy shift has been adopted in which the strengths of the individual (with a disability) are considered in order to formulate interventions that can be adapted at home or within the community (Hamelin et al., 2011). For example, medical appliances have been modified for home use, rather than requiring in-patient care, allowing individuals to remain close to loved ones with ASD. However, siblings are still faced with other caretaking tasks that may be novel to them, including the management of daily routines and access to services offered by ASD stakeholders.

Similarly, the literature regarding future caregiving is a relatively new area of exploration. Thus, the current ~~study~~ research question aims to address these gaps through the qualitative examination of sibling experiences in relation to future caregiving. The researcher attempted to walk in the shoes of the sibling by asking for first-hand thoughts through the use of interviews rather than relying on third person accounts (i.e., maternal reports) as commonly found in previous studies.

Methods

To understand the experience of having a brother or sister with ASD, it is important to learn from their frames of reference instead of testing specific hypotheses (Corbin & Strauss, 2008). Therefore, for the ~~present study~~ first research question, a qualitative research design was employed with 17 individuals who have a sibling with ASD. Through the use of semi-structured

interviews, participant narratives were obtained and then analyzed using Interpretative Phenomenological Analysis (IPA) to understand the meanings that participants attributed to their experiences as siblings.

Participants

The recruitment process consisted of convenience or snowball sampling until the saturation of themes was reached. First, participants were recruited from existing families who participated in a larger research project (see Watson, Coons & Hayes, 2013; Watson, Hayes, Coons & Radford-Paz, 2013). To increase the sample size, advertisements were posted on social media outlets (i.e., Facebook), disability-related publications, and electronically sent to agencies providing care to families of individuals with ASD. The majority of participants were recruited from sibling support groups. Inclusion criteria included being a brother or sister of an individual with ASD, but who themselves had not been diagnosed with ASD.

In total, 17 individuals completed interviews. The sample ranged in age from 18 to 53 years old. Of the 17 participants, only one was male. The majority of individuals also had a brother rather than a sister with ASD, reflecting the 4:1 ASD prevalence rate (CDC, 2014). The majority of participants ($n=11$) were older siblings to an individual with ASD and 10 participants had more than one sibling (in addition to the sibling with ASD). Of note, two participants in particular had more than one sibling with a disability. In terms of living arrangements, only two participants lived with their sibling with ASD on a full-time basis, at the time of the interview. Table 1 summarizes the demographic characteristics of all participants.

Table 1. Participant Demographic Characteristics

Demographic Characteristics	
Characteristics of participants (<i>n</i>)	17
Gender (% female)	94.1
Average age	29
Age range	18-53
Relation to child with disability	
Biological (<i>n</i>)	15
Step-sibling (<i>n</i>)	2
Other additional siblings (<i>n</i>)	11
With typical development (<i>n</i>)	9
Other disability	2
Characteristics of siblings with ASD (<i>n</i>)	19
Gender (% male)	88.2
Average age	23.1
Age range	5-56

Data Collection and Analysis

A semi-structured interview guide consisting of 19 questions (i.e., *How do you see the future for your sibling? How would you describe your sibling?*) was created and informed by a basic interpretive approach (Merriam, 2002). All questions were designed to elicit both positive and negative experiences about having a brother or sister with ASD. All questions were open-ended to encourage exploration of experiences, and prompts were given when necessary, such as asking for further detail or clarification.

Participants were informed that interviews could be conducted in-person, via telephone, or Skype. Prior to completing interviews, participants were asked to complete a consent form, which explained the intentions of the study and the voluntary nature of participation. In compliance with the Canadian Tri-Council Recommendations for Research with Human Participants, research ethics approval was granted by the Laurentian University Ethics Board, Ontario, Canada. Once consent was obtained individuals were advised that interviews would be

audio-recorded and transcribed for later analysis. Subsequently, all interviews were transcribed verbatim and scripts were analyzed using Interpretative Phenomenological Analysis (IPA).

Essentially, the focus of IPA is to understand the meaning of a particular human experience (Shaw, 2010). IPA is an idiographic and nomothetic method that is data-driven by personal accounts garnered from each participant. The analysis of individual cases (rather than at the population level) allows the researcher to make specific claims about the individuals studied (Shaw, 2010). A thorough understanding is granted through examination of personal experiences that the individual has lived and how he or she has made sense of particular experiences (Smith, Flowers & Larkin, 2009). Thus, IPA provides a particular lens that enables one to access the individual perspective of the person telling their story.

To conduct a thorough analysis using IPA, transcripts were reviewed multiple times to create familiarization with the content in the interviews. Numerous reviews of transcripts ensured that any interpretations made by the primary investigator would retain the authenticity of the participants' stories and felt experiences. Subsequently, notes and comments were made in the margins during the review of each transcript. Significant remarks or phrases were manifested into specific themes to encapsulate the overall meaning/essence found in the interview (Shaw, 2010; Smith et al., 2009). To further reduce data, a clustering strategy was employed to establish connections between preliminary themes across all participants (Shaw, 2010). The first author conducted the analysis, and discussed results with the second author before finalizing themes. This strategy led to the creation of four themes that encompass participants' perspectives and experiences in relation to future caregiving, which are: *Uncertainty and Fear*, *Aging of Current Caregivers*, *Expectations of Care* and *Making Sacrifices*.

Results

During the interviews, participants spoke about a number of issues related to their experiences of having a brother or sister with ASD. However, a topic mutually shared by all participants involved discussions about the future, notably, the likelihood of becoming subsequent caregivers. With the use of IPA (Smith & Eatough, 2007), four themes representative of future concerns were elicited from participant interviews. The first theme reflects *Uncertainty and Fear* as a result of ambiguity surrounding various aspects of caregiving. Participants felt a universal sense of these emotions towards the future due to unestablished, yet anticipated, caretaking duties (i.e., living arrangements and other preparations). The second theme, *Aging of Current Caregivers*, explains how parental aging led to participants becoming cognizant about the reality that their sibling's care would ultimately be discontinued. Hence, the passing of parents ultimately led to siblings being the next caregiver in line. The third theme, *Expectations of Care*, refers to the perceived expectations of care by siblings (without ASD) that are self-imposed due to feelings of hyper responsibility, and discussions with parents about the transfer of care. The final theme, *Making Sacrifices*, refers to the notion of finding a balance between the siblings' own needs and desires and the needs of their brother or sister with ASD, and having to make sacrifices, if necessary. Each theme, in relation to concerns about the future, is explained further.

“What’s going to happen in the future? I have sleepless nights thinking about it”:

Uncertainty and Fear

Participants were unable to concretely describe or provide an estimation of what the future holds for their sibling, therefore, they felt varying degrees of disconcerting emotions, such as worry and fear, in relation to thoughts of future care. In particular, ambiguity revolved around

pertinent issues such as the continuation of care plans and living arrangements once siblings with ASD become older and finish school. In the same vein, they felt that a lack of informational sources and guidance further harboured feelings of uncertainty, increasing the inability to envision what the future might look like for them and their siblings with ASD. Consequently, participants were unsure about their capacity to take on new demanding roles and responsibilities.

When siblings were not informed about available prospects (i.e., respite, transportation, funding, care plans, long-term living arrangements) for individuals with ASD, uncertainty tied in with fear. Amanda describes feeling scared about her sister's future due to the ambiguity surrounding the type of opportunities or activities that will be available since the options were already limited:

I'm kind of scared for her future because there's not a lot of things out there for her right now [...] there's a lack of activities that suit Gabriela. So, just her being bored or alone cause really there's only me and my mom that visit her at [the group home].

Limited availability of resources and services prevented participants, such as Amanda, from predicting the challenges that may be encountered in the future, such as ensuring that siblings with ASD are not left alone or neglected. To minimize the fear and worry driven by uncertainty, participants often described attempts to search for answers to inform or guide their future. Answers served as an umbrella term for many informational, professional or social supports (i.e., sibling support groups) to ease worries. Participants discussed exploring multiple avenues, such as support groups, to learn about the practicalities of future care, and resources (e.g., information sessions, workshops, reading material about related issues) that were most useful. These new sources of information served as "answers" because concerns of participants

were addressed. For example, participants such as Amanda, were often uncertain about future living arrangements and whether any distance from their sibling would be manageable in the long term. Amanda also explains that there's not "a lot of things out there", referring to eligible services, such as respite programs and financial support. She alluded to perceived limitations in services and anticipated that it will worsen as her sister becomes older. Similarly, Hazel echoed the same concerns that lead to feelings of fear and worry: "I get worried. Everything is good now because he's still young, but he's still in school but I worry about like, what's after high school and stuff like that".

Hazel's quote emphasizes that the extent and degree of planning can be different for parents, as they can be outlived by their children with ASD. Simultaneously, individuals with ASD likely age out of school services, and also out of mandated services to assist at a time that parallels with siblings' (with typical development) need to provide subsequent care if parents are unable. For example, individuals with ASD no longer meet eligibility criteria for school sponsored and funded supports that are mandated by the Individuals with Disabilities Education Act (IDEA). Other limitations in services for adults with ASD include out-of-home respite offered by the Ontario Ministry. Hazel echoed these limitations as she explained that more planning in future life stages due to limited options that correspond with older age (of the individual with ASD). Consequently, greater navigation of adult disability related services and programs will be required by siblings who assume a carer role when their brother or sister with ASD is older. Without guarantees of enrollment in programs and/or services, participants such as Hazel and Amanda worried about being placed on stagnant waiting lists for supports related to practical elements of care, such as funding and assisted living. As a function of these concerns,

participants expected to have greater uncertainty over the life course in terms of transition planning.

“Obviously this is my responsibility, when my parents won’t be alive like, that is...one day that’s going to happen”: Aging of Current Caregivers

Participants discussed a range of issues related to the impending transfer of care. These issues were commonly preceded by thoughts of parental aging. The inevitability of parents becoming older and passing away caused participants to become cognizant of providing future care. It is important to note that at the time of the interviews, all parents of participants were still primary caregivers, yet siblings were already aware of the responsibilities that would eventually be bestowed upon them. Essentially, parental mortality created an impetus for provisions of care that would be required for the shift in caregiving roles (from parent to son or daughter without ASD).

Preparation for the future was frequently described by participants as a means of easing into the caregiver role. Amongst the sample, tasks described included the establishment of future living arrangements, financial planning, and social activities to maintain an optimal level of quality of life (for their brother or sister with ASD). Some preparation tasks were perceived as more challenging than others, and varied in terms of type of challenges, such as emotional and practical. While practical challenges involved planning living arrangements, emotional challenges were related to parental loss, and explaining the loss of a parent to an individual with ASD. Unlike the theme of uncertainty, participants such as Mia, were fully aware of their parents’ mortality:

The reality is that my parents are getting older, they can’t take care of him forever, he’s younger than them so...[...] I would envision [...] my other brother and I being part

of Justin's life and once my parents aren't around, being the ones to.... Take care of everything with him.

Mia accepts that her parents' older age will eventually become a factor that prevents them from providing daily care. The indication that her parents cannot take of her brother "forever" demonstrates that Mia foresees a discontinuation of care at some point in the near future. Due to her parents' eventual limited capacity to provide care, Mia has already begun to envision herself as a caregiver. She further described that the new role will involve taking care of "everything", which suggests that she likely plans to become responsible for all duties that her parents initially managed. Mia's statement also conveys that she anticipates that thorough planning will be required to transition to a full-time caregiver role. In brief, Mia mentions that her other brother (without ASD) will assist her in managing her sibling's care. In order to cope with parental loss and the simultaneous switch to a caregiving role, Mia includes her other sibling as a supportive aide in her vision of future care. The need to remain close with all siblings re-establishes a sense of family unity once the hierarchal figures, parents, are no longer present.

Reliance on brothers and/or sisters (with typical development) for future care of the sibling with ASD was frequently mentioned by participants. They explained that the possibility of delegating tasks to another person, who understood the circumstances, could ease the intensity of demands during a vulnerable time, such as mourning the loss of a parent. Participants expressed that having another sibling (with typical development) established a sense of comfort because they would not be facing new challenges alone after losing a parent. Similarly, Mia's inclusion of her other brother in her thoughts about the future suggests that the presence of another sibling could mean sharing of responsibilities when it comes to taking on daily tasks of care.

On the contrary, some participants described how parents had already started planning for the transfer of care due to aging. As a result, these siblings felt relieved to know that tasks such as living arrangements and financial matters were established, providing them with a foundation to expand from. Chloe described a similar experience regarding advance planning by parents:

I'm doing what I can now, to prepare for that...They've [Chloe's parents] been looking at residential places for him and I'm very involved in that [...] There is some sense of relief that my parents are working on doing some planning, and they'll surprise me sometimes, like oh we already did that or we have him on the waitlist for this, so there are pieces in place.

Chloe expressed gratitude towards her parents for organizing necessary arrangements in advance. These pre-arranged plans assist in the maintenance of current standards of care when parents are no longer able to provide care themselves. She emphasized how early preparation allows her to acquaint herself with tasks and responsibilities that she will have to manage once she transitions to permanent caregiving. Additionally, advance planning grants her the ability to take on responsibilities one task at a time, which eases the intensity of the shift from sister to fulltime caretaker. Chloe described "some sense of relief", suggesting that she still feels some degree of uneasiness about the shift despite pre-arrangements made by parents. To cope with anxiety-evoked responses, Chloe focused on preparing for future tasks of care. Having "pieces in place" such as potential residential places and being placed on waiting lists indicates that Chloe will likely have fewer decisions and novel territory to navigate through. Thus, arrangements made with parents in the present assist in making the transition process less overwhelming later on, especially when parents are no longer around for reference.

“My mother’s not really putting it on me that I need to actually take care of him but... I’m probably going to end up being a guardian in some way”: Expectations of Care

Although responsibilities of care had not yet been transferred, participants held presumptions about future roles. Participants described expectations that were self-imposed rather than by parents. In addition, the acceptance of expectations differed across multiple life stages. Initially, in adolescent and teenage years, the idea of taking over care was not viewed favourably. Siblings reflected about how they preferred to interact with peers within their social circle instead of looking after their brother or sister with ASD. However, as adults, they began to place expectations on themselves. Not only did they feel that it was important to become involved in practical elements of care, but they also wanted to exceed basic caregiving expectations by becoming advocates for their siblings’ needs. A common example includes the establishment of respite supports and increasing awareness about ASD by joining multiple platforms (i.e., organizations, community agencies) for advocacy. Accordingly, the majority of participants, including Makayla, described a sense of responsibility toward their sibling with ASD, which had developed due to an increased level of understanding and acceptance of their sibling’s condition: “I didn’t really want to take care of him sometimes [...] when I was younger [...] but now I just think of him as someone who has special needs and I try to do what I can to help him.”

Makayla discussed self-imposed expectations due to a greater understanding of ASD and insight of her sibling’s difficulties. She recalled past experiences during her adolescence in which she detested caregiving duties. Gradually, she accepted that difficult behaviours, such as tantrums, were a manifestation of ASD, and external to her sibling’s personality. Furthermore, she learned that he required a different level of care than her other siblings or other individuals of

the same age. An increased awareness of her brother's limitations also encouraged Makayla to willingly provide supports within her means. She explained that she "tries" to do what she can, meaning that she wants to assist her brother but is unsure of how to meet his expectations of care. Regardless, Makayla's increased ability to empathize more with her brother allowed her to place forth more effort into care.

Participant responses, such as Makayla's, describe a heightened sense of responsibility that is self-imposed, rather than attributed to parental expectations or desires. Based on the analysis of transcripts, an enhanced sense of responsibility was also influenced by the presence of guilt for some participants. For example, participants such as Makayla, described feeling guilty for not having a greater understanding about ASD and patience towards her brother during adolescence. Thus, expectations of care can also be tempered by the presence of remorse in addition to genuine concern for the continuation of their siblings' well-being.

Participants also thought about the implicit expectations that would be placed on them by parents. In particular, Jasmine described discussions with her mother about issues associated with caregiving. She explained that her mother waited for her to reach a mature age in order to begin having discussions about taking on fuller guardianship:

She's [mother] not really putting it on me that I need to like, actually take care of him because I have a lot of health problems myself and it's not realistic, umm but I'm probably going to end up being a guardian in some way, like taking care of finances, like his legal, medical decisions.

In their interviews, parental expectations did not appear to be explicit as many participants described discussions in which they were encouraged by parents to live their own lives, independent of their sibling with ASD. However, siblings were still regarded as guardians

to varying degrees. For example, some siblings described guardianship in terms of legal and medical decisions whereas other discussions were more explicit in terms of expecting siblings to become fulltime caregivers in a supportive and financial manner. An example of varying degrees of care can be seen in Jasmine's account, in which she explained that she would assume guardianship, but not to the extent of adopting a "mother" role. Furthermore, expectations appeared to be magnified when the participant had no additional siblings (aside from the sibling with ASD). As the only available nuclear family member to provide care, these participants felt an obligation to adopt caregiving responsibilities to prevent siblings from feeling abandoned.

"Are we going to have a normal life, like everyone else?": Making Sacrifices

Making a sacrifice was determined to be a significant theme as participants reflected about their sibling experiences. They expressed genuine love and care for their sibling but positive emotions were occasionally tempered by feelings of antipathy, as they desired to live their own lives. Additionally, participants were still learning how to adjust and adapt between their needs and the needs of their brothers or sisters with ASD to establish a balance. Based on participant accounts, a satisfactory balance was characterized by providing some degree of care, but within the parameters of being able to live their own life. For example, younger participants contemplated the ability to embrace their interests, while considering the needs of their sibling. In these cases, establishing a sense of balance was immensely difficult as participants wanted to travel but also stay physically close to their siblings. These participants anticipated having to sacrifice frequent travel in the future in order to take care of their brother or sister with ASD. Other individuals questioned the ability to have a "normal life", which consisted of starting a family, rather than providing care for an adult sibling. Participants often compared their lives to the lives of friends, who had siblings of similar ages and were leaving home to begin college.

They reflected about how making sacrifices was not an issue for others, as their adult brothers and sisters were able to live independently.

Hailey, a sister of a 29 year old brother with ASD, described the desire to have her brother's presence in her life, but maintained that there are limitations in the sacrifices that she will make. Her goals include frequent contact and involvement rather than primary caregiving:

I'm planning on starting a family so I'm happy. I'm wanting Michael to be involved with my family life, as well. So I still want to be involved, but I don't want to be the main caregiver. I understood when I moved out of my parents' house, that I couldn't be doing that.

Hailey recalled past experiences of taking on increased duties of care to help her parents while growing up in the same household. As a result, she felt that she needed more time for herself which was eventually remedied with a degree of separation when she moved out of her family's home. Due to strains experienced in the past, Hailey felt that it was important to maintain a sense of personal space and autonomy outside of providing care for her brother. To avoid returning to a difficult stage in their relationship, Hailey determined that being the primary caregiver would not be a viable option, or a sacrifice, that she could make in the future.

Accordingly, the theme of making sacrifices captures participants' accounts about a conflicting desire to engage, yet distance themselves from their sibling. For example, Hailey described a close relationship with her brother, yet she still distanced herself from him in order to focus on her life. Although participants cherish time with their sibling, they still want to have a "normal life" that includes the freedom to make decisions that are not dependent on future care. Chloe, another participant who plans on starting a family soon, described the tug between taking care of her brother and living her life:

It's difficult to think about, you know, how much am I gonna continue to be a sibling and how much will I have to be a mom in the future. And that impacts thinking of having kids of your own and that impacts thinking about, could my partner and I move away? What if one day, we wanted to take jobs in another province or in another country?

Chloe's concern for her sibling's welfare and happiness further added to her struggle when thinking of the future. Although sacrifices have not yet been made, she anticipates eventually having to make such choices in order to be a "mother-like" provider to her brother. For example, she may have to reject a new job if it requires moving away from the province or country where her brother's supports are located. Thus, before making each decision, she has to anticipate how it can affect her brother before the consideration of her own preferences or needs.

Discussion

A review of the family literature demonstrated that the perspectives of siblings are often not captured in studies about families of individuals with ASD. Accordingly, the present study employed a qualitative approach, permitting an in-depth investigation of overall findings that revealed that sibling experiences are heavily tempered by concerns about the future. In particular, concerns circulated around the reality of aging parents, the uncertainty of what lies in the future, satisfaction of expectations, and the ability to establish a balance between making sacrifices as a caregiver and living their lives. Ultimately, results of the study serve as insightful lenses to view the emotional processes and challenges encountered by siblings in anticipation of providing care. The findings of the current study are also considered in the context of existing studies, followed by a discussion of future directions in research to further inform gaps in the literature.

As results show, the aging of parents served as a timely reminder of the inevitable discontinuation of care, prompting the requirement for a subsequent caregiver. A significant number of siblings reported feeling worried about the inevitable aging of parents, and having to explain the loss to their brother or sister with ASD. Herein, the transition to full-time care is further compounded by the grief and stress of losing a parental figure. The complexity of coping with loss and simultaneously becoming a permanent guardian (to siblings with ASD) has not been noted in the scarce studies examining siblings as the next generation of caregivers. These findings illuminate emotional difficulties that can also hinder preparation for future care. However, participants noted that establishing future care was not always an open discussion with parents. These experienced struggles are consistent with studies that have found that parents often do not include their children in the planning process (Heller & Arnold, 2010; Heller & Caldwell, 2006). Parents of participants in the current study may have felt that the discussion of future care would be a burden, thus reducing the likelihood of discussing plans with their children (without ASD).

The reluctance of parents to assign such substantial responsibilities to their children also makes it difficult to clearly understand expectations (i.e., maintaining the same degree of care, constant supervision) in an explicit manner (Bigby, 1997). Heller and Caldwell (2006) argue that without planning and tailored supports, individuals with disabilities such as ASD have a greater likelihood of being placed in unsuitable settings. Avoidance of preparation for the future can also leave siblings with inadequate financial and legal safeguards when parents are no longer able to be primary caregivers (Freedman, Krauss & Seltzer, 1997). Dew and Colleagues (2004) suggest that post-parental care should be negotiated and discussed within the familial unit in advance in order to have services and practices prepared. Furthermore, a circle of support should be

established within the family, such as a social network. This type of network refers to a group of close individuals who provide the individual with a developmental disability with social interaction and assistance regularly. This form of support assists with the care of the person with a developmental disability and prevents the main caregiver from experiencing higher levels of stress and fatigue (Ontario Ministry of Community and Social Services, 2013).

Results from the current study also emphasize other concerns and positive aspects regarding the transition to fulltime care. Siblings commonly spoke about how relieved they felt to have another sibling (with typical development) who could assist them with daily care management. However, an implication that arises from this finding is that some siblings in the general population may not have another brother or sister to share the onus of care. Notably, a majority of participants did not mention other social supports, such as extended family, friends and/or neighbours. Thus, individuals without other siblings (with typical development) may be placed at a disadvantage due to unavailable resources. As a consequence of minimal aid, levels of stress could also increase for new caregivers. In line with existing research, stressful caregiving experiences can increase the risk of experiencing negative effects such as depressive symptomatology (Zablotsky et al., 2013). Therefore, individuals without other siblings or social supports may require more assistance with care management to minimize caregiver burden that can be exacerbated by growing demands of care.

Many reports by participants were also characterized by an inner conflict of experiencing fear and worries about the future, yet feeling empathy for their brother or sister with ASD. Notwithstanding the anxiety harboured from thoughts about the future, the sense of hyper-responsibility for siblings served as a strong impetus for assuming duties of care. These findings differ from previous studies (i.e., Gold, 1993; Kaminsky & Dewey, 2001; Kaminsky & Dewey,

2002) in which siblings of brothers or sisters with ASD were reported to spend less time together and experience a lower level of closeness compared to sibling dyads in which a brother or sister has Down Syndrome (Kaminsky & Dewey, 2001). Conversely, participants of the current sample strove to maintain physical and emotional closeness, even at the expense of making sacrifices in the future (i.e., moving to a particular city to be closer to their siblings, taking on greater financial responsibility).

It is important to note that all participants discussed future care prospectively, as they had not yet assumed caregiving responsibilities of their siblings. Although participants foresaw imminent caretaking duties, research has shown that expectations of individuals anticipating future care differentiate significantly from individuals who have already taken on fulltime care (Burke et al., 2015). Overall, short-term studies have found that between 20-44% of individuals who have brothers or sisters with ASD intend to become subsequent caregivers (Freedman et al., 1997; Krauss et al., 1996). However, longitudinal studies demonstrate that fewer siblings actually become, or continue to provide care, at a 3-year follow-up (Burke et al., 2015; Freedman et al., 1997; Griffiths & Unger, 1994; Krauss et al., 1996). Thus, the extent to which a sibling feels that he or she can manage caregiving responsibilities (or be willing to become a caregiver) may not accurately predict whether they will become caregivers in the future.

Avoidance or discontinuation of care stems from multiple challenges, as noted in past studies (i.e. Cridland et al., 2016; Roper et al., 2014). The unexpected loss of resources once brothers or sisters with ASD reach the age of majority, difficult sibling behaviours (i.e., tantrums, noncompliance), and a lack of preparation for daily care have been reported as prominent obstacles (Burke et al., 2015). These challenges suggest that transition planning should be initiated early within families, including siblings. To prepare families, ASD

stakeholders such as Geneva Centre for Autism have developed programs that provide insight into the transitions that family members will face, such as becoming a caregiver. An example of these services includes the Young Carers Sibling Group, a 6 week program designed to assist young siblings (aged 8 to 12 years old) with caregiving responsibilities that they may already manage (Geneva Centre for Autism, 2007.). Such challenges make the adjustment to permanent caregiving exceedingly difficult. Only a few participants in the current study described plans that were already arranged, possibly increasing the likelihood that siblings will follow through on caregiving plans in the future. However, the majority of participants expressed a global uncertainty regarding various aspects of future care, suggesting that new caregivers may not be prepared for future demands. To that end, service providers need to include siblings within the discussion of planning for future care. For example, siblings would benefit from practical workshops located within community agencies that focused on related issues such as: guardianship, assistance with decision-making, options long-term living arrangements, and entitlements for caregivers within the legal and financial system. Furthermore, the movement of deinstitutionalization has reduced long-term living and/or care options for individuals of siblings with ASD (Ebrahimi, 2010; Hamelin et al., 2011). In order to prevent overburdening long-term facilities that may not sufficiently meet the demand, it is crucial to help siblings moderate levels of stress to accept, and then maintain caregiving roles.

Limitations and Strengths

Due to the higher incidence of ASD in males, the majority of the current sample consisted of opposite-sex sibling dyads in which participant narratives reflected the experience of having a brother with a disability. Given the gender effects found in the literature, it would be informative to learn more about the subjective experiences of having a sister with ASD. Past

studies (i.e., Stoneman, 2005) have conveyed that gender (of the sibling without ASD) could have implications for future caregiving as sisters have been found to have higher levels of emotional closeness and care for individuals with a disability.

Another limitation considers the applicability of the results to the larger population of siblings who have brothers or sisters with ASD. The majority of the sample was recruited from adult sibling support groups. It is plausible that active involvement in these groups introduced some siblings to the realization that caregiving should, or perhaps would be a concern for the future. Consequently, all siblings who participated in the study can be considered to be among the most involved siblings (due to their attendance in sibling support groups) leading to a potentially biased sample. Thus, individuals receiving less or no support may be struggling to a greater extent during the planning process of future care.

On the contrary, the current study presents various strengths in examining sibling experiences of individuals with ASD. A qualitative approach allows researchers to become the instrument for the collection of data (Merriam, 2002). Consequently, interpretations of participant experiences can be more informative than predefined items such as standardized measures or variables incorporated alone. Phenomenological methods hold immense value as a tool for understanding the human experience and meaning (Merriam, 2002). It ensures a commitment to learning about the participants' experiences.

Trustworthiness of Data

To obtain the trustworthiness of a qualitative analysis, transparency needs to be created to show the progression from raw data to the final results. In the current study, transparency was established through the creation of an audit trail (Smith et al., 2009), which provides an account of the procedures employed, and decisions and questions made in relation to the raw data. In

accordance with trustworthiness recommendations, participants were invited to review the transcript of their interview in a member check (Merriam, 2002). This process elicits comments from participants about the interpretations made from transcripts. Although some participants did not respond to follow-up emails to provide consensus of themes, the majority of the sample (94%) was able to recognize their experiences in established themes. Additionally, peer review was completed by the second author, another qualitative researcher who analyzed the data independently. These reliability strategies ensured throughout the study also ensures rigour (Merriam, 2002; Smith et al., 2009) throughout the study and confirms that findings were plausible based on the narrative accounts of participants.

A significant degree of engagement was also maintained throughout the data collection process by re-reading transcripts multiple times to increase familiarity with all participant accounts. Immersion into the data resulted in an in-depth understanding of the phenomenon of sibling experiences. Continuous engagement with data also ensured that saturation of themes was reached to capture a full understanding of various sibling experiences in relation to future care. Participant recruitment continued until it was determined that the findings from each participant interview were similar or parallel to accounts of previous participants, thus increasing the generalizability of findings (Cridland et al., 2016). The current study also eliminated the limitation of erroneous reporting of experiences, as siblings provided first hand reports.

Conclusion and Future Directions

Due to innovative advances in health care, technology and research, longevity of life has increased for individuals with ASD. As a result, the onus of caregiving responsibilities on siblings has become a fairly new area of research within family studies. The transition of care emphasizes the importance of examining how siblings are involved in the planning process and

what expectations are held of their future roles as caregivers. For example, the concerns vocalized by participants ~~in the study~~ may assist in the creation of standardized guidelines to help adult siblings who want to become full-time caregivers prepare for their transition.

Preparation for future responsibilities can prevent the disruption of care when an individual with ASD suffers a parental loss. In a study examining the experiences of aging caregivers and their children with disabilities, over 75% of adults with intellectual and developmental disabilities (IDD; including ASD), reside with their aging parents (aged 60 and over) until they are removed from waitlists to receive services based in the community (Braddock et al., 2009). During these periods of transition, siblings frequently assume the caregiving role when aging parents are no longer able to provide care (Heller & Arnold, 2010). Whether siblings decide to become subsequent caregivers or not, it is imperative to have family discussions to establish future plans in advance so siblings are not burdened. For example, if siblings choose to not become future caregivers, families should be prepared to make other arrangements (i.e., housing, fulltime care programs).

For siblings who decide to become caregivers, it is of utmost importance to be involved in discussions for future care at earlier life stages when parents are still the primary caregivers. Inclusion in the planning process at a younger age can familiarize siblings with requirements of care and learn about services, such as respite or transportation, which can significantly facilitate the daily activities of living for brothers or sisters with ASD. Additionally, financial preparations should be included in these practicalities so that siblings are forewarned about potential circumstances that may be costly (e.g., not meeting eligibility criteria for funded services, requiring medications that are not covered by personal insurance or provincial health insurance plans). Similarly, siblings can obtain the guidance of a financial advisor and/or a case worker

who is cognizant of the short and long-term needs of the individual with ASD. Together, a multidisciplinary circle of care (i.e., case worker, financial advisor, respite worker, other family members or friends) can be formed to assist the sibling (without ASD) with providing future care.

In order to decipher which supports reap the most benefits for siblings, it is important to comprehensively understand the potential challenges that could be experienced. Future studies can further disseminate sibling experiences by conducting longitudinal studies to examine how caregiving roles differentiate over time and what types of challenges can be anticipated for becoming caregivers. Although participants in the current study had not yet assumed full caregiving responsibilities, the thought of an impending change in roles commonly evoked feelings of uncertainty and stress. As such, information is needed to understand how siblings are going to accept and manage these potentially overwhelming and anxiety-invoking responsibilities of future care.

Sibling experiences vary from individual to individual yet there are common concerns that interrelate all individuals, such as aging parents, expectations, the need to make sacrifices, and an overall uncertainty about the future. As the literature has shown, individuals with disabilities such as ASD are outliving parents at a rapidly growing rate. Consequently, they are at a risk of being left without a permanent caregiver when parents are no longer able to provide care, which necessitates the availability for more community-based services. Therefore, it is important to examine sibling experiences qualitatively, in relation to concerns and worries attributed to future care. Further understanding within this area of research can support aging and new caregivers, and ultimately, individuals with ASD who are at risk of being left without care.

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“We were all in survival mode”:

The Balance between Demands and Capabilities when a Sibling has Autism Spectrum
Disorder

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Abstract

Background: Previous studies have shown that living with an individual who has Autism Spectrum Disorder (ASD) can have an impact on the sibling with typical development. However, the extent of supports can moderate the impact of stressors and demands that may be present.

Method: The present study employed a mixed-methods approach using semi-structured interviews and standardized questionnaires to explore the subjective experiences of siblings of individuals with ASD. Furthermore, the Family Adjustment and Adaptation Response (FAAR) Model was used as a framework to understand how these individuals may adjust and adapt to particular hassles and uplifts.

Results: Siblings frequently oscillate between managing demands and finding new resources to strengthen capabilities. Advocacy and informal supports, such as sibling support groups were commonly accessed by participants.

Conclusions: The use of available resources and supports can help siblings adapt and thrive within their unique circumstances and challenges.

Keywords: Adult Siblings, Autism Spectrum Disorder, Supports, Family Adjustment and Adaptation Response (FAAR) Model

“We were all in survival mode”: The Balance between Demands and Capabilities when a Sibling has Autism Spectrum Disorder

Introduction

Over recent years, Autism Spectrum Disorder (ASD) has become a more common diagnosis that influences the lives of individuals with the disorder, and their families (Jordan & Turns, 2016). ASD is a neuro-developmental disorder that is pervasive in nature (Tsao, Davenport & Schmiede, 2012). Although behaviours and deficits vary along the spectrum, individuals with ASD typically experience some degree of impairment in reciprocal social communication that interferes with the creation and maintenance of relationships with others (Zablotsky, Bradshaw & Stuart, 2013). The prevalence of ASD has also risen to 1 in 68 children (CDC; 2014), therefore many families are affected by the disorder.

Families of Individuals with ASD

The family unit plays a primary role in establishing the development and protection of children, typically until late adolescence (Gass, Jenkins & Dunn, 2007). However, family members of individuals with ASD encounter many demands and challenges that can affect their overall well-being compared to families of individuals with typical development (Baker-Ericzen

et al., 2005). Severe symptomatology associated with ASD has been reported to be an influential factor in high levels of stress, as perceived by parents (Hayes & Watson, 2013; Watson, Coons & Hayes, 2013; Watson, Hayes et al., 2013). Compared to families of individuals with other disabilities (e.g., Down Syndrome, Fragile X Syndrome and Intellectual Disability), higher levels of parenting stress are evident (Blacher & McIntyre, 2006), which has been associated with a lack of family cohesion and adaptability (Higgins, Bailey & Pearce, 2005). Elevation in stress levels is likely attributed to continuous attempts to manage the ASD-related behavioural challenges and communication deficits (Zablotsky et al., 2013). Without appropriate supports and preventative interventions, risks for adverse outcomes, such as depressive symptomatology in parents are increased (Zablotsky et al., 2013). As ASD is a lifelong disability, it is crucial to educate families about the symptoms associated with ASD, as well as coping mechanisms that are necessary for family members to deal with multiple and frequent stressors (Lantos, 2007). Although there is an abundance of research on the parent and ASD experience a paucity of literature remains evident in regards to the experiences of siblings.

Siblings of Individuals with Autism Spectrum Disorder

The parent-child relationship has commonly been the focal point of clinicians and researchers to further understand the development and psychological functioning in children with ASD; however, siblings of individuals with ASD manage a complexity of roles, including that of caregiver, teacher and confidant (Tsao et al., 2012). Consequently, studies have begun to emphasize that living with an individual with ASD can impact the sibling with typical development. For example, elevated risks for internalizing and externalizing disorders compared to a normative population are evident (Green, 2013). Past studies have found that non-diagnosed siblings can experience feelings of loneliness and embarrassment (Mascha & Boucher, 2006).

Due to increased needs, the individual with ASD is often provided additional attention, which may not fully be understood by the sibling without the disability. Thus, siblings can have perceptions of parental impartiality, with favouritism toward the child with ASD, which can lead to difficulties in sibling adjustment (Cridland, Jones, Stoyles, Caputi & Magee, 2016). Moreover, in comparison to siblings of typically developing individuals and individuals with Down Syndrome, relationships are characterized by lower levels of nurturance, intimacy and prosocial behaviour (Kaminsky & Dewey, 2001). Therefore, brothers or sisters of individuals with ASD may not have the necessary skills or techniques to manage the behavioural difficulties that can compromise the sibling relationship. Although non-diagnosed siblings experience varying extents and degrees of challenges related to having a sibling with ASD, past findings emphasize a need for greater supports aimed at assisting siblings of individuals with ASD (e.g., Stoneman, 2005; Tudor & Lerner, 2015).

Supports for Siblings of Individuals with Autism Spectrum Disorder

Past studies (e.g., Cridland et al., 2016; Tsao et al., 2012; Walton & Ingersoll, 2015) have also highlighted the benefits of early intervention services and supports for individuals with ASD and their families. The existing literature on supports for the non-affected siblings has noted two common types of services: informal supports (e.g., sibling support groups) and formal supports (e.g., family-based clinical interventions). Empirical evidence supports the effectiveness of informal supports which warrants opportunities for siblings to share their emotions and experiences with others in similar circumstances (Conway & Meyer, 2008). However, benefits have also been noted in the examination of formal supports such as family-based cognitive-behavioural interventions (McLinden, Miller & Deprey, 1991) and training programs. These structured interventions directly teach social skills (e.g., behaviour modification techniques to

address conflict) to respond appropriately to the needs of their brothers or sisters with a disability (Stoneman, 2005). However, few studies have actually evaluated sibling experiences with service delivery and other supports.

This paucity within the literature strikes concern as interventions and appropriate resources can promote positive outcomes, ultimately strengthening sibling relationships (Mascha & Boucher, 2006). A review of the literature demonstrates that the focus on other types of formal interventions and support groups remains limited, prompting the need to improve availability and accessibility to ASD-related services. Greater supports can foster positive perceptions and experiences associated with the sibling relationship, which in turn can increase the likelihood of successful adaptation to having a brother or sister with ASD (Taunt & Hastings, 2002). With consideration to the existing literature, the present study explored the use of supports (e.g., coping mechanisms, services provided by ASD stakeholders and social networks, as informed by the Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988, 1989; Patterson & Garwick, 1994).

Family Adjustment and Adaptation Response (FAAR) Model

The Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988, 1989; Patterson & Garwick, 1994) focuses on the family system and its efforts to create and maintain homeostasis by using sufficient capabilities (i.e., resources and coping behaviours) to balance with demands (i.e., stressors and strains). To the knowledge of the first author, there are no models that specifically assess sibling adjustment and adaptation. Thus, the FAAR was utilized because it captures the cyclical patterns of sibling relationships as they adjust and adapt to their brother or sister's diagnosis across the lifespan. During the adjustment phase, siblings experience an imbalance and attempt to meet demands with existing capabilities. When siblings

attain new resources to reduce demands or change their meanings, balance is established and they enter the adaption phase.

Stressors (e.g., death), strains (e.g., financial limitations) and daily hassles (e.g., rushing during the morning routine) are three types of demands that lead to an imbalance within the family's current level of functioning (Patterson, 1988, 1989; Patterson & Garwick, 1994). Consequently, these demands create tension in the familial system that prevails until the family adopts capabilities to restore balance once again. A state of balance is also mediated by the global and situational meanings that families attribute to events that occur in their lives (Patterson, 1988, 1989; Patterson & Garwick, 1994). Situational meanings include the appraisals of specific circumstances (e.g., needing to reschedule work meetings around medical appointments) while global meanings encompass beliefs about life and family in general. Therefore, it is imperative to know which meanings participants ascribe to their experiences of living with a sibling with ASD.

Methodology

In order to achieve the aim of analyzing the supports and challenges associated with having a sibling with ASD, a mixed method design was employed. Semi-structured interviews were conducted and two standardized questionnaires were administered. An example of an interview question includes, "*Are there any supports you would like or is there anything that would help you in your relationship with your sibling?*" Both interview questions and questionnaires were informed by the FAAR model (Patterson, 1988, 1989; Patterson & Garwick, 1994). Additionally, this study integrated both quantitative and qualitative methods. Specifically, the chosen analysis was a convergent parallel design (Creswell, 2014), which warranted an

individual analysis of each type of data before triangulating results (Creswell & Plano Clark, 2011).

Participants

The current study was part of a larger study investigating families of children with various disabilities, including ASD. Siblings in these families were contacted and asked to voluntarily participate in the current study. Additionally, participants were approached through community agencies in Ontario, such as sibling support groups and Autism Ontario. Convenience or snowball sampling was another method that was employed, through the use of postings on the media platform, Facebook and word of mouth. Finally, participants were also recruited by contacting sibling support agencies in the greater Toronto area and Sudbury region.

Table 1. Participant Demographic Characteristics

Demographic Characteristics	
Characteristics of participants (<i>n</i>)	17
Gender (% female)	94.1
Average age	29
Age range	18-53
Relation to child with disability	
Biological (<i>n</i>)	15
Step-sibling (<i>n</i>)	2
Other additional siblings (<i>n</i>)	
With typical development (<i>n</i>)	9
Other disability	2
Characteristics of siblings with ASD (<i>n</i>)	19

Gender (% male)	88.2
Average age	23.1
Age range	5-56

In total, data was collected from 23 participants, ranging from 6 to 53 years in age. Initially, there was no cut-off age given for participants in order to maximize recruitment. However, once data collection was completed, it would found that a majority of siblings were in adulthood, therefore participants younger than 16~~8~~ years of age were excluded from the data analysis due to large differences in age. The revised sample resulted in 17 participants, aged 18 to 53 years, as seen in Table 1. In order to maintain confidentiality of participatory accounts, pseudonyms were provided for all individuals, including brothers and sisters of participants. Any other identifying information was also modified for the purpose of anonymity.

Qualitative Interviews

Semi-structured interviews were conducted with siblings of individuals with ASD. Prior to beginning interviews with participants, the first author established rapport with each participant to facilitate discussion. Each interview lasted approximately 30 to 45 minutes in duration and were informed by a basic interpretive approach (Merriam, 2002). Essentially, this approach is driven by an aim to understand how each individual interprets or makes sense of particular experiences or circumstances (Merriam, 2002). Interviews were conducted in-person, via Skype or telephone, at the convenience of the participant. Twenty-two open-ended questions were asked (e.g., “Are there any supports you would like or is there anything that would help you in your relationship with your sibling?”), in addition to prompts when further information or clarification was needed (e.g., “please tell me more about that”).

The FAAR model was also chosen as a theoretical approach to inform the analysis of the current study. Once audio-recorded interviews were transcribed verbatim, a six phase standardized model of Thematic Analysis was employed (Braun & Clarke, 2006). This approach involves the identification, analysis and reporting of patterns evident within data in rich detail (Braun & Clarke, 2006). First, familiarization with the data was accomplished by reading the transcripts multiple times while making initial notes throughout the process, which in turn facilitated the identification of initial ideas within the data. This strategy allowed the first author to organize the data into meaningful groups through the creation of initial codes (Tuckett, 2005). The third phase involved further grouping of codes into prospective themes by noting repetitions of codes within the data set. Themes were then refined to ensure internal homogeneity (i.e., similarities of codes in each theme) and external heterogeneity (i.e., themes that are distinctively different from each other; Patton, 1990). Analysis continued by defining and naming themes. Lastly, as part of a final report, representative quotes are chosen from interviews to support themes.

All decisions and interpretations made by the first author were reflected in the audit trail to demonstrate how final conclusions were ultimately drawn from raw data. Inter-rater reliability was also established with other members of the research team by having data coded independently followed by a comparison codes that were mutually agreed upon.

Quantitative Questionnaires

Two questionnaires examining sibling relationship quality were employed in addition to interviews. Based on the preference of participants, questionnaires were completed online via REDCap, a secure research web application used for online surveys, or by paper and pencil following the completion of the interview. Both questionnaires are described in detail below.

The Sibling Inventory of Behaviour Scale (SIBS; Hetherington, Henderson & Reiss, 1999): The SIBS is a standardized questionnaire designed to measure sibling relationship quality. The questionnaire consists of 32 items which corresponds to six subscales: Companionship/Involvement, Empathy/ Concern, Rivalry, Avoidance, Aggression and Teaching/Directedness. These scales were designed to measure eight particular dimensions of sibling behaviour (Volling & Blandon, 2006). Across all scales, Cronbach's alphas were acceptable: empathy ($\alpha=.88$), rivalry ($\alpha=.77$), aggression ($\alpha=.80$), avoidance ($\alpha=.85$), companionship/involvement ($\alpha=.88$). Participants completed the questionnaire by providing a response for each item using a 5-point Likert Scale, which ranged from 1 (never) to 5 (always). Summed responses of corresponding subscales yield composites of "Positivity" (which are collated responses of Empathy/Concern, Companionship/ Involvement and Teaching/Directiveness) and "Negativity" (sums of Aggression, Rivalry and Avoidance). Composite scores represent the extent of positive or negative involvement evident in sibling relationships.

The Sibling Daily Hassles and Uplifts Scale (SDHUS; Giallo and Gavidia-Payne, 2005): The SDHUS is a standardized self-report measure that evaluates the frequency and intensity of demands ("hassles") and capabilities ("uplifts") within sibling experiences. Siblings rate the frequency and intensity of 43 hassles (e.g. "My brother or sister with a disability does strange things", "I don't feel "normal" because people are staring or looking at us") and 24 uplifts (e.g. "I know and understand a lot about disability", "They make me feel special because I know how to manage my brother or sister with a disability") on a 5-point scale. Despite modification to the questions, it continues to yield high internal consistency, ranging from 0.88 to 0.93 (Giallo & Gavidia-Payne, 2006).

In order to interpret results, a total score is calculated from the items of the corresponding subscales of Hassles and Uplifts. Elevated scores on the Hassles subscale convey a high frequency of hassles and high intensity of affect (e.g., “How bothered or upset does this make you feel?”) that is associated with those hassles. On the contrary, high scores on the Uplifts subscale indicate a high frequency of factors (e.g., going out, associating with disability support groups, relationships with parents etc.) that create positive affect (e.g., how happy does this make you feel?”).

Means and proportion (%) of subscales and individual questions were integrated into corresponding themes to further support qualitative findings.

Results

For the purpose of this paper, only results related to experiences of demands and supports will be presented. The current study revealed four themes that reflected concepts within the FAAR model, which are described henceforth in further detail: Demands (Stressors, Strains and Daily Hassles), Informal and Formal Supports, Advocacy for Siblings with ASD, as well as Adjustment and Adaptation.

“Clara had a lot of bad behaviours it was, [I tried to] protect my mom [...] when I was younger, [she] would just beat my mom up all night, and that was really tough”: Demands – Stressors, Strains and Daily Hassles

During the interviews, participants spoke to a continuum of demands, ranging from stressors to daily hassles. For example, siblings reported specific life events that impacted their lives in a negative manner (e.g., learning about their sibling’s disability, loss of a parent), whereas other participants commented on strains requiring change, such as establishing structures and routines and hassles that occurred on a daily basis, such as managing difficult

behaviours (e.g., differential parental attention; management of tantrums and other physical aggression). This theme was further supported by participant responses on questionnaires; based on subscale totals on the SDHUS, a majority of the sample likely experienced frequent hassles ($M=70.25$, $SD=23.34$) that bothered participants to a higher degree, as demonstrated by the subscale of intensity of hassles ($M=72.50$, $SD=30.93$).

Additionally, participants typically reported that responsibilities became more prominent as they entered adulthood and especially when individuals with ASD entered secondary education. For example, siblings such as Jennifer described being affected by parental burnout and demands like increased caretaking responsibilities:

Once he graduated school, things got really difficult. My sister moved out and got married and I was still living at home, so I took on a lot more responsibility because my parents were burning out. That was a challenging time because he was resisting me, to the point where I couldn't eat dinner upstairs with everybody.

Jennifer's quote illustrates the experiences of many participants who described unsettled periods in their lives following multiple changes to family dynamics, such as other siblings moving out and parental aging. Similarly, the moment in which Jennifer's sister (with typical development) moved out of the family home led to increased demands for Jennifer because she was the only other sibling living at home who could assist with her brother. She was also vicariously affected by the burden that her parents were experiencing as a result of prolonged strains. In her interview, Jennifer also explained that difficulties were magnified when her brother graduated from school and aged out of mandated services. Although he was eligible for funding, Jennifer lamented that no assistive supports were guaranteed and she was left unsupported for approximately 3 to 4 years. The abrupt loss of supports occurred during a time when Jennifer's

parents were beginning to feel burnt-out from their carer roles and accordingly, Jennifer took on greater caregiving responsibilities. Consequently, the extent of demands ultimately took a toll on Jennifer. She explained that she felt isolated from the rest of her family and rejected from her brother, despite her best attempts to take care of him.

Similarly, Kathryn spoke about the initial moments following her sister's diagnosis:

We only moved to Canada because she [sibling with ASD] was diagnosed...we realized she needed more assistance and stuff so we moved to Canada so technically we wouldn't even be living in Canada if she wasn't disabled. My dad stayed [another country]... so they basically separated because of the challenges faced with trying to figure out options for Stephanie and what's best for her instead of their relationship. So we became a single parent family...in a different country.

Kathryn explained that her family had to move to another country due to a higher level of intensive care required by her sister's ASD diagnosis. The relocation caused marital difficulties between her parents, which ultimately resulted in separation. Furthermore, she emphasizes that the relocation and shift from a nuclear to a single-parent family would have not occurred if her sister did not have ASD.

Lastly, demands in the form of hassles were also found in interviews when participants described minor irritants experienced on a daily basis. To demonstrate, Susan referred to a common hassle that occurred frequently during adolescence: [I couldn't have my friends over] without Charlie kind of bothering them [...]. Those are a few difficult things...I can go on...." As expressed by Susan, living with a sibling with ASD meant that regular expectations for teenage life and behaviour (e.g., inviting friends over) were difficult to achieve.

Due to a lack of adequate supports and ongoing demands, siblings find hope in knowing that they can take matters into their own hands. Advocacy, which is discussed next, is seen as a common coping mechanism used amongst the sample to minimize demands and ultimately restore balance following a crisis.

“Looking back, it might have been more helpful to have more support. I probably could have used some one on one counselling”: Informal and Formal Supports

Various discussions of informal and formal supports were found in interview transcripts. Formal supports were characterized by the acquisition of help from organizations or agencies that provide care for families of individuals with ASD (i.e., early intervention centres, case workers, workshops led by qualified individuals, and/or counsellors). For example, workshops attended by siblings often consisted of educational components that helped siblings learn more about ASD and the behavioural strategies that could be used in response to particular symptomatology (i.e., establishing a routine to prevent tantrums). Responses on the SDHUS also reflect the usefulness of informative sessions, as 83% of the sample noted that possessing knowledge and an understanding about autism was an “uplift” for them.

In addition, siblings accessed supports and services in informal settings, which involved sharing stories and helpful information about issues (i.e., respite, stressors) related to ASD. While some participants discussed receiving formal supports, such as financial planning and counselling, the majority of the sample relied on informal supports, such as sibling support groups. The main impetus for attendance was that siblings wanted to know that they were not

alone in their unique experiences. Specifically, siblings mentioned relying on social networks established through sibling support groups in addition to confiding in friends, family and work colleagues. These social platforms led to worthwhile exchanges of information and resources, in addition to providing opportunities to share concerns, joys and coping strategies.

Although sibling support groups were not primarily designed to be clinical interventions, participants described therapeutic effects after attending a few sessions. Adam reflected about his experience of partaking in sibling support groups:

In my mind, it's like I'm not allowed to talk about this. I'm not allowed to feel any negative emotion, frustration, aggression, sadness. I'm just supposed to be happy for what I've been given in my life and I can't complain. So talking about them for the first time was an amazing experience.

Adam described a sense of catharsis after finally having an opportunity to speak about emotions that he could not divulge anywhere else. As an individual with typical development, he did not want to discuss any stressors or hassles because he was not struggling with a disorder, like his brother with ASD. Consequently, he felt that he had limited opportunities to discuss his emotions, such as sadness and anger until he connected with other siblings (of individuals with ASD) at a community support group. The mutual sharing of emotions thus provided siblings with a safe and nonjudgmental platform to vent about various issues related to having a brother or sister with ASD. In the same vein, participants commonly reported that they felt understood because other individuals (in the group) truly empathized with their experiences. These support groups provided opportunities for siblings (with typical development) to connect and normalize their experiences, which they considered beneficial.

Despite the positive experiences of some participants, it is important to note that some siblings such as Abigail felt that informal supports did not adequately address their concerns:

I went to [the sibling support group] to simply talk to other siblings who were dealing with the same feelings that I was dealing with. And it was helpful in that aspect but I felt that there was no planning or things I would be looking for now. So I don't know if it would be helpful to go back or anything.

Abigail attended sibling support group sessions in adolescence. She explained that speaking with other siblings who could relate to her feelings and circumstances was helpful within that life stage, but as an adult the benefits provided by the support group were less applicable. In her interview, she described being faced with issues such as financial planning for the future and securing residential options for her brother with ASD, which were concerns that a sibling support group could no longer assist with. Thus, Abigail did not anticipate utilizing similar informal supports, despite knowing that they were still available. Olivia echoed similar thoughts as she illustrated the need for increased availability of services that offer formal supports: "It's just something that I feel like I need someone else to discuss this with, to problem solve, like what should we do?" Her words convey the importance of having the help of a professional who is knowledgeable in the field of ASD services, in order to offer practical solutions (e.g., making financial preparations, finding and securing respite services). Although participants reported accessing support groups, greater supports that offer benefits beyond peer support still need to be created.

"I am very proud to be his sister. I feel like we can educate people about this population in the world": Advocating for Siblings with ASD

Participants commonly expressed indignation on behalf of their siblings, especially when faced with adverse situations, such as discrimination, bullying and barriers to living life with dignity. In response to challenges, participants explained that becoming an advocate for their siblings was necessary in order for them to thrive. In line with qualitative findings, only 50% reported being a part of different groups such as Autism, and early intervention centres on the SDHUS questionnaire, suggesting that they typically advocated independently rather than through organizations. These independent advocacy efforts are substantiated in interviews, in which participants commonly discussed their motivation to act on concerns that they felt were still not addressed (e.g., bringing awareness to long waiting lists for services, and loss of funding when siblings with ASD became adults). They described being active agents in the navigation of services and addressing concerns for their siblings. Furthermore, the subscale reflecting teaching and directive behaviours ($M=13.50$, $SD=3.25$) (e.g., helping siblings in new situations) was rated as the third highest score, demonstrating that participants tried to serve as guides and teachers for their siblings.

Collectively, participants felt an impetus to advocate for ASD as an important cause after experiencing a dearth of supports. Notably, advocacy was seen through lobbying for supports and services, promoting rights of siblings by addressing issues that can facilitate change, and educating others about ASD. To demonstrate, Jennifer asserted: “We advocated super hard - to the government, to the ministry and to our MPP’s - and finally got David passport funding which has just changed our lives. That was the beginning of getting David more out in the community.” Jennifer discussed the limitations encountered during her attempts to manage demands sufficiently at home and the stagnancy of placement on wait-lists led to growing stressors as a result of limited services. Ultimately, the struggle for assistance promoted the need for advocacy.

These needs involved lobbying for funding at multiple levels including federal and provincial governments. Jennifer's story illustrates how advocacy can occur on broader levels, as she advocated on behalf of her brother, but also strove to implement greater systemic changes to help others in similar circumstances.

Additionally, Jennifer described a sense of altruism when she spoke about how the funding improved the lives of her family members. The gains achieved through advocacy enabled a sense of empowerment in the ongoing process of community involvement. By stating that these changes were "the beginning", Jennifer alluded to the extent of perseverance required by long-term advocacy efforts. However, her words also convey that successful advocating fostered a greater sense of hope in knowing that the eradication of barriers to service delivery had begun.

Siblings also described specific crises that prompted their motivation to advocate on behalf of their siblings. In the words of Susan: "There was this one instance when my brother was actually physically harmed by a staff member. So that was something that was a very serious time in our lives". Susan described feeling profound fear and sadness in regards to her brother's negative experience; especially in an environment that she previously believed was safe and welcoming. As evident in various accounts, such as Susan's, siblings of individuals with ASD feel protective of their brothers or sisters with ASD. Participants described events in which they felt that their siblings with ASD were not treated appropriately and adequate provisions of care were lacking. Susan in particular, reported contacting multiple platforms and individuals (e.g., principal, superintendent, special needs coordinator), in order to address the concerns of her brother's safety. Similar to other siblings, Susan felt a necessity to push for services and educate

herself on required procedures (e.g., application processes, placement on waiting lists) to assess and attain supports.

Unfortunately, other participants such as Annabelle echoed similar experiences:

[Curtis] had an “accident” [...] but apparently, the smell got really bad so they took all the other classmates out of the classroom and they left Curtis [there]. It took a while for my mom to get to school, and by the time she got to school, Curtis was alone in the classroom, and he was trying to put his snow pants on but they were wrapped around his neck [and he] would have choked if my mom would have shown up later. [...] This isn't right. But then again, it did push me to where I am today. I'm heading towards this career, because I want to go into schools and create better programs for kids [with ASD]

Anabelle recalled the incident that influenced her motivation to make systemic changes. She described a feeling of injustice and shock as her 6-year old brother was segregated from his classmates due to a bowel indiscretion. Rather than being offered assistance, her brother was isolated and left unsupervised. Anabelle believed that the school had failed her brother, and she thus later enrolled in an Autism Behavioural Sciences program with the intention of working in institutions such as schools. Anabelle, like other siblings, was deeply affected by the mistreatment experienced by her brother and sought to take matters into her own hands. Consequently, she aspired to become the change and compassion that she had hoped would be evident in her sibling's environments.

Interestingly, nine of 17 participants in the study entered helping professions in ASD related fields, suggesting that siblings strove to create supports that they wished were available to them. These qualitative findings were further supported by questionnaire data from the SIBS, in which all (i.e., 100%) participants answered “always” to being concerned for their sibling's

welfare and happiness, and 92% reported always wanting their sibling to succeed. The collective advocacy efforts and career choices of participants characterize the altruistic motives to create a systemic impact by educating others, and facilitating the accessibility to supports. Most importantly, the power of advocacy also allowed these participants to feel a sense of control after feeling isolated and uncertain about whether help could be obtained.

“It was a bit rough when we were children, but once we hit late teenage years, things got really good. Now that we’re adults, things are awesome between us”: Adjustment and Adaptation

In line with the FAAR model (Patterson, 1988, 1989; Patterson & Garwick, 1994), adjustment and adaptation occurs continually within sibling relationships when a brother or sister has ASD. In the current study, siblings experienced hassles or stressors that necessitated adjustments that were either practical (e.g., taking classes to manage difficult behaviour associated with ASD, establishing routines) or personal (e.g., understanding more about ASD, ascribing different meanings to situations, focusing on ones’ own goals and desires) in nature. As described by participants, these adjustments resulted in a greater balance whereby resources and supports effectively addressed demands.

Participants’ depictions of their sibling experiences also suggested that adjustment and adaptation occurs in a cyclic nature as they face new challenges or events. Rebecca described an oscillation between “ups” (positive events, such as having fun with brothers or sisters with ASD) and “downs” (negative events such as tantrums, limited one-on-one time with parents): “There’s certainly been some ups and downs. Right now things are pretty good.” It is important to note that Rebecca described her experiences retrospectively, from growing up with a brother with ASD until presently as an adult. The reflection over the lifespan demonstrated that the process of adjustment and adaptation is constantly in progress and it is influenced by each developmental

stage across the lifespan. For example, in Rebecca’s interview, she described having a difficult time adjusting to the questions or comments that her classmates made towards her brother. Conversely, in the later stage of young adulthood, Rebecca shifted towards a more protective and supportive role. However, it is important to note that the words “right now” potentially implies that the current state of balanced functioning may be temporary and subject to change depending on the challenges that are encountered in subsequent life stages or even on a daily basis.

Within participant accounts, it became highly evident that balanced functioning was facilitated by the adoption of new capabilities (such as obtaining knowledge about ASD) in order to maintain balanced functioning. By way of example, Erin described gaining an understanding about how to help individuals, such as her brother, enabling the implementation of behavioural strategies in response to particular behaviours (i.e., yelling, pushing, running away):

I think even my understanding of what autism is has kind of morphed and now even the program I’m in [Autism and Behavioural Sciences] helps because now I understand my brother better [and that] shifts my perception [...]. So I’m not really frustrated with him anymore because I get what’s going on so that helps.

Essentially, Erin reported a state of adaptation as an outcome of developing adequate capabilities (e.g., knowledge about ASD and behavioural strategies) to manage daily demands. This positive approach ultimately allowed Erin to reframe her brother’s challenging behaviours, subsequently minimizing the frustration that she would have typically experienced in the past.

The process of adjustment and adaptation was triangulated by composite scores on the SIBS. Positive involvement ($M=56.3$, $SD=9.22$) was evident amongst the sample, reflecting a state of adaptation. The positivity composite consists of subscales, such as Companionship ($M=19.4$, $SD=5.2$), Empathy ($M=23.43$, $SD=2.50$), and Directive/Teaching ($M=13.5$, $SD=3.25$).

These results supported the notion that siblings ultimately adapted effectively, which fostered shared activities (companionship), experienced sympathy for their siblings when they experience struggles, and demonstrated concern for their siblings' overall well-being. Additionally, these results represent efforts by participants to teach their siblings new skills and appropriate behaviours, which potentially facilitated the road to adaptation. In the same vein, a total composite score was found in the SIBS, reflecting lower negative involvement ($M=28.21$, $SD=5.25$). Negative involvement included subscales that reflected rivalry, aggression and avoidance (of the sibling with ASD).

Potentially, these lower scores of negative relationship qualities reflect that, at the time of their interview, siblings (with typical development) had adjusted accordingly to issues discussed in interviews, such as rivalry (harboured by differential parental treatment and competition between siblings) and aggression (tantrums, physical fights). Participants commonly discussed issues, such as lack of parental attention and frustration (in response to the symptoms of ASD) as issues of the past which had been overcome. In the same vein, participants discussed the utilization of resources such as workshops and educational sessions to manage challenging aspects related to ASD: "My mom and I took a lot of parenting classes, like how to deal with kids with ASD and after that, it was much easier" (Angela, sister to a 4 year old sister and 8 year old brother, both with ASD). In her interview, Angela mentioned problematic issues including aggressive behaviour and prolonged levels of stress. However, she later reported that parenting classes taught her how to perceive her brother's frustration as a consequence of unmet needs, which were remediated by established routines.

As a result of incorporating structured routines and established supports (e.g., help from other family members and external assistance in the form of respite care) some participants

described an established state of adaptation. However, a couple of other participants explained that they were still trying to achieve a sense of balance between demands, and finding capabilities such as resources and coping mechanisms (e.g., finding a hobby, speaking with other siblings in similar circumstances). Adam, for example, explained that disruptive behaviours, such as tantrums, are challenges that he has become accustomed to: “When he was younger especially, he’d have a lot of tantrums, he’d just cry, in public, at home, and it’s something I guess you get used to.” Throughout his interview, Adam never described finding adequate supports or accessing services. Instead, he felt that difficulties such as challenging behaviour, was something that he would have to “get used to” since no solutions had been available to remediate the circumstances (e.g., attaining respite, spending more time with parents). Instead, he appeared to change his situational meaning to normalize stressful behaviours associated with ASD. This appears to become a factor in achieving balanced functioning but is prone to fluctuation as concrete supports are not in place.

Together, the themes of supports, demands, advocacy and adjustment and adaptation reflect the experience of having a brother or sister with ASD. Additionally, these themes illuminate the notion that siblings of individuals with ASD require additional supports given the extent of responsibilities and challenges undertaken across the lifespan.

Discussion

As demonstrated by a few studies (e.g., Conway & Meyer, 2008; Cridland et al., 2016), siblings have the most contact with individuals who have ASD over the life span compared to peers, parents and other extended family members. This prolonged duration and degree of involvement allows siblings to make beneficial contributions to the lives of their brothers and sisters with ASD. However, siblings require supports and resources for themselves in order to

manage the difficulties of having a brother or sister with ASD. The current study aimed to understand the state of supports and stressors experienced by siblings through a mixed-methods approach. The incorporation of both qualitative and quantitative results yielded four themes: Adjustment and Adaptation, Demands, Advocacy for siblings with ASD and Supports.

Specifically, siblings attempted to achieve and then maintain balanced functioning by utilizing capabilities (i.e., resources and supports) to meet demands characterized by multiple stressors and daily hassles. The theme of adjustment to adaptation reflected the process described by participants as they described feeling destabilized when they encountered tremendous stressors, such as behavioural challenges and problematic incidents at institutional levels. In these particular cases, siblings employed advocacy skills as a means of obtaining support. These capabilities eventually led to a state of adaptation, which resulted in a sense of balance. Interviews substantiate this progression towards adaptation as participants described having better relationships as adults, than as children or adolescents. According to siblings, gaining knowledge about ASD and associated symptomatology also played a significant role in the management of their brother or sister's behaviours. This current finding is in line with past research (i.e., Tudor & Lerner, 2015) that has shown that siblings' understanding of their brother or sister's ASD can modify their perspectives, ultimately increasing empathy and acceptance.

Overall, current findings demonstrated a significant lack of supports in early life stages. Siblings reflected retrospectively about how adolescence was a difficult period when living with their brother or sister with ASD. Researchers explain that the wide range of physical, emotional, and social changes during the adolescent developmental period are further compounded by ambiguous and conflicting feelings such as protection, love, resentment and guilt toward the sibling with ASD (Pinkerton & Dolan, 2007). These replicated findings suggest considering a

lifespan approach during the development of formal supports to address concerns typically experienced in particular life stages, especially in adulthood as siblings take on greater responsibilities.

Participants varied in terms of what supports were considered most helpful. For example, some participants valued sibling support groups highly, while others expressed that it still did not address practical elements of their lives, such as financial supports and future living arrangements. Based on these findings, siblings may require more comprehensive supports that include psychosocial and psychoeducational components, in addition to interactions with other siblings of individuals with ASD. The inclusion of parents within tailored supports can also be beneficial for siblings (with typical development). Although participants in the current study were accepting of their brothers or sister's need for more parental attention, siblings such as Jennifer expressed the desire to spend more time with parents, or participate in family activities that did not revolve around her brother's routine or desires. In light of these findings, parental involvement should be implemented more often as a component in the development of supports. Results of the current study replicates previous findings that reveal that siblings with typical development experience less parental attention. This lack of attention creates a conflicting desire to both distance from, and engage with their families (Cridland et al., 2016). Thus, providing siblings with additional one-on-one time with parents can cultivate healthier familial relationships and buffer potential feelings of resentment towards the brother or sister with ASD. The addition of this component can be made possible by providing parents with further respite, which would allow them to spend time with their children who do not have ASD.

The findings reported herein are consistent with previous research that revealed increased utilization of sibling support groups (Cridland et al., 2016). A majority of participants were

involved with sibling support groups, which suggests that siblings may be unaware of other available interventions that could provide gains beyond peer support. It is important to note that Sibshops were primarily designed to provide social support and are not alternatives for clinical supports such as therapy (Tsao et al., 2012; Tudor & Lerner, 2015). Thus, an implication exists in which siblings may be relying on supports that may not sufficiently address their needs, depending on the severity of their sibling's ASD. For example, Pilowsky and colleagues (2004) found that in a sample of 88 siblings of individuals with ASD, 16% met the threshold for a DSM-IV-TR diagnosis, such as Attention Deficit Hyperactivity Disorder (ADHD), necessitating clinical supports. The FAAR model also emphasizes that siblings can experience repetitive cycles as they adjust and adapt following a new crisis (e.g., significant loss of supports) or other demands (e.g., additional financial responsibilities) throughout the life span (Patterson & Garwick, 1994). Therefore, individuals of siblings with ASD need provisions of care that can provide long-term solutions in order for benefits to be maintained.

In order to cater to the needs of siblings of individuals with ASD, the level of awareness regarding supports needs to become more widespread. Although siblings play a significant role in the lives of their brothers and sisters with disabilities, they are often “overlooked” in the formulation of services and supports tailored for families (Conway & Meyer, 2008). Services can only truly adopt a family-centred philosophy of care once siblings are fully integrated into the functional definition of “family” that agencies utilize (Conway & Vadasy, 1997). Thus, results of the current study promote the need to make systemic changes to fully address the concerns of siblings with brothers or sisters who have ASD.

Considerations and Future Directions

Although all siblings ($n=17$) participated in interviews, only 14 participants completed both questionnaires. The incompleteness of the data set prevented a case-by-case comparison between qualitative and quantitative findings across the entire sample. Additionally, a small sample size prevented further analyses of subscale scores obtained from questionnaires. Notwithstanding these limitations, the study presented a significant strength; the mixed methods approach warranted a thorough investigation of supports and stressors experienced by siblings of individuals with ASD. Credibility was further established through the triangulation of themes using questionnaire subscales and individual items. Member checks were also conducted, which involved receiving confirmation of final themes from participants. Most importantly, the results of the current study contribute to the literature regarding sibling supports, which was characterized by previously inconsistent findings. It is of utmost importance to clarify these inconsistencies in order to identify which siblings may benefit from services, and to what extent or type of support is needed (i.e., intensive clinical interventions, or informal social supports). Outcome measures for these supports should also be developed to decipher between services or resources that are most effective throughout the siblings' lifespan.

Conclusion

The peer nature of the relationships between siblings places them in a unique position for long-term support and advocacy efforts. For example, siblings of individuals with ASD will witness their brother or sister experience events and transitions across the lifespan, ideally including education, employment, relationships and the establishment of independent living. Therefore, siblings are highly informed about what is needed by individuals with ASD and their families across the lifespan. They can influence recommendations and policies on a broader level to ensure that gaps in supports and services are filled. Most importantly, the inclusion of siblings

also warrants a more systemic view of disability, wherein uplifts and hassles are seen as having an influence on the entire familial unit (Walsh, 2003). In sum, the findings of the current study indicate that siblings of individuals with ASD continue to thrive and utilize strengths such as advocacy and other coping behaviours, and informal or formal supports. A continuing focus on the perspectives of siblings will serve to inform the development of support guidelines, such as future planning and fostering sibling advocacy.

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Chapter 4: Discussion

Chapter Four summarizes the findings of both studies, which offer insight into the experiences of individuals with typical development who have a sibling with ASD. Subsequently, similarities and differences to existing literature are discussed, in relation to current findings already shared within Chapters Two and Three. The applicability of the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 1988) is also explored. This final chapter also considers recommendations for future studies within sibling research. Lastly, strengths of the study, clinical implications, and knowledge translation are discussed.

4.1 Summary of Findings

Within this manuscript-based thesis, articles are included to emphasize two particular issues evident within sibling experiences when a brother or sister has ASD. These issues include provisions of future care, and the availability and accessibility of supports.

4.1.1 Future Caregiving. The first article titled, *“What Now?” Concerns and Worries of the Next Generation of Caregivers* discussed concerns for provisions of care in the future. It

adopted an exploratory design and found specific concerns that individuals had in regards to their sibling's future, as it pertained to caregiving responsibilities. Semi-structured interviews that were informed by the FAAR model (Patterson & Garwick, 1994) and a basic interpretive approach (Merriam, 2002) were completed by 17 participants. Interpretative Phenomenological Analysis (IPA; Merriam, 2002) of interview transcripts revealed levels of uncertainty and fear amongst siblings as they tried to prepare for a caregiving role. It became apparent that many individuals were already facing the realization of potential caregiving of their brother or sister with ASD for the future. The findings of ~~the study~~[this research question](#) also conveyed that siblings felt unprepared for additional responsibilities if they were to become full-time carers soon. Still, it was found that the inclusion of siblings in the discussion of post-parental care was not common. The findings reported herein reflect previous research in which siblings expressed thoughts and worries about the future and questioned their future roles (Petalas et al., 2009). Additionally, when asked about planning, future care plans were also not commonly discussed within the family (Petalas et al., 2009), as noted in the [discussion of the first research question](#). ~~first article~~. In terms of accepting full-time caregiving responsibilities, siblings of individuals with disabilities often become caregivers when parents pass away (Holl & Morano, 2014). However, studies exploring siblings of individuals with disabilities, such as ASD, have only been added to family research recently.

A previous study comparing siblings who were current caregivers with those anticipating to provide care in the future suggested that concerns (regarding future responsibilities) can be alleviated by being cognizant of the fact that siblings with disabilities may be given more opportunities and become more independent as siblings transition to caregiving roles -(Burke, Fish & Lawton, 2015). As such, they will want to be more engaged in activities or work

placements within their communities. Consequently, siblings (with typical development) will benefit from assistance throughout the navigation of community resources and supports (e.g., transportation such as Wheel-Trans and work programs) for individuals with disabilities such as Abilities Canada, and Community Living Ontario. These opportunities can also be facilitated by services and supports at multiple levels including federal (e.g., knowing about rights for their sibling with ASD through familiarization with the Canadian Human Rights Commission), provincial (e.g., being informed about government disability programs, initiatives and services to assist with matters such as education and financial support), and municipal (e.g., employment services that help individuals with disabilities find jobs).

In the same vein, participants ~~of the current study~~ described feeling more anxious as brothers and sisters with ASD become older and eventually age out of eligible programs and services, including respite and funding. Additionally, individuals with ASD will likely be graduated from school when siblings become full-time caregivers prompting further concerns of finding suitable leisure opportunities (e.g., day programs, sleep away or summer camps). In these circumstances, siblings of adult individuals with ASD would benefit from the Passport Program, which helps adults with developmental disabilities engage in communities (e.g., recreational programs, volunteer, and build daily life skills). In turn, it provides caregivers with opportunities for temporary respite and provides funding to hire a support worker (Ontario Ministry of Community and Social Services, 2013). The Ontario Disability Support Program (ODSP) is another resource that assists families with financial needs and is not restricted to younger ages. Individuals with developmental disabilities who are 18 years of age or older may apply (Good 2 Go Transition Program, 2016).

Heller and Kramer (2009) also highlighted the need for more information to ease the transition of financial, residential, and leisure responsibilities from parents to future sibling caregivers. Thus, to help siblings feel prepared, it is recommended that they be involved in discussions regarding substantial and concrete planning (e.g., established living arrangements for the future, and additional funds for new financial responsibilities) before becoming subsequent carers. The aforementioned requests for information and inclusion within family discussions (about the future) were echoed in interviews discussed in the second chapter.

Although researchers have identified in multiple studies (e.g., Heller & Kramer, 2009; Roper & Allred, 2014) higher levels of caregiver burden in parents of children with ASD (compared to children with typical development), care responsibilities by siblings have not been commonly investigated. As parents become less able to provide care due to aging, retirement or death, siblings often become subsequent caregivers (Heller & Arnold, 2010). Thus, it is of utmost importance to extend family research to siblings.

4.1.2 Supports and Stressors. A further implication within the discussion of future care involved the advent of deinstitutionalization as siblings were aware of the lack of available supports ~~available. The discussion of supports related to future concerns subsequently promoted further investigation about support availability~~ and accessibility for individuals of siblings with ASD. The second study-manuscript titled, *“We were all in survival mode”: The Balance between Demands and Capabilities When a Sibling has Autism Spectrum Disorder*, employed a concurrent triangulation mixed methods approach using semi-structured interviews and two standardized questionnaires. The aim was to further understand supports that are accessed and/or available for siblings of individuals with ASD. Due to a specific scope of experiences, rather than IPA, interview transcripts were analysed using Thematic Analysis (as informed by the

FAAR model). Thus, responses regarding the utility and availability of supports were the focus throughout the analysis. Four major themes emerged and were supported by questionnaire responses provided by participants: Informal and Formal Supports, Demands (stressors, strains and daily hassles), Sibling Advocacy, and Adjustment and Adaptation. The results of the study noted implications for the services and resources available for siblings of individuals with ASD. Sufficient resources essentially facilitate adaptation and adjustment, as demonstrated by participant accounts.

Previous research has generally highlighted negative effects within relationships when a sibling has a disability, predominantly ASD. A number of studies have posited that siblings (with typical development) may be at an increased risk for internalizing (i.e., emotional) and externalizing (i.e., behavioural) issues in comparison to sibling relationships with the presence of a different disability, or no disability (Gold, 1993; Hastings, 2003; Orsmond & Seltzer, 2007). Conversely, the extent of positive experiences remains relatively unknown. In order to obtain a fuller understanding of these relationships, a balanced investigation must consist of both positive and negative experiences. Thus, the current study expanded these findings. Albeit to varying extents, participants who were interviewed expressed positive views of their siblings. For example, many participants explained that in spite of daily hassles, their experiences as siblings ultimately shaped the person that they had become. For example, the sibling relationship created an awareness regarding the lack of quantity and quality of services for individuals with ASD. Participants harboured a desire to contribute to the growing field of ASD as a function of their vested interest in securing tailored services for families in need of similar care. These outcomes were manifested in the theme of “advocacy” within the third chapter. Participants described feeling a strong sense of agency when educating others about ASD.

Notwithstanding daily hassles and stressors, many siblings of individuals with disabilities want to cultivate closer relationships with their siblings. However, more supports, information and opportunities for networking are needed (Heller & Kramer, 2009). These results were also evident in the current study, as participants described wanting to be involved in their siblings' lives, but felt that sufficient supports were not available nor accessible. However, conflicting findings are evident. A review of the existing literature also conveyed that individuals with a brother or sister with ASD may be more avoidant compared to other sibling relationships in which no disability is present (Walton & Ingersoll, 2015). Similarly, participants of the current study recalled moments in early adulthood when they wanted to physically distance themselves from their brother or sister with ASD. Thus, as siblings adjust and adapt to their experiences, they may experience varying difficulties or uplifts at particular life stages, requiring more or less support. Siblings are also able to reflect about past experiences and view their brother or sister (with ASD) more positively when they have more resources to manage stressors (Petalas et al., 2012). For example, when reflecting retrospectively about sibling experiences, participants explained that joint activities had to be modified to avoid some degree of conflict. The presence of conflict (e.g., having to modify play, lack of cooperation) represents a need for resources and instruction at earlier life stages (e.g., childhood and adolescence) to learn how to interact with siblings (who have ASD) successfully (Walton & Ingersoll, 2015). These interventions for effective play are vital at earlier stages (during childhood and adolescence) of the sibling relationship as social play contributes to the development of cognitive, social and cultural competence (Bass & Mulick, 2007).

Taken together, current and previous findings within sibling research recommend a lifespan approach to understand the experiences of having a sibling with ASD (Orsmond & Seltzer, 2007).

4.2 Applying the FAAR Model to Sibling Experiences

The FAAR model was developed to conceptualize the processes in which families adjust (indicated by relative stability) following an event perceived to be a crisis. Accordingly, the findings of the current study were interpreted through the FAAR, warranting insight into sibling dynamics and adaptability when a brother or sister has ASD. In particular, adaptation occurs, and is characterized by the balanced act of utilizing capabilities (e.g., resources and coping behaviours) to effectively manage demands. The efforts to maintain a balanced state of functioning within the family system are also mediated by the meanings attributed to events by the members of the family. Over time, families continually experience repeated cycles of adjustment and adaptation (Patterson & Garwick, 1994)

The FAAR model identifies the variables that influence adjustment and adaptation in the midst of stressful situations. Therefore, this model can describe the processes taken by siblings to restore balance once demands and capabilities are in equilibrium. A strength of the FAAR is that it serves as a family resilience model (Patterson, 2002) that focuses on the capacity of the entire family system, including siblings, to recover from adversity and become more resourceful as a unit (Walsh, 2003). This approach accepts that resilience is dynamic in nature, frequently changing over time in varied responses to different situations and attributions of individualized meanings (Patterson, 1988). For example, in reference to article one, which discusses future caregiving, siblings commonly accept additional caregiving responsibilities once parents age or become overburdened. Thus, it is important to consider the varied contributions of members in

the family network, such as siblings, as they become involved in a caregiving team (Walsh, 2012).

Moreover, the FAAR explains that family experiences are not stagnant, resulting in a cyclical model (Patterson, 1988). This ongoing process was frequently experienced by siblings in the current sample as they described experiences that varied along life stages, requiring adjustment to new demands (e.g., loss of supports, lack of parental attention) and establishing new capabilities (e.g., becoming advocates to attain supports). Similarly, the FAAR theorizes that families oscillate between stages of adjustment and adaptation across time (Patterson, 1988). In addition, the FAAR accurately captures the nature of family dynamics when a member has a disability, as the milestones and other events differentiate from other families. For example, participants mentioned that siblings of their peers were expected to become independent as they went to university or college; however, they could not have the same expectations for their brothers or sisters with ASD. Hence, the meanings that they attributed to their experiences were different from other siblings of individuals with typical development.

Lastly, the applicability of the FAAR to sibling experiences is important as it can inform clinical guidelines in the development of supports. For example, interventions can be designed as strength-based approaches in which individual capacities are capitalized on to avoid crises or manage stressors more effectively (Walsh, 2016). Focusing on resilience and capabilities such as advocacy will assist siblings in achieving goals despite continuous stressors or new challenges. Autism stakeholders and/or other mental health professionals can be cognizant of the adjustment and adaption process and help siblings develop capabilities (e.g., healthy coping mechanisms) or resources (e.g., workshops to provide information about issues such as financial planning, completing required documentation to enrolling for appropriate respite programs) to address

demands (e.g., feeling unprepared for the future). Further discussion in regards to interventions and other supports will be provided in the Clinical Implications Section.

4.3 Considerations and Recommendations for Future Research

The current study consists of many strengths that will be discussed further in this section. However, limitations were also present. Several considerations should be noted when conducting studies within sibling and disability research including: obstacles within recruitment strategies and procedures, the requirement of additional demographic information of participants and their siblings, and the use of research measures for adult siblings as a population. Ways in which these limitations can be used to inform and strengthen future research will be discussed.

First, obstacles were encountered during the recruitment process. To elicit participation, a database of ASD stakeholders and groups across communities was compiled and point persons were contacted. Moderate response rates were given by support groups, which influenced a large portion of the study's sample. Although siblings who were engaged in support groups provided valuable and informative accounts of their experiences, it lent a bias to the sample. Generally, participants recruited through support groups had already developed a familiarity with informal supports such as sibling support groups. As a result, the current study may not capture the experiences of siblings who have not sought informal or formal interventions or services. It would be informative to investigate other outlets of supports that these families are potentially employing or to examine barriers that may reduce accessibility or utility of supports.

A secondary issue evident during data collection includes the completion of both interviews and questionnaires. Some participants completed questionnaires, but were unwilling or unable to complete an interview, or vice versa. Although data were still effectively used for the interpretation of sibling experiences, it weakened the ability to triangulate personal accounts

using both qualitative and quantitative methods. In attempts to obtain further data, participants were reminded via e-mail or phone calls; however missing data is still evident. In hindsight, offering an incentive to participants as recognition for their time and sharing their experiences may increase motivation to fully complete all components of the study.

Within the scope of study protocol, it is also important to implement a standardized order in which research measures are administered. An implication that arose during the study was whether questionnaires should have been given before or after the interview. Questionnaires were provided via REDCap (an online research platform) when interviews were scheduled. However, some participants opted to complete the questionnaires before the interview whereas others took longer periods of time to complete the questionnaires following their interviews. For example, some participants explained that they wanted to add further details in the interview to supplement their responses on the questionnaires or they wanted to clarify that particular stressors were only relevant in certain life stages (e.g., feeling concerned about their sibling's future as an adult). Thus, the completion of questionnaires before the interview may help participants think about what they would like to talk about or clarify within the interview so that sibling experiences are understood fully rather than being misconstrued during data analysis.

Due to recruitment difficulties, participation mainly consisted of adult siblings (i.e., 17 to 53 years old). The uneven group distribution led to a limitation within the use of research measures, notably the Sibling Daily Hassles and Uplifts Scale, and the Sibling Inventory of Behaviour Scale. The reason being, the SDHUS was normed for 7-16 year olds (Giallo & Gavidia-Payne, 2006) and the SIBS was normed for individuals aged 4 to 17 years old (Hetherington et al., 1999). Because these measures were initially normed for children ranging in ages 4 to 17 years old, results should be interpreted with caution as sibling experiences were

understood through the lens of adults. Due to the exploratory nature of the study, the decision was made to continue the administration of both questionnaires, as they were in accordance with the FAAR model. Both questionnaires complemented the overall scope of the study which included the combined understanding of negative and positive experiences rather than focusing on negative sibling dynamics, as done in past studies. Additionally, both scales assisted in the assessment of relationship quality, and the SDHUS, in particular, considered the presence of disability in sibling relationships when measuring hassles and uplifts.

Although both questionnaires employed in the study were normed for a younger population, participants found it difficult to respond to questionnaires without answering retrospectively from a lifespan perspective. For example, one participant noted that she felt strongly bothered by her brother's behavioural difficulties (e.g., kicking, screaming) on the SDHUS during adolescence but wanted to clarify that she no longer felt that frustration as an adult. Thus, it is important to note that the use of questionnaires alone would inadequately capture sibling experiences when a brother or sister has ASD. The strengths presented by a mixed methods approach will be discussed further in this chapter. In addition, future studies should consider norming measures of sibling relationship quality for an adult population, as a rising number of siblings are becoming subsequent caregivers for their brothers or sisters with ASD, especially in late adulthood. As such, the assessment of sibling relationships in adulthood can assist in creating supports that address difficulties experienced in this particular life stage.

Upon further examination it also became apparent that additional demographics or sibling factors could contribute significantly to the interpretation of sibling experiences. For example, knowing the socioeconomic status of each participant may shed light on the ability to obtain greater supports, such as respite. Within the understanding of the FAAR, if participants have

access to services as a result of economic stability, stressors would be reduced and facilitate adaptation. Conversely, these experiences may vary in families that may not receive such supports, further emphasizing the need to promote service availability and accessibility within communities. Expansions of the current study would also benefit from a longitudinal approach in order to investigate how siblings conceptualize their experiences as they age and utilize capabilities (e.g., coping strategies) within different life stages to address daily stressors or demands. Past studies have noted that age plays a role in perceptions of sibling experiences (e.g., Cridland, Jones, Stoyles, Caputi & Magee, 2016; Tudor & Lerner, 2015). For example, as individuals mature from concrete to abstract thinking (Glasberg, 2000) the meanings that they ascribe to experiences or situations (e.g., difficult behaviours, increased responsibilities at home) reflect a greater understanding about ASD. As a result, increased knowledge and concern for their brothers or sisters with ASD occurs (Glasberg, 2000), which can contribute to resilience.

Another limitation that exists within the current study is that most participants were female, reflecting a predominantly “sister” experience. With consideration to gendered notions of care evident in past studies (e.g., Cridland et al., 2016), a predominantly female sample provides valuable insight into caregiving, uplifts [e.g., feeling good about helping their brother or sister with ASD (Cridland et al., 2016), and perceived stressors (e.g., adopting a “parentified” role; please see second chapter for further detail). For example, past research has found greater likelihoods of caretaking (Cridland et al., 2016) and risks of psychological distress (Khajehpour et al., 2011) among female siblings (of individuals with ASD), compared to brothers.

A final limitation that can inform evolving research includes the consideration of ASD severity of each individual in the study. The current study accepted all ASD diagnoses in siblings (as reported by participants), but the severity of each diagnosis was not specified.

However, diagnosis severity may have a significant bearing on interpretations of sibling experiences. Specifically, it may impact the challenges faced by participants and their ability to relate to siblings with ASD, making it a crucial variable to consider.

A final recommendation for future research concerns the effectiveness and utility of informal supports. In the current study, a majority of participants were involved with informal supports (e.g., sibling support groups), ranging from sporadic to consistent utility. A few studies also refer to support groups as a highly utilized psychosocial support, yet a dearth of published research examining the effects of these interventions exists (Tudor & Lerner, 2015). Specifically, continuing studies in sibling research should examine the efficacy of informal supports such as peer support, and assess the longevity of beneficial or therapeutic effects that are gained. Such an investigation will help determine whether it is a sufficient support, or supplementary to other interventions. Furthermore, it could provide recommendations to improve supports. For example, support group protocols can be established then replicated in additional locations or settings (depending on its effectiveness with participants). Within the same vein, standardized measures can also be included to gauge levels of functioning (e.g., behavioural and emotional adjustment) of participants. Such an assessment may assist in providing an appropriate referral for higher intensity level supports (e.g., one-on-one counselling) if required.

Existing literature thus far, has yielded mixed findings (as discussed in Chapter One) however the inclusion of specific demographic factors, such as age, gender and disability severity may provide a comprehensive understanding of complex sibling experiences. Recommendations for future research discussed in this chapter aim to clarify obscured findings and reach a consensus on particular factors that may ascertain which siblings are struggling or flourishing. In addition, a greater understanding of the latter can assist with the formulation of

empirically supported interventions, as mentioned, and identify which siblings may benefit the most from particular supports (Tudor & Lerner, 2015).

4.4 Strengths of the Study

The establishment of trustworthiness within qualitative research demonstrates that results are supported by sound evidence (Shaw, 2010). Specifically, four components ensure trustworthiness: Credibility (i.e., internal validity), Transferability (relates to external validity or the extent to which results can be generalized), Confirmability (i.e., objectivity within the study to ensure that results are not based on researchers' biases), and Dependability (i.e., reliability) (Merriam, 2002). To adhere to rigorous standards of valid and reliable qualitative analysis (Merriam, 2002; Shaw, 2010; Smith, Flowers & Larkin, 2009), and ensure that all four components of trustworthiness were established, multiple strategies were employed in the current study: reflexivity, audit trail, member checks, peer review, and triangulation (which are discussed further).

In qualitative research, the main instrument used to make sense of others' experiences is the researcher who conducts the study (Merriam, 2002). Naturally, the researcher can lend bias to an analysis, thus transparency is required throughout the study. The maintenance of transparency promotes trustworthiness, proving that results are credible and supported by sound evidence from the data (Merriam, 2002). Accordingly, a reflexivity section was included in the first chapter to explain any personal or professional experiences that may have influenced components of the study, such as the collection of data or interpretation of findings (Shaw, 2010). When conducting qualitative research, it is also advisable to maintain an audit trail (Shaw, 2010). This method encourages the researcher to include notes of any thoughts, decisions, or processes during each stage of the analysis, from raw data to final interpretations (Smith et al.,

2009). This trail was maintained throughout the duration of the study to illustrate how the first author progressed from raw data to finalized interpretations.

Peer review was also conducted to strengthen findings. All themes that emerged from data analysis were discussed among members of the research team until consensus was achieved. Lastly, member checks can also play a significant role in the verification of study findings (Merriam, 2002), and were conducted prior to finalizing themes. Following the completion of interviews, participants were provided with transcripts and a summary of findings gathered from the discussion. All siblings who participated in the study were asked to confirm the accuracy of the findings and to provide any additional feedback or comments.

In addition to a qualitative approach, questionnaires were also used to triangulate themes from qualitative analysis in the second paper (e.g., see Chapter 2). The mixed-methods approach with a convergent parallel design allowed the first author to quantify positive and negative experiences of participants, while attaining further detail through qualitative interviews. In addition, questionnaire data supported themes leading to the confirmation and corroboration across all participant responses. An additional benefit of this approach is that data collection occurs in a convergent manner, which allows both methods to overcome a weakness in one method while optimizing the strengths of another (Creswell, 2014). Thus, limitations that may exist through the use of a single method are overcome by addressing the main research question differently (quantitatively and qualitatively) (Creswell, 2014).

Lastly, the most significant strength of the study concerns the therapeutic nature of interviews. Semi-structured interviews essentially served as a platform for individuals to voice their concerns and feelings in an open manner. As mentioned previously, due to existing stress in the household, participants commonly described feeling unable to disclose their thoughts about

being the sibling of an individual with ASD. For example, guilt often prevented participants from sharing their difficulties at home because they felt that it would contribute to parental burden. Although the interview guide was designed to obtain relevant information from participants, it also manifested as a therapeutic environment by providing opportunities for disclosure of difficult experiences. Consequently, individuals reported feeling relieved because they were given permission to speak about their experiences. For example, one participant in particular spoke about how the interview was the first opportunity he ever had to tell his story. Hence, semi-structured interviews not only serve a research purpose, but can provide therapeutic benefits to participants as well.

Existing sibling research has noted that clinical practice has not kept up with demands faced by siblings of individuals with ASD, especially in the midst of deinstitutionalization (as discussed in the second chapter). Professional environments may still lack sufficient awareness of the complex and unique challenges that are faced by siblings of individuals with ASD (Jordan & Turns, 2016). Future research can continue to inform clinical practice in similar ways that are discussed in the next section.

4.5 Clinical Implications

Although participants of the current study discussed positive sibling experiences, they still described difficult obstacles that were endured on a daily basis. Siblings reported being affected in diverse ways, such as family separation, feelings of isolation and the desire to physically distance themselves from their brother or sister with ASD. Hence, evidence of these challenges suggests a need for greater availability and accessibility to services and resources for these siblings.

Siblings can find guidance in the form of advice or mentorship as they navigate within their social environment (Ungar, 2010). Several siblings in the present study recounted times in which they found comfort and solutions within support groups. Given the importance of peer relationships during life stages such as adolescence, social supports are especially valuable (Tsao, Davenport & Schmiede, 2012; Ungar, 2010). In line with this suggestion, providing opportunities for siblings to talk freely about their feelings and experiences is imperative. Sibling support groups in particular have been reported to increase positive feelings towards the sibling with a disability (Tsao et al., 2012). Furthermore, these sources of support have equipped individuals with useful coping strategies to use in the event of challenging behaviours or problematic issues with their sibling with ASD (Conway & Meyer, 2008). Participants in the current study also explained that older siblings served as peer mentors and provided advice for challenges that they had previously encountered during past life stages (e.g., childhood, adolescence, and early adulthood). These comments from siblings can inform the types of supports that can be offered. For example, individuals with brothers or sisters who are further along in the disability lifespan can mentor siblings of individuals with ASD in the earlier stages (Orfus, 2008).

Support groups evidently provide a beneficial platform to provide immediate relief for individuals, but due to the complexities that can arise from living with a sibling who has ASD (or in cases in which ASD is more severe), structured and clinical interventions may be required to ensure long-term benefits. This limitation was reiterated in participant accounts, as they explained that sibling support groups provided temporal relief but felt that they still needed more formalized and structured supports. For example, professionals within the field of ASD can provide information about the disorder, and teach or model strategies that effectively manage

challenges (e.g., reducing or managing aggressive behaviours or communication difficulties). In the same vein, clinicians and other mental health professionals may facilitate how siblings make sense of the events and feelings that they experience. Participants of the current study mentioned that learning about ASD prompted the realization that their siblings' behaviours were symptoms specific to the disorder, rather than intentional acts of emotional or physical harm. However, these participants were enrolled in programs to prepare for careers in the ASD field, such as Applied Behaviour Analysis (ABA). Hence, informative supports for siblings who do not pursue these vocations may be useful in understanding challenging behaviours associated with ASD.

In cases characterized by increased behavioural issues or emotional distress, it may also be necessary to work solely with the sibling with typical development using a validated therapeutic modality to help them explore their thoughts and emotions regarding their sibling experiences (Mascha & Boucher, 2006). Referrals may also be made to other counselling or psychological agencies or professionals when the current provider is unable to provide sufficient services (Walton & Ingersoll, 2015) depending on the sibling relationship quality and severity of ASD.

Siblings of individuals with ASD can be faced with multiple barriers, such as geographical distance to service accessibility. For example, a number of siblings in the present study reported living in remote areas and cited location as a barrier for supports. With this in consideration, interventions such as online supports may be an alternative. Past research has examined the efficacy of internet social support and found that siblings were provided with emotional support to help cope with physically violent behaviours by siblings with ASD, and informational support including information about ASD as a diagnosis, such as behavioural symptoms and treatments (Tichon & Yellowlees, 2003). As such, it is exceedingly necessary to

reach siblings who may be isolated from supports. Furthermore, the standardized assessment of overall adjustment in siblings with typical development is important in determining the consequences of lacking supports, and how to outsource supports to such individuals if outcomes are poor.

To adopt a family centered perspective of healthcare, clinicians and other health professionals should also offer family-based services (e.g., family therapy) to include all members, especially siblings. Clinicians and other health care providers who work with families of individuals with ASD should be cognizant of potential difficulties and negative emotions that are felt by siblings of typical development. As the focal point tends to be fixated on the child with ASD, asking siblings how “they are doing” has become a rarity. In the same vein, siblings with typical development may also be overlooked by parents. For example, many participants described a sense of relief and catharsis when confiding to peers who also had a sibling with ASD. On the contrary, they felt unable to speak about similar issues with their families, especially if they perceived caregiver burden experienced by parents (due to new or increasing demands).

Although participants understood that a lack of attention was not intentional, they described having to become more self-reliant at an earlier age to ease parental burden (e.g., increased financial responsibilities, waiting for services). This finding replicated past studies that found that older siblings with a brother or sister with a developmental disability reported feeling a greater sense of responsibility to manage their own problems alone, rather than relying on parents (Orfus, 2008). Interestingly, as participants of the present study reflected on their childhoods, they commented on a lack of parental attention, but also demonstrated an awareness and profound understanding of why they received limited attention. Specifically, siblings with

typical development made sense of their environment by understanding their situation from their parents' perspective. Chan and Goh (2014) echoed these findings and explained that siblings with typical development are active agents rather than victims of issues such as receiving less parental attention and can employ strategies to adjust effectively.

However, other studies have shown that differential parental treatment of siblings can still be associated with social and emotional adjustment problems (Feinberg & Hetherington, 2001). Siblings who undertake parentified roles (please refer to Chapter Two for further detail) may struggle with individuation within the family unit, and consequently, develop resentment towards other family members (Nealy, O'Hare, Powers & Swick, 2012). Parentified roles undertaken by the siblings were evidenced in some narratives of female participants of the current study, as they questioned the difference between their roles as a sister, and a possible "mother-like" role in the future. A similar study by Cridland and colleagues (2016) specifically examined the experiences of sisters of individuals with ASD and found that parents were unaware of their daughters' desire for parental support, additional family time, or their perceptions of unfair diffusion of responsibilities. These findings stress the need for open communication between children of all ages and their parents. To that end, professionals, such as therapists and/or counsellors should act as facilitators in familial discussions. The sharing of experiences can address any existing negative or ambiguous feelings such as resentment, guilt or neglect. As a result, mutual support between all members of the family is fostered and further efforts can be put forth to counter challenges, such as discussions about future caregiving.

Consideration should also be given to the provision of supports in multiple modalities such as practical workshops (e.g., essentials of financial planning for providing future care, managing challenging behaviours associated with ASD) or community-based services (e.g.,

respite, peer support groups). Moreover, interventions can be provided in varied formats from brief one-on-one consultations to weekly or monthly peer interventions (e.g., support groups) to offer flexibility for siblings.

Finally, the most imperative clinical implication that arose from findings of the current study was that interventions and clinical programs should be cognizant of the variability of challenges faced by siblings over the lifespan (as demonstrated in both chapter two and three of this document). As evident in participant accounts, various types of demands were experienced across time as siblings moved from childhood to adulthood. Challenges and uplifts experienced by siblings in different life stages can inform the development of psychosocial services and the development of community-based programs (e.g., sibshops). For example, supports tailored for childhood or adolescence life stages can include activities mutually shared by both siblings. An example of activities within the community includes local Cineplex movie theatres, which present sensory friendly screenings for young individuals with ASD and their families (Autism Speaks Canada, 2015). Shared interests, such as films, warrant bonding experiences between siblings indifferent to levels of development. Thus, a lifespan approach provides a framework for the training of mental health and services as they have to consider developmental stages in their approaches or intervention plans (Walsh, 2003).

4.6 Knowledge Translation

Knowledge Translation (KT) has been regarded as the mechanism of transferring empirical evidence in to practice (Fredericks, Martorella & Catallo, 2015). The process includes the synthesis, dissemination, exchange and application of knowledge to develop beneficial outcomes, such as strong healthcare services (Fredericks et al., 2015). As will be discussed in the following sections of this chapter, research plays a crucial role in informing services. Without the

study of outcomes, the effectiveness and utility of supports in actual practice remains unknown (Tudor & Lerner, 2015). Therefore, KT can also be characterized as a cyclic process (Bjork et al., 2013) in which the creation and application of knowledge is constantly needed to further advance supports within the service system.

With this in consideration, the knowledge gained about ASD through research will be shared in an integrated manner. Various domains such as clinical psychology, education, paediatrics, and social work should be unified in a collaborative effort to provide insight into where particular supports or services may be most beneficial for siblings (e.g., within schools, private clinics, community centres; Tudor & Lerner, 2015). Thus, the results of the current study will be shared amongst the research team, which includes professionals from fields including: Psychology, Disability, Nursing, and Social Work. As a multidisciplinary team, discussions will circulate around ways in which changes can be enacted into practice within these fields. The knowledge gained from this study will also be used as a tool for the development of new supports by providing summaries of findings to ASD stakeholders and siblings who participated in the study in multiple formats such as newsletters and final reports. This dissemination of results can emphasize existing needs that are evident within service availability and accessibility.

Lastly, dissemination of findings will be completed by presenting results at related conferences that are attended by individuals in academia and professional arenas. In addition, findings will be submitted for publication in high impact academic journals (e.g., *Journal of Autism and Developmental Disorders*, *Journal of Intellectual & Developmental Disability*) to further inform researchers and health professionals about areas of improvement for siblings of individuals with ASD, particularly to emphasize areas of concern that have been overlooked, such as future caregiving and supports across the lifespan for siblings.

4.7 Conclusion

As an extension of the larger project investigating families of individuals with developmental disabilities such as ASD, this manuscript-based thesis extends, replicates, and strengthens the arena of family research. Both papers, including the FAAR as a framework, provide a greater understanding of how individuals make sense of their experiences as a sibling of an individual with ASD. Specifically, an explanation is provided to illustrate how siblings use their capabilities (e.g., informal and formal supports, sibling advocacy) to cope with demands, including stressors and daily hassles (e.g., lack of respite, challenging behaviours such as tantrums, uncertainty and fear about the future) and the meanings that they ultimately attribute to those experiences (e.g., assuming caregiving responsibilities when parents are no longer able to do so).

Together, ~~both studies~~both research questions emphasize the need to fully integrate siblings into the philosophy of family-centred care to formulate services and supports for families of individuals with ASD (Conway & Meyer, 2008; Conway & Vadasy, 1997). Additionally, this comprehensive investigation highlighted the importance of considering the challenges and supports within a lifespan approach, as variations of each exist at different developmental stages. To conclude, brothers and sisters share an important and unique relationship within the family unit (Volling & Blandon, 2006). Thus, it is highly beneficial for family researchers to learn more about these relationships, especially when a disability is present.

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Appendix A: Laurentian University Research Ethics Board Approval



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS
 Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New <input checked="" type="checkbox"/> / Modifications to project / Time extension	
Name of Principal Investigator and school/department	Marilia Carvalho, supervisor, Shelley Watson Psychology
Title of Project	Living with a Sibling with Autism Spectrum Disorder: A Mixed-Methods Analysis of Sibling Experiences
REB file number	2015-03-12
Date of original approval of project	April 23 2015
Date of approval of project modifications or extension (if applicable)	
Final/Interim report due on: (You may request an extension)	May 2016
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.



Rosanna Langer, PHD, Chair, *Laurentian University Research Ethics Board*
Appendix B: Study Flyer

“Living with a Sibling with Autism Spectrum Disorder”

Are you the sibling of a child with ASD?
Are you a parent of a child with ASD who has a brother or sister without ASD?
Would you like to tell your story or have them tell theirs?

If so, please contact Marilia Carvalho, B.A. at mcarvalho1@laurentian.ca; (647) 881-8049 or
Shelley Watson, Ph.D. at 705-675-1151 X4223 (or toll free 1-800-461-4030);
swatson@laurentian.ca for more information

Birth and adoptive siblings are invited to participate.

Marilia Carvalho, B.A.
Department of Psychology
Laurentian University
935 Ramsey Lake Road
Sudbury, ON, Canada
P3E 2C6

Appendix C: Interview Guide for Siblings

1. How old are you?
2. How many siblings do you have?
3. How old are they?
4. How old is (insert name of sibling with ASD)?
5. Did your sibling grow-up in the same home as you?
6. Was your sibling adopted?
7. How did you find out that your sibling has ASD?
8. How would you describe (insert name of sibling with ASD)?
9. What is it like to be (insert name of sibling with ASD)'s sibling?
10. Tell me about a typical day in your household.
11. What is a favourite memory you have with him/her?
12. What are some of your favourite activities to do with (insert name of sibling with ASD)?
13. What is the best part of being a sibling to (insert name of sibling with ASD)?
14. What are some difficult parts of being a sibling to (insert name of sibling with ASD)?
 - a. What helps you handle the difficult parts (insert name of sibling with ASD)?
 - b. How often do you engage in these activities?
15. How do other children/classmates act towards you and your sibling?

- a. How do you react to this?
16. How do you see the future for your sibling?
- a. What do you worry about?
 - b. When you worry, how do you cope?
 - c. Who do you talk to when you are worried?
17. How do you see your future?
- a. What role do you think you will play in your sibling's future?
18. Are there any supports you would like or is there anything that would help you in your relationship with your sibling (insert name of sibling with ASD)
19. Is there anything else you think I should know about your relationship with your sibling?

Appendix D: Sibling Inventory of Behaviour Scale

Describe how _____ (brother or sister) behaves towards you. For each item, please circle the number that shows how often _____ (brother or sister) behaves in the way described.

_____ (Brother or Sister)

	<u>Never</u>	<u>Seldom</u>	<u>Sometimes</u>	<u>Often</u>	<u>Always</u>
1. Is pleased by progress you make	1	2	3	4	5
2. Teases or annoys you	1	2	3	4	5
3. Gets angry with you	1	2	3	4	5
4. Accepts you as a playmate	1	2	3	4	5
5. Is embarrassed to be with you in public	1	2	3	4	5
6. Wants you to succeed	1	2	3	4	5
7. Stays away from you if possible	1	2	3	4	5
8. Gets ideas for things the two of you can do together	1	2	3	4	5
9. Fusses and argues with you	1	2	3	4	5
10. Has fun at home with you	1	2	3	4	5
11. Acts ashamed of you	1	2	3	4	5
12. Shows sympathy when things are hard for you	1	2	3	4	5
13. Frowns or pouts when he/she has to be with you	1	2	3	4	5
14. Teaches you new skills	1	2	3	4	5
15. Helps you adjust to a new situation	1	2	3	4	5
16. Treats you as a good friend	1	2	3	4	5

17. Tries to avoid being seen with you	1	2	3	4	5
18. Is concerned for your welfare and happiness	1	2	3	4	5
19. Makes plans that include you	1	2	3	4	5
20. Hurts your feelings	1	2	3	4	5
21. Tries to comfort you when you are unhappy or upset	1	2	3	4	5
22. Shares secrets with you	1	2	3	4	5
23. Babysits and cares for you	1	2	3	4	5
24. Tattles on you	1	2	3	4	5
25. Is jealous of you	1	2	3	4	5
26. Has physical fights with you (not just for fun)	1	2	3	4	5
27. Is nosey and has to know everything about you	1	2	3	4	5
28. Tries to teach you how to behave	1	2	3	4	5
29. Takes advantage of you	1	2	3	4	5
30. Blames you when something goes wrong	1	2	3	4	5
31. Is very competitive against you	1	2	3	4	5
32. Resents you	1	2	3	4	5

Appendix E: The Sibling Daily Hassles and Uplifts Scale

Me and My Sib: The Daily Experience Scale for Siblings of Children with Disabilities...

Things that Make Me Happy: Experiences about Growing up with a Brother or Sister with a Disability

There are good things that happen in our lives that make us happy. Below are some things that can make you feel happy. For each event, we would like to know:

1. How often does the good thing happen?
2. How happy does this make you feel?

This is how to fill it out:

	How often does this happen?					How happy does this make you feel?				
	Never		Sometimes		Always	Not very happy		A little bit happy		Very happy
My friends get along and play nicely with my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5

In the example, this person feels that their friends sometimes get along and play nicely with their brother/sister with a disability and it makes them very happy.

WHEN WE GO OUT....

	How often does this happen?					How happy does this make you feel?				
	Never	Sometimes			Always	Not bit happy	very Very happy		A little happy	
1. I get to be part of different groups (e.g., Down Syndrome Victoria, Autism Victoria, Early Intervention Centres) because of my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
2. I know and understand a lot about disability	1	2	3	4	5	1	2	3	4	5
3. My brother or sister with a disability is happy	1	2	3	4	5	1	2	3	4	5

IN MY FAMILY....

	How often does this happen?					How happy does this make you feel?				
	Never	Sometimes			Always	Not bit happy	very Very happy		A little happy	
4. I get to spend time alone with my mum and dad while my brother or sister with a disability is being looked after by somebody else	1	2	3	4	5	1	2	3	4	5
5. I get to share experiences and do things with my family (for example., go on a holiday, go on bike rides)	1	2	3	4	5	1	2	3	4	5
6. My mum/dad are in a good mood	1	2	3	4	5	1	2	3	4	5
7. My mum/dad tell me that I am being a big help around the home.	1	2	3	4	5	1	2	3	4	5
8. My mum and dad tell me how happy they are of me (for example., for getting a good grade at school)	1	2	3	4	5	1	2	3	4	5

WITH MY FRIENDS...

	How often does this happen?					How happy does this make you feel?				
	Never	Sometimes			Always	Not bit happy	very Very happy		A little happy	
	1	2	3	4	5	1	2	3	4	5
9. They understand my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
10. They get along and play nicely with my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
11. I can trust they won't make fun of me or tease me because of my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
12. They don't treat me differently because I have a brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
13. I get to spend time alone with them without my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
14. They show an interest in my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
15. They make me feel special because I know how to manage my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
16. I go to their house and I am able to feel 'normal' with another family.	1	2	3	4	5	1	2	3	4	5

AT SCHOOL... *If you do not go to the same school as your brother or sister with a disability please go to the next section – “my brother/sister with a disability...”*

	How often does this happen?					How happy does this make you feel?				
	Never	Sometimes			Always	Not bit happy	very Very happy			A little happy
17. My brother or sister with a disability is good fun and is entertaining (for example, does funny things)	1	2	3	4	5	1	2	3	4	5
18. My brother or sister with a disability gives me time to play alone with my friends	1	2	3	4	5	1	2	3	4	5
19. I am able to be there and look after my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5

MY BROTHER/SISTER WITH A DISABILITY...

	How often does this happen?					How happy does this make you feel?				
	Never	Sometimes			Always	Not bit happy	very Very happy			A little happy
20. Learns something new (e.g., a new word, good math or writing)	1	2	3	4	5	1	2	3	4	5
21. Does cute things.	1	2	3	4	5	1	2	3	4	5
22. Is in a good mood and is smiling.	1	2	3	4	5	1	2	3	4	5
23. Plays with me like other brother and sisters.	1	2	3	4	5	1	2	3	4	5

Things that Bother, Upset or Stress Me out: Experiences about Growing up with a Brother or Sister with a Disability

Everyone has problems or hassles that bother them from time to time. Below are some things that can make you feel upset, bothered or stressed out. For each problem, we would like to know:

1. How often does the problem happen?

2. How bothered, upset or stressed out does the problem make you feel?

This is how to fill it out:

	How often does this happen?					How bothered or upset does this make you feel?				
	Never	Sometimes			Always	Not bothered or upset	A little bit bothered or upset			Very bothered or upset
When we go out people stare or look at us.	1	2	3	4	5	1	2	3	4	5

In the example, this person feels that people are always staring or looking at them and it bothers them a little bit

WHEN WE GO OUT....

	How often does this happen?					How bothered or upset does this make you feel?				
	Never	Sometimes			Always	Not bothered or upset	A little bit bothered or upset			Very bothered or upset
24. My brother or sister with a disability does strange things.	1	2	3	4	5	1	2	3	4	5
25. My brother or sister with a disability runs away.	1	2	3	4	5	1	2	3	4	5
26. My brother or sister with a disability draws attention to us.	1	2	3	4	5	1	2	3	4	5
27. People stare or look at us.	1	2	3	4	5	1	2	3	4	5
28. I don't feel 'normal' because people are staring or looking at us.	1	2	3	4	5	1	2	3	4	5
29. We have to stop what we are doing (for example, leave the supermarket) because of my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
30. My brother or sister with a disability takes things from the shelves (for example, a DVD)	1	2	3	4	5	1	2	3	4	5

IN MY FAMILY....

	How often does this happen?					How bothered or upset does this make you feel?				
	Never	Sometimes			Always	Not bothered upset	A little bit bothered or upset		Very bothered or upset	
31. We can't do things that other families can do (for example, go to the movies as a family) because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
32. I have to do more jobs/chores around the home because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
33. I worry that my mum and dad don't get enough rest because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
34. We miss out on things (for example, getting a pet) because of my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
35. We have to change our plans all the time because of my brother or sister with a disability	1	2	3	4	5	1	2	3	4	5
36. I feel like I don't have time to myself because of my brother or sister with a disability.	1	2	3	4	5	1	2	3	4	5
37. My parents won't let me do things that my brother or sister with a disability can't do	1	2	3	4	5	1	2	3	4	5

WITH MY FRIENDS...

	How often does this happen?					How bothered or upset does this make you feel?				
	Never	Sometimes			Always	Not bothered upset	A little bit bothered or upset		Very bothered or upset	
38. I have to talk about my brother or sister's disability or illness	1	2	3	4	5	1	2	3	4	5

39. My brother or sister with a disability does embarrassing things	1 2 3 4 5	1 2 3 4 5
40. I don't invite them over because of the way my brother or sister with a disability will behave	1 2 3 4 5	1 2 3 4 5
41. I worry that they will tell other people about my brother or sister with a disability and I will get teased.	1 2 3 4 5	1 2 3 4 5
42. I worry that they won't want to come back and play if they come over and see my brother or sister with a disability.	1 2 3 4 5	1 2 3 4 5
43. I get sad when they say mean things about people with disabilities (for example, he runs like someone with Down Syndrome)	1 2 3 4 5	1 2 3 4 5

AT SCHOOL... If you do not go to the same school as your brother or sister with a disability please go to the next section – “my brother/sister with a disability...”

	How often does this happen?					How bothered or upset does this make you feel?				
	Never	Sometimes			Always	Not bothered upset	A little bit bothered or upset		Very bothered or upset	
44. I worry that my brother or sister with a disability is going to run away	1	2	3	4	5	1	2	3	4	5
45. I worry that my brother or sister may get hurt if he/she runs away and no one would know.	1	2	3	4	5	1	2	3	4	5
46. My brother or sister with a disability is clingy and wants to be around me all the time	1	2	3	4	5	1	2	3	4	5
47. My brother or sister with a disability comes and finds me for help (for example, can you show me how to climb up the monkey bars? / how to dig in the sand pit?)	1	2	3	4	5	1	2	3	4	5

48. Teachers ask me how to manage the behaviour of my brother or sister with a disability at school.	1 2 3 4 5	1 2 3 4 5
49. Other students come to get me because they know my brother or sister with a disability is looking for me in the school yard.	1 2 3 4 5	1 2 3 4 5
50. I worry about what new people will think about my brother or sister with a disability.	1 2 3 4 5	1 2 3 4 5

MY
BROTHER/SISTER WITH A DISABILITY...

	How often does this happen?					How bothered or upset does this make you feel?				
	Never	Sometimes	Always			Not bothered upset	A little bit bothered or upset	Very bothered or upset		
51. Hurts, hits, pushes, scratches or kicks me or others	1	2	3	4	5	1	2	3	4	5
52. Touches or takes my things	1	2	3	4	5	1	2	3	4	5
53. Always gets his/her own way in order to stop a tantrum.	1	2	3	4	5	1	2	3	4	5
54. Doesn't know how to talk properly so I don't know what he/she wants or needs	1	2	3	4	5	1	2	3	4	5
55. Does annoying things (for example, bites his/her hands or bangs on the wall) until he/she get what they want.	1	2	3	4	5	1	2	3	4	5
56. Wakes me up early in the morning.	1	2	3	4	5	1	2	3	4	5
57. Makes me feel like I don't have a 'real' brother or sister because they have a disability.	1	2	3	4	5	1	2	3	4	5

<p>58. Makes me miss out on things (for example, being able to play football,) that other brothers and sisters can do because he/she has a disability.</p>	<p>1 2 3 4 5</p>	<p>1 2 3 4 5</p>
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