

The Impact of Autism on Family: Three Themes

by

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Abstract

Autism is a developmental disorder which effects approximately 1 in every 68 children. There are unique stressors apparent in raising a child with autism, specifically those of explosive behaviours, lack of socio-emotional reciprocity, repetitive actions, and restrictive interests. In researching the impact of autism on family, there are three key themes which emerge; impact on parental stress, impact on parental mental health, and impact on the family system as a whole. Parents of children with autism have been found to experience more stress in comparison to both parents of typical children and parents of children with other developmental or medical challenges. These parents also exhibit heightened risk of mental health concerns, including depression and anxiety, which is particularly visible in mothers of children with autism. Along with this impact on parents, the family system as a whole is effected by autism in the family, including the marital and sibling subsystems. This information is pertinent to those in the mental health profession, as more support needs to be given to parents and families of children with autism by way of counselling and psychoeducation in order to better the lives of everyone impacted by this lifelong challenge.

Keywords: autism, parent stress, parent mental health, family system, counselling

Introduction

Parenthood is a life transition which many individuals look forward to. When we create a family, it becomes the most crucial emotional system which we will belong to (McGoldrick, Carter, 2001). The relationships within our families become those which shape and determine the outcome of our lives. Our family relationships are interdependent, with each change compensated by another (McGoldrick, Carter, 2001). As our families grow through the addition of children, this cycle of interdependence becomes ever more visible. We have expectations, hopes, dreams, and goals for our children and for ourselves as parents and spouses to live up to; but what happens when these expectations are quashed? What happens when our expectations must be adapted, as our child cannot meet them for developmental or medical reasons? This is the reality faced by many parents of children with Autism Spectrum Disorder. The impact of the presence of autism is far reaching, as parents search for answers as to why their child is affected by this life changing difference affecting nearly all areas of both social and psychological functioning. Family life is significantly altered, as every moment of the day seems to revolve around the care of an autistic family member. Although autism includes a spectrum of symptoms and behaviours, the typical case is all-encompassing, requiring consideration of the impact which an autistic child has on overall family functioning. More specifically, what impact does the presence of autism have on parental stress, and in turn, the family system?

A major premise of this thesis is that coping with autism places a significant amount of stress on family life, leading to increasingly strained family relationships including that between parents. This premise implies a crucial need to understand the relationship between autism and parental relationships. This is especially timely because more and more parents are faced with

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the reality of this life-changing challenge on a daily basis. Statistics from 2012 suggests that of every 110 school-aged children, one will be diagnosed with autism (Hock, Timm, Ramisch, 2012). A 2014 report released by Autism Speaks suggests that this rate has increased to 1 in 68 children (Autism Speaks, 2014). With autism becoming more prevalent in our society, practitioners must become aware of the stressors affecting parents, which in turn affect their familial and marital relationships.

Nature of Study

There are stressors apparent in raising a child with autism, and this thesis will address them through three separate themes; parental stressors related to autism, the impact this stress has on parental mental health, and the impact of autism on the family system as a whole. Through conducting a literature review for each of these themes their significance will be theoretically and empirically understood. Following each literature review will be a section discussing the clinical implications these themes have for those within the helping profession, including family counsellors. Each section will end with a discussion, highlighting the meaning which these themes have for future research. A final discussion chapter will present the impact these three themes have on the field of autism support and research, suggesting the importance of considering the entire family unit when addressing children with autism.

Purpose

The purpose of examining the stressors inherent in the lives of families of children with autism is to highlight their need for specialized supports, to define those supports, and to emphasize the consequences that accumulate to both families and society when these needs go unaddressed. Raising a child with autism is by far one of the most stressful experiences a parent will endure, as it affects every aspect of their lives and the family system (Meadan, Halle, Ebata,

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2010). Through examining the impact which autism has on parents, and in turn the family system, we can begin to determine which factors must be present in order for these families to remain resilient. The lack of support apparent in the lives of parents of children with autism is a significant contributor to feelings of aloneness, anxiety, and depression (Daire, Munyon, Carlson, Kimemia, Mitcham, 2011). By telling the narrative of these families, society can begin to offer those social and emotional supports which are crucial to parents and families becoming resilient in the face of this challenge and other adversities.

Definitions of Autism

In 2015, we understand autism based on the definition provided by the American Psychiatric Association. In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, Autism Spectrum Disorder encompasses Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and Childhood Disintegrative Disorder (American Psychiatric Association, 2013). Symptoms include deficits in social communication and interactions, and restrictive and repetitive patterns of behaviour and interests (American Psychiatric Association, 2013). Social issues will often manifest as deficits in nonverbal communication, including the recognition of facial expressions, deficits in social-emotional interactions, and issues developing meaningful relationships (American Psychiatric Association, 2013).

The modern definition of autism on which we base our opinions of the disorder is 70 years in the making. The field of autism research is built upon the ground-breaking work of Leo Kanner. In 1943, Kanner began to publish his first observations of 11 children whom he felt were affected by a disorder previously undocumented. His first article, published under the title “Autistic Disturbances of Affective Contact”, reported his findings of these 11 children whose

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unique symptoms were given the terminology “early infantile autism” (Eisenberg, Kanner, 1956). The symptom which Kanner found most interesting and unique in these children was their extreme inability to relate to others in normal fashion. Previously, Kanner had observed older schizophrenic children withdraw from previously existing relationships, but never had he seen children who from the beginning of life were completely withdrawn from social relationships (Eisenberg, Kanner, 1956). In discussing the children’s symptoms with parents, Kanner found that this was the first observation of parents as well; their child, since infancy, did not interact with them in a normal social manner. The infants did not anticipate or adjust their postures when picked up by their parents, and did not display “the plastic molding which the normal child shows when cradled in his parent’s arms (Eisenberg, Kanner, 1956, pp. 556). While parents communicated initially that they were pleased with the amount of independence their infant displayed, they later became concerned with the fact that their child did not seem to notice the comings and goings of the parent (Eisenberg, Kanner, 1956). One could suggest that these were early manifestations of the parental stress which we often see in modern parents of autistic children, as they begin to realize that their child is lagging behind in terms of developmental milestones.

Living with Autism

The social deficits apparent in Kanner’s observations of autistic children may be difficult for parents to accept, as they are faced with a child who seemingly has no interest in interacting with loved ones (Kanner, 1965). Grief, as well as blame may begin to enter the narrative of the parent, as they begin to recognize that their expectations of parenthood are likely to change drastically. These feelings may become heightened, as the restrictive and repetitive behaviours of the autistic child can become overwhelming, and even violent towards the parent (Tehee, Honan,

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Hevey, 2009). Children with autism are often highly restrictive in their interests, which can lead to highly explosive behaviours when these interests are disrupted. Unpredictable behaviours, lack of social reciprocity, societal judgement, inadequate social supports as well as the prospect of life long care lead to significant stressors for parents of children with autism (Tehee, Honan, Hevey, 2009). It is evident, even through this brief definition of autism and associated symptoms, that these parents are placed in highly stressful situations on a daily basis which in turn affect nearly every aspect of their lives. This crucial aspect of lack of parental supports will be touched upon in great deal throughout this thesis.

Along with his observations around lack of social-reciprocity, Kanner noticed that his 11 subjects did not use speech in the appropriate, communicative fashion which would have been expected of a child their age. Of the 11 children, 3 did not possess any form of speech, while 8 were able to engage in repetitive speech which was seemingly useless (Eisenberg, Kanner, 1956). These children could list from rote memory numbers, rhymes, and names, but could not combine these into meaningful phrases. Speech was not used to convey meaning or feeling; it was simply a repetition of words (Eisenberg, Kanner, 1956). This is reminiscent of echolalia, the meaningless repetition of the words of others, which today is often an associated feature of autism (Grossi, Marcone, Cinquegrana, Gallucci, 2013).

A third characteristic which Kanner observed in these children was an obsessive desire for sameness. The children displayed fear if their activities were changed, and interference with patterns of behaviour would often be met with rage and panic (Eisenberg, Kanner, 1956). Kanner observed his subjects driven to rage due to changes in routine, furniture arrangement, and the order in which daily activities were carried out (Kanner, 1944). This description of the need for maintenance of routine likely resonates with many parents of autistic children today, as they

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point to their child's excessive routines and resulting violent behaviours as a significant source of stress and despair in the lives of themselves and family members (Lee, Harrington, Louie, Newschaffer, 2008). Along with this need for sameness, Kanner observed repetitive activities which are often associated with autism today. These include spinning, hand-flapping, and repetitive routines such as the turning on and off of lights (Eisenberg, Kanner, 1956).

A final pattern which Kanner observed in these 11 children was a "fascination for objects which were handled with skill in fine motor movements" (Eisenberg, Kanner, 1956, pp. 557). The children were hypersensitive to changes in these objects, including the ability to recognize the slightest change in position. This hypersensitivity to change is recognized in the current American Psychiatric Association definition of autism, in terms of highly restricted and fixated interests (2013). Parents can be left with little options in the way of satisfying their autistic child's interests, as only a few activities and objects will suffice. There may be fear attached to breaking these bonds with objects, as they often end in explosive tantrums or violent behaviours, which are a significant stressor for parents (Pisula, Kossakowska, 2010).

These four observations made by Kanner over 70 years ago are the basis for the modern definition of Autism Spectrum Disorder. Given the overwhelming nature of not only the characteristics associated with autism, but the behaviours apparent in autistic children, one should not be surprised by the stressors associated with parenting a child with autism. It is observed and documented that parents of children with autism exhibit the highest degree of stress in comparison to those parents both with typical children, and children with other medical and developmental conditions (Hoffman, Sweeny, Hodge, Lopez-Wagner, Looney, 2009). Theory has moved away for Kanner's original assertion of suggesting that parental emotions were the

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cause of autism in their children (Kanner, 1944), and towards the realization that autism is the source of these emotions, and thus high degrees of parental stress (Hoffman et al, 2009).

Parenting Stress

If one has not spent time with an autistic individual, it may be difficult to comprehend the amount of stress apparent in the lives of their parents. Consider this; there is a member of your family who has a limited ability to communicate through speech. In addition to this, they do not understand typical social rules of “give and take”, and have difficulty learning new concepts due to their too rigid or too generalized mindset. They are obsessive with certain objects and types of stimulation, and become emotionally explosive when interrupted or asked to relate to others.

Would this situation be stressful? Would it impact not only you, but the entire family system?

Would it not impact all the relationships and functioning of the family system? This hypothetical situation offers a snapshot of the lived experience of parents of children with autism. There are pervasive, persistent, and unavoidable stressors inherent in parenting a child with autism.

Given that autism is pervasive and very resistant to change (Lovaas, Smith, 1989), as well as the significant challenging behaviours associated with the condition, it is of importance to consider the stress placed upon parents. A diagnosis of autism not only means a loss of parental dreams for the child, but also a loss of many significant relationships in the lives of the parent, leading to a great deal of grief and isolation (Daire et al, 2011). The financial impact of having a child with autism is substantial, with many specialized resources needed for treatment including medical specialists, respite care, nutritionists, speech pathologists, and behaviour therapy (Daire et al, 2011). These additional financial stressors add to the emotional stress which the parent is already feeling around the autism diagnosis, leading to significant concerns for parental mental health.

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Parents of children with autism are at high risk to develop social, physical, and emotional problems (Cappe, Wolff, Bobet, Adrien, 2011). In comparison to parents of typically developing children and children with other special needs, parents of autistic children display the highest amount of stress in association with parenting (Yamada, Suzuki, Suzuki, Tanaka, Shindo, Akechi, Furukawa, 2007). This is often a result of the great deal of stress surrounding the life of their autistic child, including disturbed sleep patterns, self-injurious behaviours, and lack of social and emotional reciprocity (Cappe et al, 2011). Mothers often face more challenges to their mental health than fathers, as they are more involved in the care of their child in the majority of families (Yamada et al, 2007). The most common mental health symptoms displayed in parents of children with autism are depression and anxiety, with these symptoms heightened as the problematic behaviours of the child increase (Yamada et al, 2007). The sources of stress in these parents are vast, with the most significant including the permanency of the child's condition, judgement of the child's behaviour by family members and society, and insufficient personal and professional support (Dabrowska, Pisula, 2010). The stigma attached to autism is vast, forcing parents to constantly advocate for their child, resulting in a great deal of stress and constant elevated emotion. Social supports become few and far between, as parents may isolate themselves and become jaded by the lack of support with which they are faced. This pattern is crucial for professionals to recognize, as effective social supports have been identified as a key ingredient in well-adjusted parents of children with special needs (Daire et al, 2011).

The Psychology Coping with Stress

Many of the stressors associated with raising a child with autism are unavoidable, as they are a product of the symptomology. What is possibility avoidable is the degree to which these stressors impact the daily lives of parents. Identifying both effective and ineffective coping

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responses is crucial to offering parents of children with autism the tools which they so desperately need in order to improve their quality of life, and the quality of the relationship they share with their affected child. Problem-solving, or problem-focused coping strategies are predictive of less psychological distress in parents, along with closer parent-child relationships (Pottie, Ingram, 2008). Parents who engage in problem-focused coping take action, and look for solutions in order to help their child, as well as themselves. This includes researching treatment options, seeking help, and engaging in social supports such as autism support groups (Pottie, Ingram, 2008). Emotion-focused coping is predictive of higher stress in parents of children with autism, as this strategy can often result in withdrawal, blaming, and escape-avoidance strategies. It is these parents who require the most support from family, friends, and professionals, as they are at most risk of developing mental illness due to associated stressors (Pottie, Ingram, 2008).

Impact of Autism on Family Life

Parents of children with autism may become so engulfed in the stressors associated with raising their child that other members of the family become significantly affected. From a family systems framework, autism is thought to affect not only parents, but the entire family unit including the marital subsystem, the parental subsystem, the sibling subsystem, and the extended family subsystem (Meadan et al, 2010). Understanding the interactions of the family as a whole, as well as through these subsystems, creates a holistic picture of what the life of the autistic child and their family truly looks like. From this family systems framework, it is not just the child with autism's impact on the family that is considered; the impact of the family on the autistic child is reflected upon as well. This aids in eliminating the blame which may become attached to the child for bringing stress upon the household, while bringing to light those instances where the

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child has a positive impact on the subsystems within the household. This is crucial to consider should resilience become a contributing factor to the reduction of familial stress.

Within the marital subsystem of the family, autism has a “detectable overall negative impact on marital adjustment” (Meadan et al, 2010, pp. 21). These parents report the lowest level of family harmony in comparison to parents of children with other special needs, which understandably is associated with the significant amount of stress placed upon parents (Meadan et al, 2010). Parents portray parenting a child with autism as an experience which stresses their relationship, with parents often using dichotomous language to explain their marriage (Hock et al, 2012). Language used to describe the marital relationship included “make it or break it”, and “sink or swim (Hock et al, 2012, pp. 409), suggesting that parents feel they can either work together to parent their child, or separate as a result. The most stressful time observed in the marital subsystem is directly following a diagnosis of autism (Hock et al, 2012). Emotional tension between partners is high, as they look to understand both the diagnosis, as well as the impact it will have on their lives. At this time, it is crucial for parents to communicate and support one another, as this relationship can essentially form the basis for the social supports which have been identified as so crucial to the reduction in parental stress (Daire et al, 2011). The marital subsystem is a key factor in resiliency, as it can be a constant support system for the parents in a time which is filled with uncertainty and significant life transition.

Much like the marital subsystem, the parental subsystem is one which may potentially suffer when a child with autism is introduced into the family system. As has already been described, there is a significant amount of stress placed upon parents of children with autism, more so than on typical parents. The three most stressful factors impacting parents of children with autism as identified by researchers are; the permanency of the condition, the lack of

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acceptance of the behaviours associated with autism by family members and society, and the low levels of support provided to parents (Meadan et al, 2010). Financial stressors are an additional pressure placed upon parents, as raising a child with autism is three times more costly than raising a typically developing child (Daire et al, 2011). This is compounded by the fact that many parents, particularly mothers, are faced with a reduction in their ability to work, as the care of their child becomes the primary concern. It is crucial to recognize that parents of children with autism are a unique population, with a unique set of stressors which impact their lives on a daily basis. Autism is characterized by disruptive behaviours, such as repetitive motions, tantrums, and self-injury, in addition to restricted interests and social-emotional communication skills. What this translates to for parents is often a significant amount of isolation, as they fear their child may act out in public, and a significant amount of grief, as they adjust their expectations of the child's life. Professionals, such as counsellors, are in a position to offer these parents skills, as well as validation for the very real struggles which they are facing. Of utmost importance is to recognize that there are parents who come out of an autism diagnosis with resilience, and there are concrete domains which are present in most well-adjusted parents of children with special needs. These domains include social support, positive coping skills, parental relationship adjustment, and effective parenting (Daire et al, 2011). In order for the parental subsystem to flourish, parents need to be offered a significant number of supports in order to gain the skills to reduce their stressors and emerge resilient.

The sibling subsystem is highly affected by the introduction of an autistic child, as not only does the sibling need adjust to an autistic brother or sister, they need to adjust to a life with less parental support and attention. Though likely not intentional, the siblings of autistic children are often without the same degree of parental support as their brother or sister (Nealy, O'Hare,

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Powers, Swick, 2012). Unequal attention is given to the sibling, as the parent is focused upon the immense needs of the autistic child. With this lack of support, the sibling is often forced to grow up quickly and without the guidance that many children and youth rely on from their parents (Nealy et al, 2012). This neglect of the sibling may cause a great deal of strain within the family unit, both for the sibling and the parent. This lack of joint attention between parent and sibling is another significant source of parental stress, as the parent may be consumed with feelings of guilt around neglecting the needs of their other children. When the family unit is weakened, there is a higher chance of negative outcomes, including lower family coherence and less effective coping strategies (Zablotsky, Bradshaw, Stuart, 2013).

Assumptions, Limits, and Scope:

As an advocate for the rights of autistic children and their families, it is difficult to put aside ones opinions and experiences with this unique and inspiring population. Spending the past decade working with this population, it is nearly impossible for me to ignore the children and families whom have inspired this piece of work. Their struggles are forever in my mind, and rightfully so, as their stories parallel those presented in much of the literature on this topic. The limitation of a literature review means that the stories of these families are not told, but instead empirical research is presented in order to validate the struggles which families of children with autism face on a daily basis. The scope of the following piece remains small, although the implications may be massive for families struggling to gain support and recognition for the stressors apparent in their daily lives. Some assumptions to recognize within the literature include; mothers are the primary caregiver in the household, mothers experience more stressors than fathers of children with autism, and fathers cope through detaching from the family. These

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assumptions bring about bias, and also limitations as to the populations which this work will effect, but these assumptions have been empirically validated through the research.

Implications for Counsellors

The stressors placed upon the parental and family system of autistic children are arguably vast and pervasive in such a way which can overwhelm the resources of most families. These stressors still require a great deal of research to understand. There are internal and external sources of stress, including self-doubt, the misunderstandings of society, and unreachable expectations. A narrative which seems to emerge in these families is one of stress, one of uncertainty, but possibly one of resiliency. While coping with the stressors associated with autism requires a great deal of sacrifice and effort on the part of the family system, there is strength which can be built upon. As counsellors the ability to recognize strengths within a family unit and build upon them is crucial. Before this becomes possible, counsellors must first educate themselves to the stressors inherent in raising a child with autism, as they are very different from those present within a typical household. From a family systems perspective, the counsellor can begin to discuss with families not only how autism is affecting their family, but how they are affecting the autistic child. Here, each member of the family can begin to see their influence, and begin to appreciate the impact which they have in the family unit. Once again, this can aid in reducing blame attached to the diagnosis of autism, while highlighting ways in which the family can work together to reduce the stressors inherent in the household.

As counsellors and mental health professionals become more aware of the impact a child with autism has on the family system, more support can be offered by way of psycho-education, coping strategies, and strength-based counselling and support. The stressors in these households are inherent, and will likely never dissipate, therefore it is the responsibility of the mental health

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profession to ensure that these individuals are aware of and are obtaining the supports which they deserve. Through exposing the stressors experienced by parents of children with autism, the hope is to raise awareness for the need to extend support and empathy to these families, as it has been proven that social support is a significant contributor to resilience (Daire et al, 2011).

Counsellors who educate themselves as to the symptomology and impact a diagnosis of autism has on the family unit can become the missing link; they can become the advocates for both these children and their families, and can work to dissolve the archaic stigmas attached to autism and those affected by it.

Autism has a significant impact on both those whom are affected by it, and those whom live with these individuals on a daily basis. Much of the literature suggests that stress is inherent to raising a child with autism therefore this is an important hypothesis to examine. Due to the seemingly constant presence of stress in the households of autistic children, it is no surprise that parental stress will often translate to stress within the family unit, including siblings, extended family, and the marital unit. It is of utmost importance to review these ideas within the literature, as they bring about the crucial aspects of support which must become available to parents of children with autism in order for resilience to prevail.

Theme I- Parental Stressors Related to Autism

It is a premise of this thesis that parents have a culturally mediated set of expectations when they assume their role as caregivers to their children (McGoldrick, Carter ,Garcia-Preto, 2011). The role of parent is one which is filled with joy, love, compassion and wonder. The news of expecting a child is met with overwhelming congratulations and support, leaving parents with feelings of anticipation and excitement. Parental dreams for their child are shared, as nurseries are decorated, strollers are purchased, and university funds begin to be saved. The day of birth is a joyous occasion, as parents and family finally meet the little one who has been growing for the past nine months. Family and loved ones gather around the newborn, each with their own thoughts and expectations around the future of the child. The mother and father are brimming with joy as they hold the new addition to their family, as the world seems to come to a stop and they are the only ones who exist. The stressors associated with parenting are far from their minds, as they take in every inch of their new family member. All that matters in the world is the present, and the future of the child looks bright. The newborn is safely buckled into their car seat, and driven home slowly and carefully by the new parents. They are warmly welcomed to their new home, with a freshly decorated nursery, new toys, and a cozy blanket to be swaddled in. However, at this point, where autism is in play, an idealized transition into parenthood starts to depart from the standard or expected pathway. Days and months pass, and the love for the child grows as parents watch them mature and learn their place in the world. Books are read and websites are searched as parents check on the developmental milestones that their child should be surpassing. Anxiety heightens as parents question whether their child is developing at an acceptable rate; the child is not interacting with the parent as expected. The child is not smiling

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or offering those social nuances which are associated with a healthy and happy baby. The child is not talking. The child is not interested in playing with others.

This narrative may sound familiar to those parents faced with the challenge of autism in their family, as their lives begin to revolve around the care of the child affected. Daily life can be consumed by “damage control”, as parents are faced with the stress inducing symptomology of autism. The lack of reciprocity apparent in social interactions with the child (Kanner, 1965) may become a source of stress for the parent, as they wonder how the child will function in the world without knowledge of basic social norms. Parents may worry whether their child will have a “meltdown” in public should their environment become too overwhelming. A range of fears and dreadful fantasies almost always follow. Will their child be arrested, should they attack another individual seemingly unprovoked? These are questions which are all too real for many parents of autistic children, and these hypothetical situations associated with their child’s challenges are likely a significant source of daily stress.

Literature Review

The following review will outline early theories of autism, specifically that of Leo Kanner (1944). This is of importance to include as prior to Kanner’s research there was no developmental disorder of “autism” (Kanner, 1965). Through reviewing the work of Kanner and his contemporaries, such as Bettelheim and Bakwin, literature is presented with regards to the roots of current autism research. As a bridge between early and current autism research, Lovaas’ behavioural model of autism is presented in sharp contrast to earlier medical models of autism (1979). Lovaas is of importance to the current field of autism research, as he presented an empirically validated science based treatment model for individuals with autism, entitled “Applied Behaviour Analysis” (Smith, Eikeseth, 2011). This behavioural model of autism moves

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the blame away from the parent as causing autism, and towards a definition of autism distinguished by certain universal behaviours, such as aggression, self-stimulation, and repetitive actions (Lovaas, Smith, 1989). Following the behavioural model of autism is a discussion of current research focusing upon the inherent parental stressors apparent in raising a child with autism. The following literature review will not attempt to determine a “cause” of autism, but instead review definitions and challenges which are inherent in the lives of parents. Literature was obtained through scholarly peer reviewed journal searches, using keywords “autism” “early definitions of autism” “autism treatment” and “parental stressors associated with autism”.

The Roots of Current Autism Symptomology- Leo Kanner

In order to present those behaviours associated with autism which lead to parental stress, it is important to consider the roots of current autism research. Prior to 1943, there was no “autism”; these children were simply institutionalized with no hope of treatment or rehabilitation into the community. Through an examination of early literature Bettelheim found that children, who would be labeled as autistic after 1943 and the acceptance of Leo Kanner’s work, were thought to be “feral” wild children, raised by animals rather than humans (Bettelheim, 1959). This label of “feral” was given due to the animalistic behaviours that autistic children exhibit including a lack of speech, the shunning of human company, and ferocious attacks (Bettelheim, 1959). As observed by Bettelheim, the more we consider the behaviours of so-called feral children, the more they resemble those which we would consider today as autistic (1959). Another aspect contributing to the thought that these children were indeed raised by animals was the state in which they were sometimes found; alone with seemingly no adult supervision. According to Bettelheim, this is due to parents becoming “disengaged” with their child, leaving

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them to fend for themselves in the wilderness, or by not pursuing them when they wandered away from the family home (1959).

The ground breaking research of Leo Kanner changed the fate of these children and their parents, as the symptomology previously associated with “feral “ children became accepted in mainstream psychology as “early infantile autism” (Kanner, 1944). Through his longitudinal observations of 11 institutionalized children, Kanner solidified those symptoms which today we freely associate with autism; the disability to relate to others in ordinary ways, oddities in speech, an anxiously obsessive desire for sameness, and an obsessive fascination with objects (1944). Though these four observations of Kanner’s have been broadened, they are still at the route of our current definition of autism. We still consider the most striking and unique symptom of autism to be that of the inability to relate to others, something which evokes a great deal of stress and despair in parents (Silva, Schalock, 2012). Through discussing the symptomology of their children with mothers, Kanner found, “almost every mother recalled her astonishment at the child’s failure to assume at any time the usual anticipatory posture preparatory to being picked up” (1944, pp. 211). This behaviour is thought to occur in children universally at four months of age, but nearly all of Kanner’s original sample of 11 mothers stated that this did not occur with their child (Kanner, 1944). Given the lack of knowledge to the cause of this behaviour, it was attributed to the mother and her lack of warmth in interacting with the child (Kanner, 1965). In fact, a significant amount of observations were made in regards to the characteristics of parents of children with autism. A great deal of their observed behaviours were similar to those displayed by the child, suggesting a common biological or genetic source (Kanner, 1965). In his observations of 55 parents of autistic children, Kanner found that parents mechanized human relationships, were undemonstrative as partners, and displayed perfectionist tendencies (Kanner,

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1944). The mechanization of human relationships was defined by those parents who were not comfortable in the company of others; they preferred reading, writing, music, or thinking (Kanner, 1944). The married lives of these parents was seen as cold and formal, with little romance and glamour (Kanner, 1944). Kanner discovered that though marriages were devoid of romance and emotion, there were little disputes, with only one out of 55 couples separating (Kanner, 1944). Kanner also discovered that nearly all parents of autistic children whom he interviewed were sophisticated and successful. All but 5 mothers had attended university, and all but one of the mothers had a successful career outside of the home (Kanner, 1944).

Given the significant number of observations Kanner made with regards to the parents of children with autism, many of his contemporaries felt that he was suggesting a parental role in causing autism. Bakwin suggested that in Kanner's view, the personalities, attitudes, and behaviours of parents caused autism (1954). Parents were cold, obsessive, and mechanical in their attitude towards the child, therefore reinforcing the etiology of autism. Bakwin began to speak out against Kanner's suggestion of parental etiology, pointing to normally developed siblings, as well as autism in children of warm and affectionate parents (1954). While Kanner observed little improvement in those institutionalized children whom he studied, Bakwin suggested that the best course of treatment for these individuals would be to surround them with warm and affectionate adults, though he offered little evidence to support this hypothesis (1954). Autism was seen as a disease which caused the behaviours in the child, therefore little was found with regards to appropriate treatments.

The Behavioural Model of Autism- Lovaas and Applied Behaviour Analysis

The disease model of autism prevailed until the 1960's, when Ferster began to challenge this notion that the child's behaviours were caused by the disease of autism. Ferster suggested

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that the behaviour of the autistic child is simply the result of inadequate reinforcing stimuli in the environment (Lovaas, 1979). While typical children are reinforced by the smiles and verbal approval of their parents, this is simply not the case for those with autism (Lovaas, 1979). They require different reinforcements for their behaviours which do not involve social reciprocity, as this is an area of difficulty for them (Lovaas, 1979). Other researchers, such as Lovaas, began to demonstrate that mute autistic children could be taught to imitate sounds and words, given the appropriate reinforcement (Lovaas, 1979). In 1987, Lovaas suggested, “at present, the most promising treatment for autistic persons is behaviour modification as derived from modern learning theory” (pp. 3). In a 15 year longitudinal study, Lovaas demonstrated that with intensive behavioural treatment, complex behaviours such as language can be built up, which in turn help to suppress undesirable behaviours such as aggression (1987). Through treating autistic children during most of their waking hours over this 15 year period, with treatment including all significant individuals in the life of the child, Lovaas found significant improvements in both intellectual functioning and behaviour (1987). Children were given 40 hours a week of intensive behavioural treatment, with programs targeting each undesirable behaviour, practiced by all significant individuals in the child’s life including parents (Lovaas, 1987). These programs consisted of the use of discrimination learning, with aggressive and self-stimulatory behaviours reduced significantly by being ignored (Lovaas, 1987). These behaviours were also reduced by shaping an alternative, more socially acceptable form of behaviour. If this did not affect the behaviour, a last resort was a loud “no” or a slap on the thigh of the child (Lovaas, 1987). Parents were trained extensively so as treatment could be consistent across all individuals. At the end of the 15 year period, Lovaas found that of those who received this treatment, 47% achieved normal intellectual and educational functioning in contrast to only 2% of the control group subjects

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(Lovaas, 1987). This pioneering treatment today is referred to as Lovaas Applied Behavioural Analysis, and is an empirically validated treatment for the behaviours associated with autism (Smith, Eikeseth, 2011).

Current Autism Research- The Inclusion of Parental Stressors

Current research continues to reflect the core symptoms of autism observed by Kanner in 1943, but there is a new focus on the impact these symptoms have on parental lives. Keller, Ramisch, and Carolan suggest that no parent is prepared for the life-changing diagnosis of autism (2014). Autism is a lifelong developmental disorder, involving a triangle of impairments in communication, social reciprocity, and increases in repetitive behaviours and interests (Hartley, Barker, Seltzer, Floyd, et al, 2010). As suggested by Tzoy, Connolly and Novak, “Unlike other illnesses or events, autism is not short lived but rather it is a lifetime of multidimensional issues and demands placed upon the family” (2007, pp. 254). Autism affects those from all ethnic groups and socioeconomic backgrounds. It is considered the third most common developmental disability, behind intellectual disability and cerebral palsy (Dardas, Ahmad, 2014).

Parenting stress can be defined as a situation “when the family is unable to restore functioning following the introduction of a stressor related to parenting” (Hayes, Watson, 2013, pp. 630). The most significant sources of parenting stress for parents of children with autism include the permanency of the condition, disapproval of the child’s behaviour by society and other family members, and insufficient professional support (Dabrowska, Pisula, 2010). In addition to these stressors, parents are also faced with fears for their child’s future, difficulties in communicating with their child, reduced chances of their child becoming independent, and significantly more behavioural problems than typical children (Pisula, Kossakowska, 2010).

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Research has also suggested that as the behavioural problems of autistic children escalate, so do the stress levels of parents (Hoffman et al, 2009). The traditional parenting stress index, which includes a child domain and a parent domain, has been applied to parents of children with autism by Hoffman et al (2009). The index includes 101 items which parents respond to using a Likert-type scale. The child domain of the index includes questions related to child distractibility, hyperactivity, mood, and the ability to reinforce the parent (Hoffman et al, 2009). A high score on the child domain indicates a parent whose stress originates from the child's characteristics or behaviour problems, which in a study of 104 mothers of autistic children was common (Hoffman et al, 2009). The parent domain of the parenting stress index includes competence, attachment, isolation, health, depression, role restriction, and spouse related stress (Hoffman et al, 2009). A high score on the parental domain indicates that parental stress originates from a form of parental functioning including parent and family context factors which affect the ability of the parent to be a competent caregiver (Hoffman et al, 2009). Once again, Hoffman et al found that mothers of children with autism reported higher levels of stress in the parental domain (2009). While this information is valuable in terms of suggesting that stress is present in the households of many families touched by autism, it may not consider the unique situation which many of these parents are in. Given the inherently stressful nature of parenting a child with autism, a parenting stress index intended solely for parents of children with autism has been created.

The Autism Parenting Stress Index is designed to identify areas where parents of children with autism need support, while assessing the effect interventions have on parenting stress (Silva, Schalock, 2012). This stress index was created with the consideration of co-morbid symptoms which are often seen in children with autism including sleep disruption, gastrointestinal disorders, abnormal sensory responses, and self-injurious behaviours (Silva,

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Schalock, 2012). The uniqueness of the Autism Parenting Stress Index allows clinicians to review how parents are coping with the multiple demands associated with parenting a child with autism. The items included on the stress index are divided into three categories; the core social disability, physical issues, and difficult to manage behaviours (Silva, Schalock, 2012). These categories were established through 100 parent interviews, in which parents were asked to identify the three most stressful items they attached to parenting their child with autism (Silva, Schalock, 2012). Through collected data from 107 parents of children with autism, Silva and Schalock found that for these parents, the most significant sources of stress include; social development, communication, tantrums/meltdowns, transitions, diet, acceptance from others, and future independence (2012). The highest amount of stress was identified by parents in relation to their child's ability to communicate (77.6%) and the acceptance of their child by others (72.2%) (Silva, Schalock, 2012, pp. 569). When comparing the stress levels of parents of children with autism to those of typically developing children using the Autism Parenting Stress Index, it is apparent that parenting stress in the autism group is four times higher than that of the typical group (Silva, Schalock, 2012). In comparison to parents of children with other developmental disabilities, parents of children with autism score two times higher on the Autism Parenting Stress Index (Silva, Schalock , 2012).

Clinical Implications- Supporting Optimal Parent Functioning

It is clear within the literature that raising a child with autism is one of the most stressful experiences a parent can be exposed to. The stressors inherent in the lives of parents of children with autism, including their child's disturbed sleep patterns, agitation, self-injury, and difficulties in feeding and toilet training (Cappe et al, 2011), point to the need for more understanding on the part of clinicians in order to offer appropriate supports. Through analyzing current research, it is

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apparent that a direct correlation exists between child behaviour and parental stress levels (Osborne, Reed, 2009). There are also those stressors unique to parents of children with autism, including impaired communication and inappropriate social interactions (Harper, Dyches, Harper, Roper, South, 2013). Clinicians must consider the supports which these parents need in order to reduce the amount of stress they experience in their daily lives, which may include support through the diagnostic process, forms of behaviour therapy such as Applied Behaviour Analysis, and other supports such as respite care.

Obtaining a diagnosis of autism may be difficult both logistically and emotionally for a parent. When working with these parents, it is important for clinicians to understand the hurdles which must be cleared in order to obtain a diagnosis of autism (Stuart, McGrew, 2009). Parents have identified their interactions with providers during the diagnostic process to be stressful, as the need for comfort and empathy is ignored (Stuart, McGrew, 2009). As these interactions are often the first which parents may have with clinicians, a negative experience can profoundly affect their feelings towards the diagnosis of autism, as well as the amount of caregiver burden which they in turn take on (Stuart, McGrew, 2009). For those parents who experience the diagnostic process as long and winding, they can quickly develop a mistrust for helping professionals such as counsellors, making it all the more crucial that clinicians understand what a autism diagnosis means for parents (Soloman, Chung, 2012). For instance, a family therapist who understands autism and its impact on parents can aid in the creation of treatment plans which work to minimize the negative impact which the child has on the parent (Soloman, Chung, 2012). Though a family therapist cannot deliver behaviour interventions such as ABA, they are in a position to support parents through the process of the diagnosis and treatment of their child.

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A therapist who is aware of effective and empirically validated treatment options can guide parents in a direction which may change their lives and their relationship with their child.

The behaviour treatment of Applied Behaviour Analysis (ABA) is empirically validated and has been shown to significantly improve the lives of children with autism (McPhilemy, Dillenburger, 2013). Through the introduction of Lovaas' work in the 1970's and 1980's, it became apparent that with effective behaviour interventions, children with autism do not need to be confined to hospitals, and can in fact live successfully within communities (Smith, Eikeseth, 2011). When behaviour intervention occurs in the early stages of life, there is considerable improvement in the symptomology and overall functionality of the child with autism (Lovaas, 1987). According to Lovaas, when behaviour intervention is applied to children on the autism spectrum, complex behaviours including language can be built (Lovaas, 1987). In addition to these behaviours, undesirable behaviours such as aggression and self-stimulation can be reduced. While there is evidence that ABA therapy is effective in improving the lives of autistic children and their families, the therapy must be intensive and consistent, with the therapy extending through most waking hours for many years (Lovaas, 1987). In addition to highly trained therapists in the home, each significant person in the autistic child's life must be involved in the treatment in order for maximum efficacy- this includes parents (Lovaas, 1987). Given that ABA therapy has been proven to not only increase language, but teach socially appropriate behaviours (Lovaas, 1993), many parents are eager to discover how to introduce the treatment to their child (McPhilemy, Dillenburger, 2013). Unfortunately, ABA therapy is costly and not covered by many government medical plans leaving parents to pay out-of-pocket (Dabrowska, Pisula, 2010). In addition to the added financial burden of behaviour therapy, some parents only hear of evidence based treatments, such as ABA, through their own research methods (McPhilemy, Dillenburger, 2013).

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This highlights the importance of clinicians not only offering parents support through the diagnostic process, but also in the treatment process through recommendation of effective interventions. Parents with autistic children involved in ABA treatment report improvements in their child's communication, behaviour, and independence, which in turn affect the entire family system in a positive manner (McPhilemy, Dillenburger, 2013). Through these changes in the autistic child, parental stressors are significantly reduced, and their view of autism is "completely changed" and no longer viewed as "an insurmountable thing" (McPhilemy, Dillenburger, 2013, pp. 156).

While ABA therapy is highly effective in reducing parental stressors (McPhilemy, Dillenburger, 2013), it is also essential for parents to have a break from the everyday chaos of the home. This can be accomplished through the use of respite care services (Doig, McLennan, Urichuk, 2008). Respite care gives the entire family a chance to rest, relax, and recuperate, while allowing parents to shift their attention to other needs such as spending time with spouses and other children (Harper et al, 2013). With regards to the parental relationship, just one hour a week of respite care has been shown to increase marital quality by six to seven points (Harper et al, 2013). These services can act as an emergency relief for parents, which can help to improve family functioning by reducing the immediate stressors in the household. Mothers who receive at least six hours of respite care per week report significantly less stress, which in turn assists in the development of a positive relationship with the child (Lessenberry, Rehfeldt, 2004). When the day to day levels of stress are reduced in the home, parents can begin to build back their parenting confidence (Twyoy et al, 2007).

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Discussion

Clinicians and researchers have moved far from the notion of the “feral child” as described by Bettelheim in 1959. The introduction of Kanner’s “early infantile autism” (1944) began an evolution into our understanding of the autism spectrum, leading to the groundbreaking treatment recommendations of Lovaas (1979), and the recognition of inherent parental stressors associated with autism. While parenting is inherently stressful, the addition of autism means the addition of unique stressors which require special attention. Stress within the family system is compounded by the addition of communication difficulties, explosive behaviours, developmental delay, and repetitive stimulatory behaviours (Gau, Chou, Chiang, Lee, Wong, Chou, Wu, 2012). As the number of children affected by autism rise, so do the number of parents impacted by stressors associated with the challenge. It is crucial for clinicians to recognize that autism is not going away, and there is a significant need for parental and familial supports, as well as concrete supports for those with autism.

Through supporting the parents of children with autism, the entire family system is impacted. When parental stress is reduced, as evident with the use of respite care (Lessenberry, Rehfeldt, 2004), there is more space within the family system to care for others, and attend to others in need. While the break offered by respite care is crucial, so too is the introduction of appropriate treatment for the autistic child. Lovaas gave the world the empirically validated treatment of ABA, yet many governments are still not recognizing it as a crucial addition to medicare systems (Dabrowska, Pisula, 2010). A shift needs to occur in government policy in order to reduce the financial burden, and in turn the stressors faced by parents looking to offer their child effective treatments, and a bright future.

Theme II- The Impact of Autism on Parental Mental Health

The stressors introduced into the lives of parents when a child has autism are immense and significantly impact emotional well-being (Sharma, Winter, McCarthy, 2013). Not only are parents dealing with the daily stressors of parenthood in general, but they are exposed to specific stressors related to parenting a child with autism. Explosive behaviours, consuming routines, and lack of social supports can all negatively impact parental emotional health (Smith, Grzywacz, 2014). The emotional health of parents of children with autism is also affected by the ambiguous loss which occurs with an autism diagnosis (Nealy et al, 2012). Parents may feel that they must abandon their previous expectations for the future of their child, and develop new ones which take into account their challenges. It is crucial for parents to recognize the ambiguous loss attached to an autism diagnosis, and give themselves permission to feel those uncomfortable emotions attached to their child (Nealy, et al, 2012). It may not be an easy task for parents to accept the negative feelings which they may have towards their child, which can in turn create a great deal more guilt and sadness in their lives. Again, the ambiguity as to the cause of autism is frustrating for parents, leaving them little answers as to why their family has been touched by the disorder. This lack of clarity may lead the parents to ultimately point the finger at themselves, as there seems to be no other logical explanation. The overwhelming sadness and grief which parents experience at the time of diagnosis is great, and is compounded by the amount of uncertainty they and their family face for the future. Feelings of self-blame may become heightened, as parents recognize that they cannot fix their child, leading to more guilt and self-deprecation (Nealy et al, 2012). These feelings of guilt and sadness are especially apparent in the lives of mothers of children with autism.

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Literature Review

The following literature review will discuss empirically validated factors which contribute to emotional distress in parents of children with autism. Included are the grieving process experienced by parents once a diagnosis of autism is obtained (Nealy et al, 2012), and the social isolation of parents due to lack of informal and formal social supports (Teehee et al, 2009). Also included in the literature review is evidence of mothers experiencing the highest amount of emotional distress within the family system (Zablotsky et al, 2013). This is of importance to include, as mothers of children with autism often classify themselves as “emotionally overwhelmed”, and report higher levels of depression and anxiety than fathers (Mihshstein, Yirmiya, Oppenheim, Koren-Karie, Levi, 2010). Recognition of coping strategies which have been identified as both effective and ineffective are also included. These include emotionally focused and problem focused forms of coping (Pottie, Ingram, 2008). All literature for this review has been obtained through searching scholarly journals using the search terms “autism”, “parental mental health”, “ambiguous loss and autism”, “social supports for parents of children with autism”, and “social isolation of parents of children with autism”.

Grief Experienced by Parents Post-Diagnosis- Ambiguous Loss

Following a diagnosis of autism, parents are often faced with grief, confusion, denial, isolation, guilt, and depression (Nealy et al, 2012). The period after diagnosis has been identified by parents of children with autism as the most stressful life event associated with their child (Nealy et al, 2012). This stress is compounded by a lack of knowledge about autism, and a lack of resources to assist in comprehending the impact this challenge will have on the family system, leading to a reaction of guilt as parents search for answers as to why their child has been affected (Nealy et al, 2012). Immediately following a diagnosis, parents often do not feel a sense

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of resolution, as they may still adhere to those standards which they previously felt their child should live up to (Mihshstein et al, 2010). According to Mihshstein et al, “the process of coming to terms with a diagnosis for one’s child, that is, accepting and feeling resolved with respect to it, is a daunting challenge for most parents “ (2010, pp 89). Acceptance and resolution for a diagnosis can only occur when parental expectations of the child are adjusted to reflect their challenges (Mihshstein et al, 2010). If a parent cannot move to this stage of acceptance and resolution, they risk remaining in the grieving process for an extended period of time.

After a diagnosis of autism, parents are faced with a new reality of parenting. They have lost the child which they expected to have, and are now confronted with a new challenge. This contributes to the ambiguous loss associated with a diagnosis of autism (O’Brien, 2007). The lack of clarity in terms of the cause of autism contributes to this ambiguity, leading parents to internalize blame, which increases the amount of emotional distress which they may already be feeling (O’Brien, 2007). In addition to adjusting their dreams of parenthood, parents of children with autism must also change their expectations of family life, leading to additional feelings of loss (Cappe et al, 2011). Parents give up social lives, vacations, and personal dreams as their attention shifts to the new challenges of raising a child with autism (Cappe et al, 2011). This increases social isolation, a dangerous consequence of the grieving process, as social supports are empirically validated as contributing to positive mental health in parents of children with autism (Stuart, McGrew, 2009). It is crucial for parents of children with autism to recognize that the grieving process after diagnosis is normal and expected, as parents are faced with “an end to the future as it was going to be” (Robb, 2003, pp 9). Parents may find it difficult to think ahead to the future, as they are compounded by the amount of stress and grief associated with the diagnosis (Robb, 2003). Again, this is a dangerous consequence of grieving the loss of the

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expected life of the child, as parents must begin to assess their child's needs early on in order to gain the appropriate supports needed to live a successful life (Daire et al, 2011). In order for parents to move forward and offer their child with autism the best life which they can live, there must be a resolution of this grief (Mihshstein et al, 2010). When grief is resolved, parents can accept new representations of their child, rather than the hoped for representations of a typically developing child (Mihshstein et al, 2010).

Social Isolation of Parents after a Diagnosis of Autism

Increase in social isolation after a diagnosis of autism is a consequence which contributes to a decline in parental mental health (Hartley et al, 2010). Social supports have been identified as critical in reducing psychological distress in these parents, including informal supports such as friends and family members, and formal supports such as health care providers and schools (Ekas, Lickenbrock, Whitman, 2010). Though social supports have been identified as a highly effective coping response to the stressful nature of parenting a child with autism, some parents still respond with strategies of isolation, including constricting their world to the care of their child and losing interest in other areas of their lives (Sharma et al, 2013). Parents raising children with autism and other special needs often report insufficient supports and feelings of helplessness, leading to further social isolation and increased risk of mental health concerns such as depression (Smith, Grzywacz, 2014). The stigmas attached to autism, such as explosive behaviours, as well as the seemingly invisible nature of the disability also contribute to social isolation in parents, as they are confronted with a lack of societal understanding (Daire et al, 2011).

The increase in time and attention which is required to raise a child with autism lends itself to the social isolation which occurs for some parents (Smith, Grzywacz, 2014). Parenting a

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child with autism entails increased visits to medical providers, special equipment for therapy, and even special treats for reinforcing the child with autism (Daire et al, 2011). Days may become consumed with obtaining services for the child, such as appropriate school supports, occupational and speech therapy, respite care, as well as home and community supports (Nealy et al, 2012). Finding adequate care for children with autism is difficult, as babysitters are often not prepared for the magnitude of care which the child requires (Daire et al, 2011). This makes leaving the home difficult for the parent, as they must plan significantly far ahead in order to ensure that all their child's needs are met. Bringing the child into the community adds to social isolation, as lack of public understanding and tolerance of autistic behaviours often leave parents with little choice but to keep their child at home (Hartley et al, 2010). Parents have identified that since the diagnosis of their child, they have fewer social ties, and a decrease in the quality of their social relationships (Nealy et al, 2012). Mothers in particular found it difficult to relate to old friendships, and feared brining their children to social gatherings due to behavioural concerns and worries of judgement or stigmatization (Nealy et al, 2012). Maternal social isolation is of concern, as much literature points to mothers as experiencing more mental health concerns than fathers of children with autism (Shtayermman, 2013). Social isolation is of concern to parental mental health due to empirically validated evidence which identifies social support as contributing to reducing both parental stress and parental mental health concerns (Harper et al, 2013).

Impact of Autism on Maternal Mental Health

Literature has identified mothers as more affected than fathers by the diagnosis of autism, particularly in her manifestation of possible mental health consequences (Jones, Totsika, Hastings, Petalas, 2013). Mothers of children with autism report higher levels of psychological

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distress in comparison to fathers often correlated with the severity of child behaviours (Yamada et al, 2007). Autism possess one of the most complex behaviour profiles of any developmental disability, with those affected engaging in self-injurious behaviours, tantrums, and complex rituals (Lee et al, 2008). In addition to these disruptive behaviours, children with autism also display disturbed sleep patterns, difficulties in feeding, prolonged toilet training, and lack of social or emotional reciprocity (Cappe et al, 2011). Mothers are considered to be more affected by these instances of behaviours due to the sheer amount of time they spend with their child (Jones et al, 2013). Mothers of children with autism spend an average of 9.5 hours a day on the direct care of their child, in comparison to mothers of typically developing children whom spend 5.3 hours a day (Pisula, Kossakowska, 2010).

As the primary caregiver, the mother's stress level is highly correlated to the number of problematic behaviours which their child engages in (Yamada et al, 2007). This is particularly relevant when children engage in self-injurious behaviours, such as head banging and biting (Yamada et al, 2007). Maternal distress has also been found to correlate with their child's lower degree of self-sufficiency, social skills, and poor communication skills (Dabrowska et al, 2010). In addition to their increased levels of stress, mothers of children with autism are found to experience feelings of inadequacy and failure, and have a low sense of parenting competence (Pisula, Kossakowska, 2010). When parenting a child with autism, mothers can also feel a reduced sense of connection with their child, even leading to negative feelings toward the child (Beurkens, Hobson, Hobson, 2013).

Parenting a child with autism is complex, with mothers reporting that increased behaviours on the part of the child are directly related to the closeness they feel with the child (Hoffman et al, 2009). Specifically, the more stressful the mothers found their child's behaviours

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to be, the less closeness they felt to their child. In addition to the impact of behaviours, the cognitive and verbal abilities of children affect mother-child relationships (Hoffman et al, 2009). When the child with autism is more verbal and cognitively advanced, caregivers engage more in mutual play and positive feedback (Beurkens et al, 2013). Interacting with a child with autism can be especially challenging, as social and emotional reciprocity may not be present. This can be devastating for parents, as they desperately attempt to make their child laugh or smile, and are met little reciprocity (Meadan et al, 2010). This difficulty which autistic children have with reciprocal social interaction, both in early and later life, may interfere with the development of secure relationships with parents, leading to increased isolation for both the child and the family (Keller et al, 2014). As mentioned earlier, it is of utmost importance for mothers of children with autism to engage with social supports, the most significant of which may be autism parent support groups (Hoffman et al, 2009). The importance of these social supports will be discussed further under clinical implications.

Impact of Autism of Paternal Mental Health

Though the majority of literature suggests that mothers experience the burden of parental stress far more than fathers, it is crucial to look at the father's perspective in raising a child with autism. Not only does the father's experience impact the child with autism, but also the entire family unit, including the mother. Fathers of children with autism experience significant stressors much like mothers, although their experience of stress may be lessened simply due to their reduced time spent in the home (Pisula, Kossakowska, 2010). While mothers experience more distress due to the behaviours of their child, fathers are more affected by the impact the child has on their career and finances (Dabrowska, Pisula, 2010). Fathers are also affected far more than mothers by the communication problems which their child displays, including lack of speech and

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social reciprocity (Dabrowska, Pisula, 2010). Much like mothers, fathers express a sense of loss that occurs after the diagnosis of autism. This is particularly apparent in fathers with autistic sons, as they must redefine the father-son relationship, possibly abandoning those dreams of bonding with their son through physical activities (Keller et al, 2014). Much like maternal mental health, paternal mental health can be positively affected through social supports, such as support groups (Hoffman et al, 2009).

Coping Strategies Impacting Parental Mental Health

Coping strategies are behavioural or cognitive responses used by an individual in order to reduce their level of distress (Twoy et al, 2007). Coping is a process which encompasses ones appraisal of a stressor, individual factors such as personality, contextual factors such as others stressors, and cognitive or behavioural responses to the stressor (Pottie, Ingram, 2008). Coping strategies have been suggested to effect the lives of parents of children with autism through three methods; coping directly effects psychological well-being, coping acts as a moderator between stress and psychological well-being, and coping responses are influenced by the degree of stressor present (Pottie, Ingram 2008). Of particular importance for parents of children with autism is recognizing the fact that coping strategies will directly affect their psychological well-being (Zablotsky et al, 2013). The style of coping which a parent decides to use, problem-focused or emotional, will affect their well-being as well as their relationship with their child (Pottie, Ingram, 2008). Problem-focused coping strategies have been identified as predictive of reduced psychological distress in parents, along with closer mother-child relationships (Pottie, Ingram, 2008). On the contrary, emotion-focused coping strategies are predictive of increased psychological distress, as well as poorer mother-child relationships (Pottie, Ingram, 2008). Within these two broad forms of coping responses are smaller, more detailed coping strategies.

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Problem-focused responses include seeking support, engaging in problem solving, focusing on the positive or accepting, and compromising/negotiating (Pottie, Ingram, 2008). Emotion-focused strategies include escaping, blaming, worrying, withdrawing socially, and feeling helpless (Pottie, Ingram, 2008).

Problem-focused coping strategies are empirically validated to increase positive mood in parents of children with autism, which plays a critical role in the psychological and physical well-being of parents (Pottie, Ingram, 2008). The emotional-focused coping strategies of blaming, withdrawing, and helplessness have been identified as decreasing daily positive mood, which is detrimental to the psychological well-being of parents (Pottie, Ingram, 2008). Another critical factor in increasing the positive mood of parents of children with autism is the availability of strong external social supports (Troy et al, 2007). These have been identified as contributing to the reduction of negative psychological effects inherent in raising a child with autism, as well as increasing the presence of optimism in mothers (Ekas et al, 2010). The first social supports for parents of children with autism are often one another. Mothers have been identified as first turning to their spouse for support, pointing to the importance of cohesion, mutual support, and communication within the marital unit (Harper et al, 2013). This adds pressure to the marital subsystem, which will be discussed in a following theme, the impact autism has on the family system.

Clinical Implications- Support for Improved Parent Mental Health

Parenting a child with autism directly impacts the mental health of parents, particularly when considering the grief associated with a diagnosis (Nealy et al, 2012) child behaviours, amount of time spent parenting, and social isolation experienced by parents (Smith, Grzywacz, 2014). It is of crucial importance for mental health clinicians, including counsellors, to recognize

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that the mental health of parents is significantly impacted when the challenge of autism is introduced into the family system. The presence of a strong social support system, offered by both formal and informal sources, has been identified as positively impacting the mental health of parents of children with autism (Meadan et al, 2010). Helping parents to access resources such as support groups, establish effective personal coping strategies, and identify forms of resilience within the family system, are ways in which the mental health profession can recognize the unique struggles of these parents.

Counsellors can support parents of children with autism through first empathizing with the demands which they face on a daily basis (Daire et al, 2011). This is of particular importance for those parents experiencing social isolation, as they are not exposed to the supports of others on a daily basis (Smith, Grzywacz, 2014). Encouraging these parents to access social supports other than one another is an important factor for counsellors to consider as well. While gaining the support of a partner is important, it is also crucial to gain those supports from other informal sources, such as friends and other family members (Ekas et al, 2010). These sources of support can be seen as providing the emotional support which is instrumental to the maintenance of an optimistic future outlook. Mothers of children with autism have identified support from friends and extended family, in the form of listening and offering empathy, as increasing life satisfaction, positive mood, and psychological well-being (Ekas et al, 2010). The outcome of optimism is crucial, as this personality characteristic is directly related to positive outcomes with both psychological and physical health in parents of children with autism (Daire et al, 2011). When social supports are present, parents are empowered and hopeful about the future, suggesting that interventions directed at increasing the well-being of parents is crucial. This

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could include the use of solution-focused and cognitive behavioural techniques by professionals (Ekas et al, 2010).

Working from a solution-focused framework, counsellors can help parents of children with autism identify the strengths which they possess (Daire et al, 2011). Those parents who engage in problem-solving or problem-focused coping have been identified as experiencing less negative psychological impact, as well as closer relationships with their child with autism (Pottie, Ingram, 2008). When emotionally focused strategies are used, parents have been found to experience more psychological distress, as well as weaker parent child relationships (Pottie, Ingram, 2008). A counsellor who helps parents to identify when they are using more effective coping strategies, such as problem-solving techniques, can offer encouragement and support. When instances of successful coping are identified, it may become easier for parents to continue using effective coping strategies. In addition to encouraging parents to use problem-solving coping techniques, counsellors can encourage parents to focus on the positive aspects their child with autism brings to their lives (Freedman, Kalb, Zablotsky, Stuart, 2012). Those parents who feel resolved as to the diagnosis of autism are better able to adjust their expectations of their child, and therefore see their child in a positive light (Mihshstein et al, 2010). For counsellors, this entails recognizing the grieving process which parents may go through after a diagnosis, and supporting them to the point where they become resolved (Mihshstein et al, 2010). Those parents who feel resolved around the diagnosis of autism are more able to adjust their expectations of parenthood and engage in more effective problem-solving styles of coping (Mihshstein et al, 2010). They are able to identify areas where their child has difficulties, but are also able to see those instances where their child shines. This is crucial in terms of reducing negative impacts on parental mental health, as parents are able to reframe their definitions of their child, moving

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beyond the terminology of autism as a disorder, and towards seeing their child as an individual (Knestrict, Kuchey, 2009).

Discussion

Raising a child with autism has a significant impact on the mental health of parents, as there are increased numbers of stressors, and an increased amount of time spent taking care of their child (King, Zwaigenbaum, King, Baxter, Rosenbaum, Bates, 2006). When the challenge of autism is introduced, parents are faced with a new reality of parenting, causing grief to often be attached to the diagnosis (Nealy et al, 2012). Following the introduction of grief, parents may become socially isolated, which can impact parental mental health in a significant negative way (Hartley et al, 2010). With rising rates of autism, there is a need for mental health professionals, such as counsellors, to recognize the impact which autism has on the mental health of parents. Mothers of children with autism are particularly at risk for decreased mental health, as they spend a great deal of their time caring for the child, increasing their exposure to the behaviours associated with autism (Dardas, Ahmad, 2014). Educating parents with effective coping strategies, such as problem-solving, is an important first steps for counsellors to take, as these strategies are effective in reducing the stress which parents experience on a daily basis (Pottie, Ingram, 2008).

Mental health professionals are in the position to help parents reduce the impact which autism may have on their mental health. While there are empirically validated treatments for the child with autism, such as ABA (Lovaas, 1993), more emphasis needs to be placed on programs which also address parental mental health (Osborne, Reed, 2009). The presence of social supports, both formal and informal, has been identified as significantly impacting parental health in a positive manner (Sharma, Winter, McCarthy, 2013). Counsellors can encourage parents to

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reduce social isolation which they may be experiencing through inclusion in autism parenting support groups, as well as seeking support from health care providers and school officials

(Meadan et al, 2010).

Theme III- The Impact of Autism on the Family System

When a child with autism is introduced in the family system, there are significant changes in family structure and relationships (Nealy et al, 2012). Parents in these household report increased difficulties in family cohesion, adaptability, affection, and marital satisfaction in comparison to families whose children have no disabilities (Harper et al, 2013). There are three subsystems within the family to consider when discussing the impact of autism on the family system; the parental subsystem, which has already been discussed in great detail within theme one and two of this thesis; the marital subsystem; and the sibling subsystem. Each of these subsystems are impacted in a unique way by autism, therefore each requires individual attention within this thesis. As already mentioned, the parental subsystem is impacted by autism through significant increases in stress due to the unique nature of autistic symptoms including impairments in communication, inappropriate social engagement, and challenging behaviours (Harper et al, 2013). Parents of children with autism have repeatedly been identified as experiencing not only more stress than parents of typically developing children, but more stress than parents of children with any other developmental disability (Jones et al, 2013). The stressors experienced by these parents contribute to increased rates of mental health concerns, such as depression and anxiety, particularly in mothers (Lickenbrock, Ekas, Whitman, 2011). Much like the parental subsystem, the marital subsystem is impacted by the stressors inherent in raising a child with autism. Decreased marital quality is significantly related to increased parenting stress, therefore marital quality is impacted by autism in the family system (Benson, Kersh, 2011). Finally, the sibling subsystem is impacted by autism in a variety of ways, including decreased availability of parents and the need to cope with behaviours associated with the autistic sibling (Moyson, Roeyers, 2011).

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Literature Review

The following literature review discusses the impact which autism has on the family system. As the parental subsystem has been thoroughly addressed in themes one and two of this thesis, the subsequent literature review will focus upon the marital and sibling subsystems. Discussion of the marital subsystem centres around the impact autism has on the parental relationship, including mention of divorce rates (Harper et al, 2013). Considered is also the presence of resilience within marriage, particularly focusing upon the importance of spousal support (Tway et al, 2007). The sibling subsystem is reviewed through considering stressors apparent for siblings of children with autism (Moyson, Roeyers, 2011). Included are stressors associated with violent behaviours, limited access to parents, and acceptance of the autistic sibling (Moyson, Roeyers, 2011). Literature was obtained through searching scholarly peer reviewed journals using the search terms “autism”, “impact of autism on marriage” , “impact of autism on siblings” and “resilience in families of children with autism”.

Impact of Autism on Marriage

Marital stress is defined as “the accumulation of difficulties within a marriage, including lack of communication, difficulty resolving conflicts, and difficulty accepting each other” (Shtayermman, 2013, pp. 244). Lack of social and spousal support will cause stress within a marital relationship, resulting in a reduced quality of marriage (Shtayermman, 2013). Within the context of raising a child with autism, marital stress has been attributed to the lack of independence of the child not only in childhood, but as they enter adolescence and adulthood (Shtayermman, 2013). As children without a disability age, they move into their own lives independent of parents, decreasing the stress and demands placed upon the parental unit. The independence of the child also leaves room for parents to move their focus away from

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parenthood, and towards their marital relationship (Hartley et al, 2010). This transition is not present in the lives of many parents of children with autism, as their child care duties do not end in adulthood. Marital quality is significantly affected by the behaviours of the autistic child, with problem behaviours negatively associated with marital quality (Benson, Kersh, 2011). Within family literature, it documented that the quality of marriage is related to the psychological adjustment of the partners (Benson, Kersh, 2011). If depressed mood is present within the marriage, the quality of the marriage will suffer (Lee et al, 2008). Raising a child with autism directly impacts the psychological health of parents, particularly mothers, through the manifestation of depression (Yamada et al, 2007). The stressors associated with the child are immense, causing the relationship between mother and father to be compromised, therefore resulting in negative marital quality (Gau et al, 2012). This in turn impacts family cohesion, family adaptability, expression of affection, and marital satisfaction (Harper et al, 2013).

Marital quality is directly related to maternal adjustment is raising a child with autism (Lickenbrock et al, 2011). When mothers feel supported by fathers, they possess positive perceptions of their child with autism, suggesting that a positive marital relationship is a key component to maternal coping (Benson, Kersh, 2011). This is in contrast to some literature which suggests that fathers often cope with the demands of parenting a child with autism by becoming less involved and distancing themselves from the family (Freedman et al, 2012). Some literature suggests that due to the contrasting coping styles of mothers and fathers, divorce rates are high in families of children with autism (Hartley et al, 2010). Inflated rates of divorce, as high as 80%, have been reported by media outlets with little data to back up this claim (Freedman et al, 2012). An empirically validated study by Hartley et al suggests a more plausible divorce rate of 23.5% (2010). An explanation for this lower divorce rate can be offered by family

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systems theory, suggesting that families may feel more inclined to stay together in the face of adversity (Freedman et al, 2012). Parents may stay together because it feels safer than the unknown change which accompanies marital separation; others may stay together in order to ensure that they provide financially for their autistic child's multiple needs (Freedman et al, 2012). Also, the marital relationship may be one of primary support, and the absence of spousal support could be frightening and compel parents to stay together (Freedman et al, 2012). Along with the marital subsystem, the sibling subsystem is also impacted by autism within the family system.

Impact of Autism on Siblings

Siblings of children with autism are affected by the disorder in a manner which encompasses the entirety of the family system. They are witnesses to parental stress, as they watch their mothers and fathers deal with the behaviours of their sibling (Wood Rivers, Stoneman, 2003). They watch the suffering of their parents, as they exhibit signs of depression and anxiety in relation to the daily stressors which they must endure (Wood Rivers, Stoneman, 2003). Siblings must come to terms with the fact that they are often a second thought, as the well-being of their autistic siblings is at the forefront of their parents mind (Moyson, Roeyers, 2011). Much like their parents, siblings must adjust their expectations of their relationship with their autistic sibling, as there is often a limited range of play and social behaviour with which they can engage their sibling (Wood Rivers, Stoneman, 2003). Quality of sibling relationships are correlated with stressed marital relationships, with high marital stress resulting in less reported satisfaction within the sibling relationship (Wood Rivers, Stoneman, 2003).

Contributing to strained sibling relationships are also the behaviours of the autistic child,

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including aggression, destroying toys, limited speech, and lack of social responsiveness (Wood Rivers, Stoneman, 2003).

Through interviews with siblings of children with autism, Moyson and Roeyers identified nine domains of sibling quality of life (2011). These domains include; forbearance, mutual understanding, joint activities, private time, trust in well-being, acceptance, exchanging experiences, social support, and dealing with the outside world (Moyson, Roeyers, 2011). The presence of these aspects represents a better quality of life for the sibling, as they express a better understanding of the challenges of autism (Moyson, Roeyers, 2011). Forbearance outlines ways in which siblings cope with the behaviours of their sibling. Moyson and Roeyers found that many siblings of children with autism were empathetic to the fact that their sibling could not always control their behaviour (2011). This meant that siblings would excuse outbursts or ignore them altogether in order to not further upset their autistic siblings (Moyson, Roeyers, 2011). Mutual understanding existed between siblings, but more commonly in those relationships with autistic siblings who could speak. When engaging in joint activities, siblings were often aware that rules had to be adapted for games in order to avoid outbursts from their sibling (Moyson, Roeyers, 2011). Siblings also identified the need to be away from their autistic siblings, particularly in order to spend time with their parents. Other researchers have identified this same theme of limited time to spend with parents, as much of parent time is spent with the child with autism (Wood Rivers, Stoneman, 2003). Sibling well-being is also impacted by the well-being of the child with autism, labeled by Moyson and Roeyers as “trust in well-being” (2011, pp 48). Siblings express that they are concerned about the future of their brother or sister, particularly about social relationships such as friendships and marriage (Moyson, Roeyers, 2011). Siblings who are able to accept autism as a part of their family experience increased well-being, as do

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those with social supports such as friends who also have autistic siblings (Moyson, Roeyers, 2011). A final challenge for siblings of children with autism is dealing with the outside world (Moyson, Roeyers, 2011). The invisibility of autism means that children often appear “normal”, therefore it is difficult for those in society to understand why they are acting in a certain manner (Moyson, Roeyers, 2011). This means that siblings are often in the position of defender, ensuring that their sibling is not treated unfairly due to their disability.

Clinical Implications- Strategies to Increase Family Resilience

Family resilience has been identified as a key factor in successfully adapting to a diagnosis of autism. Those families classified as resilient are able to focus on positive factors that lead to optimal functioning in the face of adversity (Bayat, 2007). These individuals are able to make meaning out of adversity, recognize those strengths which they possess, and in some cases, identify with a spiritual belief system (Bayat, 2007). The family system is a crucial piece to the adjustment of parents, as well as children living with autism. Surrounding oneself with supportive and optimistic individuals is a leap towards improved psychological and physical well-being. Literature suggests that it is common for families to come together in times of crisis, such as with a diagnosis of autism, cooperating with each other for the benefit of the affected child (Bayat, 2007). This connects to the importance of social supports for parents, as an entire family of support is extremely empowering and influential with regards to increasing optimism. Along with becoming closer, families have identified the child with autism as impacting their belief system, including the altering of worldview, values, and priorities (Knestrict, Kuchey, 2009). These family belief systems are considered to be a crucial factor in the adaptation and resilience of families in crisis (King et al, 2006). A family’s belief system is the anchor of their connection, as it represents shared meaning and helps families come together when stressors

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become overwhelming. Families with strong belief systems cope with an autism diagnosis by looking for those positive attributes and meanings attached to their situation, helping to make sense of the disability and maintain control within the family system (King et al, 2006).

Positive changes in family values as a result of a child with autism have frequently been identified, including the development of patience, love, tolerance, and compassion (King et al, 2006). This aids the family in attaching meaning to the disability by assigning a function to it within the family unit. The disability has essentially improved the family by reminding them of those core emotions which are at the root of a strong family system. These positive results of the child's disability can help parents to regain control in their lives, by witnessing the positivity and optimism which the child injects into the household (Knestrict, Kuchey, 2009). This also aids in the parent no longer looking to the child with autism as the source of stress within the household, which is crucial in terms of experiencing a degree of closure (Mihshstein et al, 2010). Positive changes in family worldview are contributed to the child with autism as well, including the reframing of life challenges. Resilient families see their child as contributing positively to the family, as well as others in their lives. This is important for families struggling to find acceptance (King et al, 2006). Focusing upon the strengths which the child brings to the family rather than the deficits is empowering for both family members and the child with autism. Finally, the child with autism can be seen as the motivating force behind changes in family priorities, including focusing on the child's strengths and needs, rather than on trying to `fix` them (King et al, 2006).

There are concrete factors which contribute to family resilience, and in turn a significant reduction in parental stressors for those raising children with autism. These factors include rules, routines, rituals, reframing, family hardiness, and socio-economic status (Knestrict, Kuchey, 2009). When rules within the household are established and followed by all members, including

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the child with autism, order and predictability is established within the home. This aids in creating a unified environment which includes the child with autism, which can lead to a more positive outlook on the abilities of the child, as well as the supportive network of the family (Knestrict, Kuchey, 2009). Much like rules, routines create much needed structure in the homes of children with autism. A simple routine which is difficult for many families is mealtime; establishing this as a routine means that all family members will spend time together, and meaningful conversations can be had creating an environment of love and support (Knestrict, Kuchey, 2009). Rituals aid in creating this same connection and support within the family, leading to more successful and positive outcomes for both parents and children. Of crucial importance to the resilience of families is the ability to reframe; this is the ability of the family to reconstruct their understanding of what autism is, and what it means for their lives (Knestrict, Kuchey, 2009). Moving away from pathology and towards humanizing autism, the family can begin to see the child, rather than the disability. Reframing is related to hardiness within the family, as the child is looked at in a positive manner, and therefore advocated for by every member of the family (Knestrict, Kuchey, 2009).

Discussion

The stressors placed upon the family unit of children with autism are immense, and affect every system in a major way. The continued stress placed upon the family unit can be overwhelming, as the entire family system revolves around the care of the autistic child (Dardas, Ahmad, 2014). The marital subsystem is greatly affected, as heightened parental stress is directly related to marital discord (Lickenbrock et al, 2011). This is particularly pertinent when maternal stress is high, as marital relationship quality is directly related to maternal well-being (Lickenbrock et al, 2011). Along with the marital subsystem, the sibling subsystem is affected by

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the introduction of autism into the family unit. It is important for mental health clinicians to consider the well-being of siblings, as siblings of autistic children have been identified as more at risk for behavioural and emotional problems than those of typically developing siblings (Lickenbrock et al, 2011).

The importance of appropriate and effective supports for these families is crucial, with effective supports resulting in not only reduced stress, but in the resilience of these families. Identifying family resilience factors, such as social supports, making meaning out of adversity, and affirmation of strength and positivity within the family unit are key factors to maintaining resilient despite the stressors associated with raising a child with autism (Bayat, 2007). Though the amount of stressors apparent in these household are immense, reality points to family units as strengthened through adversity.

Thesis Conclusion

This thesis has reviewed empirically validated research and presented a snapshot of the daily lives of families living with autism. It has clearly presented three themes present in lives of these families, as well as the supports which families have identified as leading to resilience. By outlining the themes of parental stressors, impact of autism on parental mental health, and impact on the family system as a whole, it is apparent that autism affects the entire family unit, not only the child diagnosed with the disorder. This highlights a need for supports which take into account not only the child with autism, but the family as a whole.

Purpose and Potential Meaning of this Study

Definitions of autism and the symptoms attached to the developmental disorder have changed a great deal since the first inception of “early infantile autism” (Kanner, 1944). Children diagnosed with autism are no longer labeled as feral (Bettelheim, 1959), and no longer are cold, obsessive, and mechanical mothers blamed for its etiology (Bakwin, 1954). As autism becomes increasingly visible in society through higher numbers of diagnosis, it is more difficult to ignore the challenges which this disorder poses for not only the individual diagnosed, but for the families involved. Through discussing the stressors inherent in raising a child with autism, this thesis has presented evidence for the need of increased supports for families affected by this challenge. By analyzing past and current literature in autism research, this thesis discussed three significant themes visible in the lives of these families; parental stressors, the impact autism in the family system has on parental mental health, and finally the impact autism has on the entire family system.

A significant number of empirically validated studies have pointed to autism as causing heightened levels of stress within the household, particularly for mothers (Yamada et al, 2007).

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Through analyzing the impact a child with autism has on family life, three significant themes have developed throughout this thesis; there are parental stressors inherent in raising a child, which are considerably increased when a child has autism; these stressors have a visible impact on parental mental health, particularly that of mothers; autism has a visible impact on all aspects of the family system, including the marital subsystem and the sibling subsystem. These themes point to the all-encompassing impact which autism has on the family system, suggesting that attention should be paid not only to the child with autism, but to the family as a whole. Parents require supports outside the home, including the supports of medical professionals, teachers, counsellors, and friends in order to better adjust to the stressors placed upon them on a daily basis (Dabrowska, Pisula, 2010). Through reviewing research regarding resilience in families, social supports have consistently proven to impact families in a significant and positive manner (Lessenberry, Rehfeldt, 2004). It is apparent that supports must be put in place in order for parents of children with autism to have reduced amounts of stress and increased supports in their lives (Osborne, Reed, 2009). There are a number of supports that can be put in place in order to better support parents of children with autism, including increased social supports (Pottie, Ingram, 2008), increased awareness of autism and symptoms by professionals including doctors and counsellors (Soloman, Chung, 2012), and better accessibility to empirically validated treatments including Lovaas ABA (Lovaas, 1979). By discussing the positive impact which these supports have on the family system, this thesis is a valuable resource for both families of children with autism, as well as others in field of mental health. The meaning of these results suggest that with the appropriate social supports, as well as appropriate treatments for the child with autism, families can remain resilient in the face of this challenge.

Implications for Further Research

The evidence presented in this thesis implies a need for increased supports to be put in place for families living with the challenge of autism. Research points to formal and informal social supports as impacting families significantly in a positive manner (Pottie, Ingram, 2008), a theme which must be considered by medical and mental health professionals. Offering parents supports through autism support groups, counselling, and respite care have all been empirically validated as improving mental health (Harper et al, 2013), therefore parents should be made aware at the time of diagnosis of the need for these supports. Further research should address the lack of support present at the diagnostic stage, and how this impacts the stress level of parents and their families. This research should also include a critique of the empirically validated treatments available to parents, specifically the lack of funding which many medicare options offer for treatments such as Lovaas ABA (Nealy et al, 2012). By offering health care benefits which cover these treatments, more families can access the types of therapy which have been proven to improve the conditions of children with autism.

By highlighting the negative impact which autism has on parental mental health, this thesis points to a need for increased mental health supports for parents, including counsellors who are aware of the impact which autism has on a parent (Daire et al, 2011). This includes encouraging counsellors to become aware of not only the symptomology of autism, but the social supports which parents can engage in, positive coping skills which improve family stressors, and effective strategies for parenting a child with autism (Daire et al, 2011). What is apparent throughout the research, is that when a parent feels supported, their level of stress significantly decreases and they are more able to respond to the challenges in their lives in a positive manner

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(Pottie, Ingram , 2008). Further research should address the need for mental health professionals to be more aware of autism and its impact on parental and family life.

Limitations of the Current Study

Through conducting a literature review, it has been difficult to find the voices of those families struggling with the challenge of autism. Presenting empirically validated data is the first step towards addressing the need for further supports for these families, but the use of qualitative interviews would have been beneficial by telling the stories of real families. Another limitation is the relatively one-sided argument which research presents in relation to the impact which autism has on family life. There are a great deal of stressors inherent in raising a child with autism, but it would be beneficial to also consider the unique outcomes present in family life as well. This would change the family story from one of overwhelming stress to one of resilience in the face of challenge.

Researcher Experience

As an advocate for the rights of families of children with special needs, researching the topic of this thesis has been a rich experience. Through reading the literature, I have become more aware of not only the struggles which families of children with autism experience, but also the great privilege which I have been offered in conducting this research. The voices of families must be heard in order for society's view of autism to shift from a life sentence to a unique challenge. It is clear throughout the literature that autism introduces numerous challenges into the lives of these children and their families, but it is also clear that there are coping strategies which are successful in reducing the amount of daily stress which families experience. I have witnessed firsthand the impact which social support has on parents, as I have been invited into the homes of families not only as a therapist, but as an ally. By presenting the empirically

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validated evidence within this thesis, I hope to shed light upon the supports which need to be in place for these families in order for them to remain resilient. Conducting this research has solidified what I have already observed in the households of children with autism; parents experience heightened stress in comparison to parents of typically developing children, parental mental health is negatively impacted by this stress, and the family unit as a whole is affected by these stressors. While I was not surprised by these findings, I was surprised by the significant positive impact which simple social supports can have on parents. When working in the homes of these families, I have seen great changes in not only the child, but the family. My assumption was often that it was the therapy conducted with the child that produced this change, but I now consider the presence of myself as a friend for the parents to be of significant importance as well. The process of writing this thesis has impacted my own work in an enormous way, as I now understand the stress of parents at a higher level. They are no longer overbearing or “helicopter” parents, they are parents fighting for the rights of their child with special needs, something which needs to be recognized by educators, administrators, mental health professionals, and government officials.

Conclusion and Summary

The lives of families living with autism are unique and impacted by stressors in a significant way. The three preceding themes of this thesis present parental and family life within the context of the challenges associated with raising a child with autism. Given the increased rates of autism diagnosis, it is important for researchers, clinicians, educators, and society as a whole to consider this challenges impact on parental stress, mental health, and the family system as a whole. More than any other developmental disorder, autism heightens parental stress levels impacting the mental health of parents, particularly mothers, at a considerable rate (Smith,

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Grzywacz, 2014). In addition to expected parental stress, parents of children with autism must deal with explosive behaviours of the child, lack of social and emotional reciprocity, and disruptive repetitive behaviours (Keller et al, 2014). Compounding this stress is the lack of social supports which parents receive, including from friends, family, teachers, and medical professionals (Nealy et al, 2012). Lack of effective coping strategies leaves parents with little option but to withdraw, leading to further negative impact on mental health (Pottie, Ingram, 2008).

The stressors inherent in raising a child with autism impact parents not only on an individual level, but on a relational level. The marital relationship is impacted through lack of time spent as a couple due to the needs of the child with autism, as well as the extended amount of time which the child may spend in the household well into adulthood (Hartley et al, 2010). Given effective coping strategies, the marital relationship can be a place of resilience of parents, as they can act as supports for one another when there are few other places to turn (Nealy et al, 2012). A strong marital relationship is directly correlated to decreased maternal and paternal stress (Harper et al, 2013), arguably suggesting that strengthening marriage through the use of counselling can improve the lives of parents of children with autism.

The familial subsystem of the sibling is also impacted by autism within the household. With a great deal of parental time devoted to the child with autism, siblings can be left behind with little support (Wood Rivers, Stoneman, 2003). They become witness to the stress experienced by their parents, and are exposed to the disruptive behaviours of their sibling on a daily basis. While siblings observe these behaviours on a daily basis, what has been discussed throughout the literature is the positive impact which a sibling can have on a child with autism. The sibling can become a social role model, and can offer a great deal of opportunities for the

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child with autism to learn about social reciprocity, communication, and social norms (Moysen, Roeyers, 2011). The child with autism can also impact their siblings in a positive manner, teaching lessons of empathy, acceptance, and patience (Moysen, Roeyers, 2011).

The impact which autism has on the family system is immense, changing the lives of all those involved. Given the significant influence which this challenge has on family life, more attention needs to be paid to not only the child affected, but the family system as a whole. Offering parents appropriate coping strategies, such as autism support groups, group counselling, and other social supports can impact the family system in a significant and positive manner. In addition to this, more attention and investment on the part of government funded health care must be paid to the positive impact of empirically validated treatments such as Lovaas ABA. While parents have continually been advocates for their children with autism, it is time for society as a whole to advocate for the rights of these children and their families. Research has shown that autism has a significant impact on parental stress, mental health, and the family system as a whole. In addition to this, research has pointed to social supports as having the most significant impact on reducing parental stress. More supports need to be offered to parents by means of mental health professionals, supports groups, and acceptance of autism on the part of society. Only through supporting the parents of these children can we begin to see a shift in the lives of those affected by autism.

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