Living with “new normal:”
Fathers’ blogged experiences of parenting a child with autism

by

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ABSTRACT

LIVING WITH “NEW NORMAL:” A THEMATIC ANALYSIS OF FATHERS’ EXPERIENCES OF PARENTING A CHILD WITH AUTISM

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This thesis examines fathers’ experiences of parenting a child with autism, as expressed in online blogs. A number of studies have purported to investigate parental experiences of this nature; however, parental samples are usually maternal samples in disguise. Despite the modern shift from paternal breadwinning to co-parenting, the unique experiences of fathers continue to be overlooked in the disability parenting literature. For the present study, 180 blog posts—relating to fathers’ experiences parenting a child on the autism spectrum—from 18 father-authored blogs were analyzed. A model of Living with “New Normal” was developed to characterize the range of experiences and emotions these fathers expressed in their online entries. Central to this model were experiences of stress (often due to societal and systemic struggles) and crisis (feeling hopeless and defeated), with a shifting focus towards resilience and coping (developing a “new normal” and celebrating autism’s unique contribution to the family).
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Introduction

Autism is a developmental disorder that is characterized by: a) “Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays” (including deficits in social-emotional reciprocity, nonverbal communicative behaviours, and in developing and maintaining relationships); and b) “Restricted, repetitive patterns of behavior, interests, or activities” (e.g., “stereotyped or repetitive speech, motor movements, or use of objects; excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; highly restricted, fixated interests that are abnormal in intensity or focus; hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment” (Kaufmann, 2012, p. 28). Symptoms must be present in early childhood, and together must limit and impair everyday functioning. Generally, symptoms of autism spectrum disorders are discernible and/or diagnosed at approximately three years of age, but symptoms may not “fully be manifest until social demands exceed capacity” (American Psychiatric Association, 2013; Kaufmann, 2012; Siklos & Kerns, 2006; Volkmar & Pauls, 2003).

Once believed to be a relatively rare developmental disorder, diagnoses of pervasive developmental disorders (PDDs), including autism and autism spectrum disorders (ASDs) such as Asperger’s syndrome, as well as the catch-all diagnosis of pervasive developmental disorder not otherwise specific (PDD-NOS), are now accepted to be quite common (American Psychiatric Association, 2000; Matson & Kozlowski, 2011; Volkmar & Pauls, 2003). Indeed, estimated prevalence rates for ASDs range anywhere from five cases per 10,000 to 60 cases per 10,000 children in North American community samples (Altiere & von Kluge, 2009a; Siklos & Kerns, 2006). Diagnoses have been on the rise, so much so that ASDs are now considered by the Center for Disease Control to be an urgent health concern (CDC, 2009). With this increased rate of diagnosis, there has been a parallel escalation of autism-related research, special interest groups, activism, and public awareness of autism and its related conditions (Volkmar, State, & Klin, 2009).

Significant changes to the diagnostic criteria for autism spectrum disorder have been made with the most recent release of the Diagnostic and Statistical Manual of Mental Disorders (5th edition), which have been the subject of much debate; this discussion, however, falls outside
the scope of this paper. Importantly, though, Asperger’s and PDD-NOS are no longer diagnoses
unto themselves, but rather have been collapsed into a single diagnostic label of autism spectrum
disorder (American Psychiatric Association, 2013; Kaufmann, 2012). As the bulk of data
collection was carried out prior to the release of the most recent edition of the DSM, and given
the limited relevance of the DSM-V criteria to the participant sample’s documented experiences,
this thesis will continue to recognize Asperger’s and PDD-NOS as ASDs.

Young people with ASDs are often described as “strange,” displaying age-inappropriate
stereotypic, repetitive, and/or disruptive non-functional behaviours (e.g., hand-flapping, rocking
back and forth), myopic interests which approach obsession (e.g., trains, insects), and an acute
intolerance of change—qualities that often make developing a meaningful, relational connection
to these individuals very challenging (Ludlow, Skelly, & Rohleder, 2011; Volkmar & Pauls,
2003). As can be seen, autism and ASDs are complex and multifaceted disorders that affect
various aspects of development; no two individuals with an ASD will demonstrate the same
symptomatology.

Due to the complexity and distressing nature of ASDs, the diagnosis of a child with an
ASD has been found to be extremely stressful for parents and families of these children (Ludlow
et al., 2011), which has become an important focus of recent research in this domain. The
diagnosis of an ASD, for example, compounds parents’ concerns regarding their child’s quality
of life (e.g., concerns about bullying; Lee, Harrington, Louie, & Newschaffer, 2008) and forces
them to re-examine the hopes and expectations they had for the future of their child and their
family (Banach, Iudice, Conway, & Couse, 2010). The diagnosis of an ASD also introduces the
overwhelming task of identifying and accessing the appropriate resources for their child’s unique
needs (Benson & Dewey, 2008), and intensifies financial strains as parents need to pay for
unforeseen and previously unneeded resources (e.g., behaviour therapy; Freedman & Boyer,
2000). It has even been reported that parents of a child with an ASD are twice as likely to
divorce when compared to parents of typically developing children (Hartley, 2010). It is
therefore understandable that parents with a child on the autism spectrum report increases in
depression, sleep disturbances, and fatigue over and above parents of typically developing
There exists an abundance of research that seeks to quantitatively identify particular stresses and challenges that are encountered by parents raising a child on the autism spectrum. Much of the existing research focuses on maternal experiences (to be discussed at greater length later in this paper), which is where this project steps in to fill a gap in the current autism scholarship. In this thesis, I aim to illuminate, in greater depth, the experiences of fathers raising a child with ASD, an unacceptably ignored population in the parenting research. This study will qualitatively examine the content of online blogs that have been written by fathers who self-identify as a man actively involved in the day-to-day responsibilities of parenting a child with autism. I will be exploring an under-researched population using a novel source of rich data.

**Autism’s impact on parents**

Because of the all-encompassing nature of autism and other spectrum disorders, it has been reported that practically every decision made by parents of a child with an ASD is affected or impacted in some way by the autism. It necessitates the shifting of parents’ roles and responsibilities, and becomes central to the family’s existence (DeGrace, 2004; Hoogsteen & Woodgate, 2013). Consequently, having a child on the autism spectrum is an enormous source of stress and tension for parents (Altiere & von Kluge, 2009a; Davis & Carter, 2008; Smith, Oliver, & Innocenti, 2001), and there has been a burgeoning interest in the impact that a diagnosis of autism in a young person can have on parental, and subsequently familial, functioning. In one study, parents expressed that their primary parenting challenges were dealing with their child’s challenging behaviours, responding to judgement from others (such as during public tantrums), and a lack of appropriate support (Ludlow et al., 2011). In a study by Hoosgsteen and Woodgate (2013), parents were interviewed about the effects the autism diagnosis was having on their family and parental functioning. The parents confided that the ASD had quickly become a, if not the, central focus of family life. Slowly but surely, life began to revolve around the consequences and characteristics of the ASD and the child with the ASD diagnosis, regardless of the presence of other siblings in the family. They reported that the ASD was taken into account in every decision (e.g., where to go for family vacations), and limited family and parent activities (e.g., fewer date nights for parents). Similar findings were echoed in studies by Serrata (2012) and Luther and colleagues (2005). Parents have also reported restrictions in job and career opportunities (Hall, 2012), difficulty with spontaneous family outings (Serrata, 2012), a loss of
social relationships, and a loss of support systems that are external to the family unit (Nealy, O’Hare, Powers, & Swick, 2012), all related to the diagnosis of an ASD in their child. Conversely, the presence—whether perceived or actual—of social support (e.g., family/friends willing to babysit, absence of judgement) and institutional support (e.g., special education, parental leave, health benefits) for families with a child with an ASD have been shown to improve family functioning, increase healthy adaptation, and decrease family stress (Gray, 2002; Hall, 2012; Hall & Graff, 2011), making the availability of support tantamount to successful coping.

It is a natural—and empirically supported—assumption that parents of a child on the autism spectrum face more challenges and difficulties than families with typically-developing children. Interestingly, even compared to parents of children who are not typically developing and/or have other disabilities, parents of children with an ASD seem to experience still more pronounced negative effects. For example, parents of children with autism reported more stress and were more likely to use avoidance coping methods than parents of children with Down syndrome (Dabrowska & Pisula, 2010). Additionally, fathers of a child with autism reported more depressive symptoms than fathers of a child with Down syndrome or Fragile X syndrome (Hartley, Seltzer, Head, & Abbeduto, 2012). Evidently, ASDs pose unique challenges and obstacles for parents that impact functioning above and beyond even other developmental disorders, and thus warrant a great deal of research regarding the experiences of parents in these situations.

**Mothers and autism.** A handful of studies have specifically sought to tap into mothers’ experiences and perceptions of stress and coping when raising a child with ASD. It has been reported that mothers of a child diagnosed with an ASD are more likely to take on a primary caregiving role upon diagnosis, leave their employment, and to spend the most amount of time with their child with ASD when compared with fathers (Altiere & von Kluge, 2009b; Meadan, Halle, & Ebata, 2010), making it worthwhile to gain insight into and appreciation for their subjective experiences.

In a 2012 study, Nealy and colleagues conducted semi-structured interviews with eight women who had a child diagnosed with an ASD. The mothers reported a strong emotional impact surrounding the diagnosis of autism. Stress resulted from attempts at accessing services
(e.g., school support, speech therapy) and facing frequent barriers such as limited funding and availability of service providers, and scheduling conflicts. The participants reported a decrease in the quality and quantity of their social ties outside the family, and a sense that they no longer had as much in common with their friends; however, the mothers did note finding friendships through ASD support groups. The mothers reported worrying about the quality of their child’s future (e.g., Will they get married? Will they be able to live independently?), and felt guilty for worrying about or doubting such things. Familial relations were also reportedly affected, in a primarily negative manner, by the added stresses and strains related to caring for a child with an ASD. The mothers in this study expressed feeling neglectful of their other children, which led to feelings of guilt and inadequacy; emotions that were also echoed in their spousal relationships. The mothers reported that the ASD-induced stress led to conflict and relational deterioration, and that the fathers were often out of the home for the majority of the day. They suggested that fathers were not as in touch with the stresses of parenting a child on the autism spectrum as mothers. This thesis explores whether similar themes emerge from fathers’ recounting of their experiences raising a child with an ASD, and focuses on how fathers experience ASD-related stresses.

In another study inquiring into the experiences of mothers of children with ASDs, Kuhaneck and colleagues (2010) interviewed mothers in order to conduct a phenomenological inquiry to capture participants’ experiences and interpretations of their world. This study aimed to develop a picture of how mothers cope with an ASD diagnosis and all that parenting a child with the disorder entails. A number of themes were identified as necessary for positive maternal coping. The mothers found that “me time,” whether it be exercising or reading a book uninterrupted, played a key role in the regeneration of mental and physical strength needed to deal with ASD-related demands. It was also expressed that having a spouse and/or other support systems to share the burden was essential, positioning the fathers in a more vital role than in the previously described study by Nealy and colleagues (2012). Finally, the mothers in this study were able to reflect on the unique joys that can accompany raising a child with autism, and discussed the necessity of taking no small measure of progress or gesture of affection for granted. This reflects a degree of resilience, given that the mothers were not focusing on and/or unable to move beyond the challenges or negative events related to raising a child with an ASD,
which sets the stage for examining parents’ experiences of living with a child with an ASD through a lens of strength and resiliency.

**A brief comparison of mothers and fathers of a child with ASD.** Although the existing research is conclusive that parents of a child with an ASD face numerous obstacles and hardships, there is much less agreement as to how mothers and fathers experience these challenges. There is evidence to suggest mothers and fathers process and react to their child having an ASD in dissimilar ways; from detecting different symptoms (Matson, Hess, Kozlowski, & Neal, 2011), to reacting differently to the various impacts of the ASD on family and spousal relations (Pelchat, Lefebvre, & Levert, 2007), and displaying different coping strategies (Ludlow et al., 2011). However, there is also research to support relative similarities between mothers and fathers. For example, in the same paper, Ludlow and colleagues (2011) reported that there are actually relatively few differences between challenges experienced by mothers and fathers, and that both parents reported similar factors that helped them cope (e.g., professional support). With this lack of clarity and agreement in the existing research, an increased and exclusive focus on fathers of children with autism is necessary to clarify potential coping differences in mothers and fathers in order to identify effective coping strategies and useful interventions.

Some existing research posits that mothers and fathers may have different coping strategies and may feel the effects of the autism diagnosis in differing ways (Hall, 2012; Hall & Graff, 2011; Nealy et al., 2012; Papageorgiou & Kalyva, 2010). For example, some researchers posit that mothers experience more depressive symptoms than fathers (Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005), and cognitive coping factors such as problem-solving skills appear to be more important to fathers than mothers in adjusting to a special-needs diagnosis (Frey, Fewell, & Vadas, 1989). It has also been suggested that parents differ on which behaviours related to the autism diagnosis they find more distressing, with mothers reporting more distress over the social impairments than fathers (Davis & Carter, 2008).

The unique experiences of fathers have largely been overlooked in research as a whole, and the chronic disability and autism literatures are no exception. Research focusing on maternal experiences has been justified due to the fact that, historically, women have been largely responsible for child-rearing and therefore would arguably be the parent most affected by the
diagnosis of a chronic disability in their child (Altiere & von Kluge, 2009b; Beaton, Nicholas, McNeil, & Wenger, 2012; Meadan et al., 2010). Consequently, fathers have not been considered in many elements of treatment and are often disregarded by healthcare support systems (Beaton et al., 2012; Sterken, 1996); however, times are changing. Recent research has shown that fathers are actually much more involved in the lives and treatment of their children than has been previously assumed (McNeill, 2007). I turn now to a review of existing, relevant scholarship concerning the experiences of fathers dealing with the diagnosis of a chronic disability in a child. Because there is a lack of distinctive research related to fathers and disability, much less specifically pertaining to fathers and autism, I have turned to the chronic health and disability literature because of its commonalities with the topic of interest. Autism is a chronic disability in that there is no remission or cure, only symptom management and/or reduction, and it is therefore expected that the experiences of fathers dealing with chronic health issues in their child will likely share many commonalities with and be relevant to fathers parenting a child on the autism spectrum.

**Fathers in the chronic health and disability literature**

A handful of research studies have investigated how fathers respond to the diagnosis of a chronic illness in their child. Reviews of this research, such as one conducted by Beaton and colleagues (2012), point to notable convergences and divergences of the fathering and disability literature and will be briefly discussed here.

As previously mentioned, families who have a child with a disability are very likely to encounter different challenges and more stressful life events than are families without a child with a disability or chronic illness (Pelchat et al., 2007). Consistent with literature previously discussed, it has been demonstrated through research with heterosexual couples that mothers and fathers experience similar amounts, or levels, of stress; however, the types of stress experienced by fathers and mothers are different (Pelchat et al., 2007; Vrijmoet-Wiersma, van Klink, Kolk, Koopman, Ball, & Egeler, 2008). Fathers tend to report greater stress associated with the quality of the attachment bond between them and their child, their desire for a return to normalcy, restricted one-on-one time with their spouse, and their ability to ensure financial security (Pelchat et al., 2007). The stresses reported by fathers differed from those expressed by mothers (e.g., high care-giving demands, high emotional toll), and may be due in part to the Western
masculine identity role. The masculine identity role emphasizes fathers as providers, protectors, supports and sources of strength for their family and partner (McNeill, 2004; McNeill, 2007). Thus, even when fathers are themselves feeling weak or overwhelmed, they may feel duty-bound to show their spouse and family strength and stability—both physically and emotionally (McNeill, 2004; Nicholas, Gearing, McNeill, Fung, Luchetta, & Selkirk, 2009).

Researchers studying fathers of children with chronic health concerns have also found that fathers and mothers use different methods when coping with and adjusting to a child’s diagnosis. This work has shown that, while fathers do indeed experience an acute emotional response to their child’s health issue, they are less likely than mothers to openly express these responses; rather, they are more likely to employ self-support and/or avoidance strategies (Nicholas et al., 2009; Pelchat et al., 2007). These strategies tend to be more action-oriented than the coping strategies used by mothers, and focus on what elements of the situation can be changed or controlled. For example, fathers may respond to a diagnosis by altering aspects of the home (e.g., installing ramps to accommodate a child’s wheelchair, removing breakable objects), coming up with alternative family activities to accommodate the illness, or offering pragmatic “mini-solutions” to the issues that arise along the way. As well, fathers often focus on maintaining a positive, optimistic attitude regarding the diagnosis (Brody & Simmons, 2007; Cashin, Small, & Solbert, 2008; Flynn, 2012). Harkening back to the masculine identity role adopted by many North American fathers, research has also demonstrated that, when dealing with a chronic disability or illness in a child, men/fathers make comparatively less use of formal support services (e.g., counselling) than do women/mothers (Addis & Mahalik, 2003). Given these unique ways in which fathers appear to deal with the diagnosis of a chronic disability or illness in their child, it will be interesting and enlightening to determine how fathers are using the internet to deal with and manage the stresses inherent in living with a child with a developmental disability, such as autism.

**Fathers in the autism literature**

To date, very few studies have focused exclusively on the parenting experiences of fathers, and the same is true for the existing autism and parenting scholarship. Some may state that the focus of autism research on mothers’ experiences has been warranted; mothers have historically been the primary—or even exclusive—caregivers of children, and thus arguably are
more impacted by non-typical child development than fathers. However, with the modern shift from paternal breadwinning to co-parenting, fathers are spending an increasing amount of time caring for their children (whether on the autism spectrum or not) and are more likely to be directly involved with their children than fathers of past generations (Pleck & Masciadrelli, 2004). The standard one-parent participation model ignores these cultural shifts, and the expanding literature indicates that both mothers and fathers each play an early, vital role in the development of their children’s social and communication skills (Pancsofar & Vernon-Feagans, 2006; Shannon, Tamis-LeMonda, London, & Cabrera, 2002). There is empirical evidence that reactive and responsive fathering is a powerful predictor of improved developmental outcomes for children, including greater emotional regulation as well as improved cognitive and language development (Flippin & Crais, 2011; Shannon et al., 2002; Tamis-LeMonda, Shannon, Cabrera, & Lamb, 2004).

Researchers have also demonstrated that fathers’ more directive communication styles may be useful in facilitating the social awareness of their child with ASD (Pellegrini, Brody, and Stoneman, 1987). Pellegrini and colleagues (1987), for example, reported that fathers more often than mothers use their child’s violations of conversation conventions as an opportunity to provide constructive feedback on the not-to-be-repeated behaviours. For children with ASD, who have impaired social awareness, this directive style may thus increase the child’s awareness of the impact that their communication and social behaviours have on other people. Given that deficits in emotional regulation and language development are critical components required for a diagnosis of an autism spectrum disorder, the impact and experiences of fathers cannot continue to be overlooked in the literature.

In one of the rare father-focused research endeavors, Hartley and colleagues (2012) examined the impact that parenting a child with a pervasive developmental disability had on fathers. This study did not focus exclusively on autism, but also included fathers of adolescents with Down syndrome (DS) or Fragile X syndrome (FXS). The sample included 135 fathers of adolescents diagnosed with ASD, 59 fathers of an adolescent or young adult with DS, and 46 fathers of an adolescent or young adult with FXS. All of the fathers included in the sample were the biological father of the ASD-, DS-, or FXS-diagnosed individual, and the majority were Caucasian, married, and had a university education. To capture psychological well-being, the
fathers were given a number of measures to complete (e.g., Pessimism subscale from the Questionnaire on Resources and Stress, Multidimensional Coping Inventory). The authors found that fathers of adolescents with ASDs reported more depressive symptoms than fathers of adolescents with DS or FXS. This finding is in line with earlier studies of fathers of younger children with developmental delays (e.g., Fidler, Hodapp, & Dykens, 2000); however, Hartley and colleagues’ study was limited in its methodology (only using three relevant scales), and demonstrates the inclination in this research domain to assess functioning, coping, and stress using quantitative methods.

A more recent study conducted by Ludlow and colleagues (2011) sought to explore the experiences of both mothers and fathers of a child or adolescent with autism, this time departing from the quantitative tradition and instead using a qualitative approach. The researchers conducted in-depth individual interviews with 20 parents of a child with an ASD (eight children with autism and six with Asperger’s syndrome ranging in age from two to 14 years). The parent sample was made up of 14 mothers and six fathers. In their thematic analysis of the interviews conducted, Ludlow and colleagues identified categories of concerns facing these parents, many of which echo the sentiments expressed in the studies of Nealy et al. (2012) and Kuhaneck et al. (2010). The parents reported negative emotional impacts from dealing with challenging behaviours, and expressed that stress was increased by perceptions of a lack of support. A similar theme of impact upon the family was identified, with parents reporting that they often felt inadequate to the task of raising a child with ASD while maintaining positive relationships with their partner, other children, friends, and family members. The researchers reported that fathers and mothers seemed to find similar coping factors helpful (e.g., professional support), but also stated that fathers and mothers seemed to react differently to the diagnosis. The mothers in this sample, for example, reported that the father struggled with denial over the initial diagnosis—even to the point of ignoring the issue—and were also less accepting of the severity and long-term prognosis of the disorder. The mothers also suggested that fathers were less patient when tolerating ASD behaviours because they did not spend as much time with the child as the mothers. The findings from this study would suggest that there are some differences in how fathers and mothers react to and deal with the diagnosis of an ASD in their child; however, the father sample was quite a bit smaller than the sample of mothers, so the results need to be interpreted with caution. I suggest that these fledgling findings of dissimilar coping experiences
of fathers and mothers, and the fact that much of the research involving fathers has an insufficient male sample, necessitates this study that focuses specifically on the unique and important experiences of fathers.

**Theoretical Frameworks**

In the disability and difference literature, the dominant discourse surrounding individual, parental, and familial experiences focuses heavily on what challenges and stresses are encountered. While this deficit model of disability (see Harry & Klinger, 2007) may highlight sources of stress and inform the provision of services, it does not leave room for the expression of positive situations that arise from living with a certain difference. This skewed representation therefore does not give space for individuals to express the potential complexity, diversity, and duality of living with a difference. For these reasons, I drew upon the resilience lens and the contributational perspective to guide my interactions with the data, to see difference as “human variation rather than a pathology” (Reid & Valle, 2004, 473). A more thorough description of these frameworks is provided below.

**Resilience lens**

As is evident from the literature discussed previously in this paper, the diagnosis of autism or an ASD in a child is a difficult period of challenge, transition, and coping for families and fathers. At the simplest level, there are two possible reactions to difficult circumstances or life-altering events. One can either face the challenge head-on with a spirit of survival and optimism—referred to as resilience—or allow the challenging situation to derail or control their life. According to Walsh (1996), a pioneer of the resilience framework, this theoretical approach:

...aims to identify and fortify key interactional processes that enable families to withstand and rebound from the disruptive challenges they face. A resiliency lens shifts perspective from viewing families as damaged to seeing them as challenged, and it affirms their reparative potential. This approach is founded on the conviction that both individual and family growth can be forged through collaborative efforts in the face of adversity (p.261).

Inherent in the concept of resilience is the idea of bouncing back from, as opposed to breezing through, adversity and challenges (Walsh, 1996). Family resilience as a concept differs from family crisis adjustment in that it involves “multiple, recursive processes over time, from a
family's approach to a threatened or impending crisis situation through adaptations in the immediate and long-term aftermath” (Walsh, 1996, p. 7; see also Walsh, Jacob, & Simons, 1995). Instead of fracturing or becoming dysfunctional, resilient families come through hardships stronger and more resourceful than they were prior to the difficult circumstance. Walsh identified a number of key factors which contribute to family resiliency, including: 1) making meaning of adversity; 2) affirming strength and keeping a positive outlook; and 3) having spirituality and a belief system (Walsh, 1998, as discussed in Bayat, 2007). Additionally, according to Walsh (2003), families possessing flexibility, connectedness, communication, and an ability to utilize resources are the families who are able to rebound in the face of difficult circumstances (Bayat, 2007; Walsh, 2003).

In an examination of family resilience when dealing with an autism diagnosis, Bayat (2007) surveyed 175 parents/primary caregivers of a child on the autism spectrum, 30 of whom were fathers (17%). Participants were asked to: 1) describe the positive and/or negative effects of autism on their family life; 2) describe the positive and/or negative effects of autism on their personal life; and 3) describe their child. The participants’ responses were collated into themes and subcategories, including an examination of family resilience. Based on Walsh’s (1998, 2003) description of resilience factors, the investigator found that 62% of parent responses addressed pulling resources together and/or being connected; 63% of responses indicated some form of making meaning out of adversity; 39% mentioned affirmations of strength and/or becoming increasingly compassionate; and 45% discussed drawing from spiritual experiences and belief systems. It was also noted, however, that only five of the 11 subthemes pertaining to family that the author identified tied to Walsh’s resilience framework. These findings lend support to the application of a resilience lens to the study of the effect of autism on families, but also suggest that perhaps it does not capture the entirety of family experience. It does support the notion that there are indeed positive aspects to raising a child on the autism spectrum, and that simply focussing on the challenges or negative aspects that these fathers encounter is not adequate to capture the full picture of family life affected by autism.

**Contributional perspective**

Within the contributional framework, disability and difference are investigated in terms of what they add—or contribute—to an individual’s life, rather than what it may detract from it
(e.g., Turnbull & Turnbull III, 1993). Turnbull and Turnbull (1993) point out that, historically, children with disabilities and their families were typically described with pathogenic negative generalizations, and that any unanticipated positive findings were explained through a negative interpretation (e.g., someone who is demonstrating outward empathy may just be concealing a deep inner turmoil). Instead of seeking to explore how individuals and families try to work around or struggle against their difference, the contributitional perspective seeks to empower individuals by focusing on how the individual and/or family works with and accepts their circumstances. In the pioneering work for this perspective, Turnbull, Blue-Banning, Behr, & Kerns (1986) analyzed letters that had been written to Congress by parents of a child with a disability. They identified six categories of contributions, which described the “person with the disability as being: a source of happiness, a source of love, a source of learning life’s lessons, a source of fulfillment, a source of pride, and a source of strength” (Turnbull & Turnbull III, 1993, p. 2). At its core, the contributitional perspective allows researchers to “open up the end of the continuum beyond normalization” and recognize that persons and families existing with a disability or difference have unique and valuable experiences (Eiserman, 2001, pp. 237).

A critique of both the contributitional and resilience perspectives is that they focus too ardently on the perceived benefits of living with a difference, while perhaps not paying due attention or respect to the very real challenges that can be encountered by the individual and family (Eiserman, 2001). Conversely, I have worked to allow space for, and give due respect to, the diverse experiences of fathers in this thesis. I recognize that fathers’ experiences are not always relegated to either end of the spectrum of experiences—either completely stressful and heartbreaking or completely positive and uplifting—but vacillated between the two, occupying a middle ground of accepting the “good” with the “bad.” Care has been taken not to imbue fathers’ expressions of struggle with unwarranted positivity, nor expressions of joy and success with underlying pathology.

As can be seen from this review of the relevant literatures, the voices of fathers experiencing life raising a child with an autism spectrum disorder has been overlooked, or have been assumed to be adequately captured by the experiences of mothers. The present study endeavors to give fathers a stronger, more distinctive voice in autism research by focusing solely on their experiences. There is also a lack of qualitative research in this field, and little
exploration of methodological alternatives to surveys, questionnaires, or interviews; to date, the research in this field has lacked diversity. This thesis project is unique in its efforts to combine the use of a novel and emerging source of qualitative data—blogs—to explore the lived experiences of an ignored but important part of the parenting team—fathers, and seeks to advance the parenting and autism literature. I turn now to the description of the study design, analysis, and interpretations.

**Method**

**Ethical considerations**

The analysis of online information requires a nuanced approach to ethical engagement with potential data, and the line between what is public and what is private is not always clear. One must consider blog attributes, the author’s privacy intentions, researcher interaction, and harm reduction before determining how best to proceed (Eastham, 2011). There are a number of characteristics of blogs that indicate the author’s intention for a public blog. If a blog is indexed and therefore available to search engines (e.g., Google, Yahoo), does not require a password or site registration, and/or offers RSS feed (comments from and interactions with readers), it can be assumed that the author intended their blog to be available and accessible to the public. Blogs considered to be in the public domain do not require a user to log in, register, or use a password in order to view (and/or comment on) the contents of the blog, which strongly suggests that the author intended for the blog to be public (Eastham, 2011). Furthermore, Eastham’s (2011) review would recommend that “the blogger’s public intentions would obviate the need for informed consent” (p. 359). It was felt that all blogs selected for analysis fit the above criteria for intended public blogs. However, considerations to minimize the risk of identification (e.g., creating pseudonyms, omitting proper names, etc.) have been made.

In consultation with the University of Guelph Ethics Review Board (S. Auld, personal communication, April 30, 2013), colleagues familiar with the process of conducting research using internet data, and a review of current best practices (Eastham, 2011), a formal ethics application and contact with blog authors was not deemed to be required for this project.
Sample

This qualitative study involved nonparticipant thematic analysis and observation of blogs authored by men who self-identified as fathers of a child on the autism spectrum. This approach was used as it privileges fathers’ own self-driven experiences; the researcher did not influence the nature of the authors’ disclosures. The sample for this study consisted of approximately 180 blog entries of 200+ words, from 18 online blogs authored by fathers who identify as living with and parenting a child on the autism spectrum. Because of the nature of blogs, in that the authors choose what to reveal and how to reveal it, a complete demographic profile was not able to be developed for each of the fathers. In instances where the authors provided some personal, background information, it was found that the authors of these blogs were from nuclear, heterosexual households, were Caucasian, and may represent a higher education and socioeconomic bracket than the general population (Bimber, 2000). Fathers’ ages ranged from 31-42 years of age, when that information was available. It is therefore not anticipated or expected that the sample of blogs will reflect the experiences of fathers from all walks of life, but rather captures the experiences of this more specific demographic. The type and severity of the autism experienced by the father’s child(ren) varied, from low-functioning and nearly non-verbal, to higher-functioning autism or Asperger’s syndrome. The children also ranged in age from three to 14 years (when information was available; see Table 1 for child age and ASD severity demographics).

<table>
<thead>
<tr>
<th>Low-fx</th>
<th>High-fx</th>
<th>Severity</th>
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<td></td>
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<td>not stated</td>
<td>3-6</td>
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<td>13+</td>
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<td>Male child</td>
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<td>5</td>
<td>12</td>
<td>5</td>
<td>4</td>
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<td>Female child</td>
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Table 1. Age of children and severity of ASD (number of occurrences)
* -- denotes no occurrences for that category
** fx = functioning

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**Data collection**

**Blog selection criteria.** I conducted keyword searches on Google using the following queries: father of child with autism blog; father autism blogs; father of autistic child blog; fathers and autism; fathers blogging about autism. The blogs I accessed are public content, meaning they do not require the reader to be a member of a certain site, complete any sign-in, use a password, or submit any contact information in order to access the content of the blogs. Because I, the researcher, have no control of what demographic information the blog authors choose to reveal in their postings, the inclusion and exclusion criteria for the proposed study were purposefully left quite broad. Firstly, a diagnosis of ASD is implied through the blog content, so evidence of a formal diagnosis is not required; no exclusions were made based on the spectrum severity. Additionally, I have only selected blogs that are written in English, for logistical purposes, and that have been authored by fathers currently living in North America. Blogs authored by biological, step, or adoptive fathers were intended for inclusion, although all blogs included in analysis were written by biological fathers (when this information was available). Blogs that were regularly co-authored by mothers or another individual were excluded, as were specific blog posts written by guest writers. Lastly, blogs produced or sponsored by professional or academic organizations were not selected for analysis.

The blogs analyzed for this study met the following criteria: they were found through a Google keyword search or through a modified snowball convenience sample (e.g., link found in sidebar of another father-authored autism blog; see Keim-Malpass, Albrecht, Steeves, & Danhauer, 2013); required no log-in, registration or password to gain complete access; and allowed for readers to leave comments. Additionally, I did not interact with the blogs in any way (e.g., left no comments), created pseudonyms for the authors and removed identifying data (e.g., names of schools, institutions, children, etc.). In total, 18 father-authored blogs were included for analysis.

**Blog entry selection criteria.** The entries chosen for analysis were selected based on the extent that they specifically mentioned or dealt with aspects of living with and/or fathering a
child on the autism spectrum (e.g., not entries about their work meetings, etc). Entries of less than approximately 200 words were not selected, in order to ensure richness of data. Additionally, I focused on blog posts from 2009-2013 to ensure that I captured the most up-to-date and relevant experiences of fathers living with a child with ASD, and also served to maintain a manageable data set.

**Saturation.** Instead of imposing numerical cut-offs, a more positivist practice, theoretical saturation served as the indication that a sufficient number of blogs had been accessed, and that an appropriate number of entries were analyzed. Theoretical saturation refers to the researcher’s growing confidence in a theme or theory as the emerging data deepens in support of the proposed explanation (Daly, 2007). I analyzed a total of 180 blog entries; the first 100 entries served as the foundation for analysis, and an additional 80 were consulted (from different blogs) to ensure that the data were saturated, in that little new data or information emerged and no new thematic or theoretical insights were triggered (Charmaz, 2006, as discussed in Liamputtong, 2013).

**Operating under the social constructionist paradigm**

Throughout the creation and implementation of this research project, I, the researcher operated within a broad social constructionist paradigm (Berger & Luckmann, 1967), adopting a subjectivist epistemology. In research there exists a continuum of epistemologies, with researchers being able to position themselves between a wholly objectivist orientation (which seeks to access and explain an external, objective, “non-negotiable” reality) and a wholly subjectivist position (which accepts the relativity of knowledge; Daly, 2007). I find myself nearer to the subjectivist side of the scale and accept a co-created, shared reality. I recognize that the themes I identify may not necessarily represent the truths of the blog authors’ experiences or intentions, and that another researcher may find other themes and/or codes they consider important; essentially, I accept that there exist a nearly infinite number of potential alternate constructions of experiences and events (Burr, 1998). While a “true” reality may exist—especially from the participants’ perspective—I do not claim to tap into that, but rather construct and present my own “reality” of the data as I perceive it.

A social constructionist approach insists that researchers “take a critical stance toward our taken-for-granted ways of understanding the world” (Burr, 2003, p. 2). Social construction
challenges the positivist view that knowledge is based on unbiased and objective observation of the world. Applied to the present study, I take the stance that fathers’ experiences do not occur in a vacuum; rather, they are impacted by their unique social surroundings—interactions with their spouse, children, work, community—which may be fluid and ever-changing. For me to claim that my observations of fathers’ blogging behaviour are unbiased and wholly objective, and that my analysis represents a tidy, universal truth of fathers parenting a child with an ASD would devalue each individual’s social construction of their own reality. For this research project, the importance of the participants’ voices takes precedence, and my analysis is a collection of observations supported by the fathers’ expressed realities. It is recognized that removing all bias and subjectivity from analysis is unrealistic, but that best efforts were made to remain true to what the fathers are expressing.

Analysis

Research questions

In consultation and discussion with my advisory committee, it was decided to keep the research questions for this thesis very broad and inclusive due to the exploratory nature of this study—both in terms of the sample as well as the method. The questions guiding my analysis of the blogs were as follows:

*Research Question #1*: What are fathers expressing in their online blogs? How do they describe their experiences and emotions?

*Research Question #2*: What, if any, differences exist between the experiences and perceptions of these fathers when compared to the experiences of mothers in the existing autism literature?

*Research Question #3*: What, if any, similarities exist between the experiences and perceptions of these fathers when compared to the experiences of mothers in the existing autism literature?
Data analysis

To analyze my data, I followed the six-phase approach to thematic analysis prescribed by Braun and Clarke (2006), which involved: 1) familiarizing myself with the data; 2) generating codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and finally, 6) producing the report. Thematic analysis was an appropriate approach for this project due to the exploratory nature of the research questions. The data were analyzed through immersion (multiple readings), and were subsequently coded using computer-assisted qualitative data analysis software MAXQDA, Version 10 (VERBI, 1989-2012).

I engaged in line-by-line analysis of approximately 100 blog entries, resulting in 78 codes. The codes were identified in a data-driven, rather than theory-driven, manner. The identified codes were then considered and collated into various themes and subthemes, based on their relevance to the identified research questions. Analysis of the data was loosely guided by the resilience and contributational frameworks, as discussed earlier in this thesis. The lenses informed what themes were identified; in other words, I did not conduct a blind or uninformed analysis (Aronson, 1994). While these lenses informed by analysis, I was not constrained by them in that I included space for those themes and/or subcategories that did not neatly fit into the frameworks. I sought to extract general themes rather than report unique experiences (Groenewald, 2004; Zeman, Swanke, & Doktor, 2011), so due consideration was given to salient themes regardless of their relation to contributional or resilience theory. Similar codes were then collapsed into one another, and similar, salient (e.g., most universally endorsed) codes were grouped to create themes. Though collaborative discussion between myself and my advisory committee, four themes were identified, tied together by an overarching message resulting in the development of a model: “Living with New Normal.” Once the tentative themes were identified, I accessed an additional 80 blog entries from eight previously unanalyzed father-authored blogs to ensure that the identified themes were represented in this additional data and that no new salient themes or ideas were identified that had not been represented in the model. This model and its supporting themes and subthemes will be discussed in the following section.
Findings and Interpretations

Experiences of parenting and family life as described by these fathers were analyzed, and the following thematic classifications were described: stress, coping, crisis, and resilience (see figure 1). These themes were tied together under the model heading of “Living with New Normal.” It is also worth noting that the themes are not necessarily meant to be mutually exclusive; for example, subthemes may be seen as belonging to both the coping and resilience themes. Rather, it is simply a method of simplification and interpretation, and another reader may label a behaviour, quote, or theme slightly differently than I have.

Throughout the following sections, the fathers’ names (and/or blog name/title) have been replaced with pseudonyms. All proper nouns in the blog quotations have been removed (e.g., cities, schools, therapists, etc.); the names of other family members have also been replaced with “[my wife],” or “[my son/daughter with/out autism].”

Figure 1. Model of Living with New Normal
Model: “Living with New Normal”

The title for this model, “Living with New Normal,” came out of a reaction to the concept of balance. It was felt that “balance” speaks to an end goal or an idealized result, such that if one is not experiencing this ambiguous sense of equilibrium, they are parenting poorly and need to strive to correct this imbalance. Conversely, “living with new normal” is a phrase that better speaks to the continual experiences of parenting, and the evolving and changing relationship of the father to autism; it places emphasis on the journey, rather than the destination, in a non-stigmatizing and non-prescriptive way. Additionally, balance was not a concept that seemed to be heavily endorsed by the fathers; they did not identify it as a goal, but rather focused on getting through the “now” as best they could. Every day created a “new normal,” in that each day came with its unique experiences, requiring the father to respond in kind but with no one proper response. The model of “Living with New Normal” aims to capture not just the challenges these autism fathers are facing, but also the positive, life-enhancing elements of their family life with autism. A holistic perspective is the goal, to illuminate the fathers’ experiences without demonizing autism or, conversely, disregarding the challenges that may very well be encountered. The four corners of the model will be discussed in greater depth in the following paragraphs.

Stress

The first theme, “Stress”, captures fathers’ challenges and stresses related to everyday functioning—situations parents of neurotypical children might not have to face but that are commonplace for these autism fathers. For the purposes of my thesis and this model, stress denotes frustration with experiences that interrupt daily living and require (or are felt to require) action on the part of the fathers to rectify. Stress is more situation-focused than crisis, which will be discussed later in this thesis, and evoke sentiments of “righteous indignation.” The most salient sources of stress, or daily anxiety, for the blog authors appeared to be challenges navigating various systems, societal reactions and ignorance, and their reality of simply living every day under an autism umbrella.
Systemic challenges. One of the primary sources of stress and tension for the father bloggers were issues surrounding their interactions with various societal systems, and interacting with these entities on behalf of their child. Stress was experienced in dealing with ever-changing governmental policies, programs, and funding, which fathers often felt ignored the needs of families and individuals in favour of “big business.” Fathers, such as Terry, felt shuffled to the side and marginalized by the government:

Government entities are regularly trying to change the laws and rules, rarely in a way that helps our children. Policies change or become even more incomprehensible. Budgets get slashed. Our children are discriminated against in places both public and private.

The fathers discussed frustrations surrounding the education system, such as discerning which type of classroom (mainstream, special education, autism-specific) their child would best respond to, where these types of classrooms were located, if they were geographically able to enroll, tuition costs, and so on. Additionally, fathers discussed difficulty in accessing resources such as behavioural therapists/aides, and stress was induced by feeling a disconnect between the opinions of professionals involved in care, the parents’/fathers’ own feelings, and others involved in the management of autism. The fathers described the need for a good fit between the family and the management team, and stress rose as disappointments with the system mounted. As Lance wrote, “doctors may have degrees in their respective fields, but the parent has a Doctorate in their child.” Ryan describes a frustrating encounter with the school, showcasing the ambiguity and complexity that is intrinsic to navigating the education system in support of a child with autism:

My personal opinion at this point is one of doubt. I don’t doubt what the principal was telling me but instead what he was told by the teachers. What the teachers claim doesn’t mesh at all with what [my son with autism] was saying. The reality is that we will never know what was said and done. It’s entirely possible that what the teachers said was absolutely true and it was a simple misunderstanding. It’s also possible that [my son with autism] was right and they blew him off when he needed help.

Adding to the stress and frustrations of dealing with a school system that may be less than equipped to adequately address the needs of their child, the fathers noted that this stress did not fade and was not always assuaged by behavioural aides or other helping professionals. Jared and Ian describe:
We've continued to struggle with getting his aide schedule filled completely. Around the time we got our third aide, the first one quit suddenly. We interviewed several more and hired 2 that never showed up at the agency to get signed on. [Jared]

Hands touch yours, "put your hands down", moving them away from the toys. "Stop babbling." Hands pull you, "eyes, please", push you, make you do things. "Focus..." Hands on your arms, legs, shoulders, back. "Time to pay attention." Holding you still, "not right now", you don't want to be still, "don't do that", holding you still. Frustrating, isn't it? This is therapy. I would hate therapy. If someone came to your home and did all of those things to you, they would likely be asked to leave and never return. Yet, we pay people to do this to our children. We even do this to them ourselves. [Ian]

It is clear that these fathers, particularly Ian, are frustrated by the very nature of the therapy that has been deemed suitable and necessary for his child with ASD; Ian is made indignant and tense over what this process must feel like for his child. What was meant to reduce parental and familial stress—behaviour therapy—is actually having the opposite effect for these fathers, adding to rather than reducing the stress incurred in life with an ASD.

The majority of systemic stress, however, seemed to boil down to fathers being concerned that they were doing what was best for their child, and being frustrated with the struggles their child must face when dealing with various institutions. One father, Stan, expresses a common concern and source of stress for fathers and parents, relating to navigating the systems that are in place purporting to provide assistance:

We all wonder at times if we are doing enough for our child. Have we scheduled enough OT or Speech Therapy sessions? Should we have shoe-horned in some at-home ABA sessions after school? What about that music therapy I've heard about? Horse therapy? Should we look into a service dog? Biomedical treatments, special diets, feeding therapy, and on and on and on... The decisions are endless. The "expert" opinions are everywhere. There simply aren't enough hours in the day or dollars in our pockets.

Similarly, Ryan shares that, “Deep down, I had this nagging feeling that this was going to be another dead end and I simply couldn’t face it. We’ve hit so many dead ends already,” openly showcasing the stress that accompanies what fathers perceive as the peddling of unhelpful and frustrating interventions.
**Societal challenges.** Another source of chronic stress was the fathers’ perceptions of stigma surrounding autism. Much of this stress centered around the concept of other parents acting as if they were unfit parents or poor disciplinarians, without knowing the full extent of the situation. People would often think their child was simply misbehaving or rude, even when confronted by the father or mother about the nature of the situation (e.g., a hidden disability). The fathers felt that many people in society do not fully understand the range of “impairments” that can accompany autism, and that this ignorance caused their family pain. They commented on their children being bullied by peers, marginalized by teachers, and misunderstood even by extended family. The experiences of Terry, Ian, and Leon demonstrate the stress that arises from society’s ignorance:

We live in a world where help and comfort are so often handed out based on whether we think someone deserves it or has earned it. As families, we receive aid and support based on a formula in a budget. We are judged by passers-by in stores who don’t think we are adequate parents and that our kids would ‘behave better’ if we didn’t suck at parenting. If we do get help, it’s so often considered pity or charity by a society that simply does not get it. [Terry]

You don't know me. My life is more complex than just "Bad parent with an undisciplined child.” You created that label in your mind, but here's what you don't know: Discipline is not a cure for autism. I know...weird, right? [Ian]

I know there are people out there who think less of my son and feel the need to remind others that they do not approve of certain behaviors associated with autism. They may even label him different, call him slow or see his disability above all else. Seeing and experiencing these type of discriminatory actions is something that causes me a lot of sadness and frustration... ...I just sit there and wonder why is it so hard for special needs parents and families to find compassion and patience from others... [Leon]

Oftentimes, the fathers perceived that the stigma against and ignorance towards autism spectrum disorders both interacted with and was influenced by the larger systems at play. They found themselves and their child stigmatized in settings, such as schools, that are supposed to be inclusive and supportive. Randall described a situation where “[I] had a school administrator say to me “he was talking out of his head, like he was crazy!” and urges others to suspend judgement before fully comprehending a given situation.

Other fathers also pointed to autism’s label as a “hidden disability” as a source of stress, noting that many people are not sensitive to the differences that frequently coincide with an
autism diagnosis. Fathers even expressed that they themselves entered post-diagnosis life with their own set of preconceived ideas or lack of information. Jason recalls:

After the twins were born, we were looking into adopting another child. We attended workshops and in one class there was a questionnaire in which we had to mark how comfortable we were with children with special needs. There was a long list of diseases, disorders and life experiences. I recall having no reservations about accepting a child living with HIV/AIDS but feeling a lot less certain I could parent an autistic child.

These experiences of their own lack of knowledge, coupled with the stigmatizing comments of other adults, often led the fathers to feel misunderstood. They described feeling misunderstood by other parents, and the discrepancy between their reality and the perceived reality of others caused stress. Some fathers, like Jared, expressed the guilt that accompanied this stress stigma, saying, “I heard somewhere that you're never supposed to apologize for your parents or your children, but I feel like I should.”

Charlie discusses the simplistic ideas that most people seem to espouse when it comes to discussing autism, or putting themselves in the autism parent’s shoes:

Every day someone is asking you if you’ve read the marvelous essay that compares your journey, or your son or daughter’s journey to an unplanned trip to some tulip filled flood plain. Or whether you’ve seen Rain Man. Or if your child can calculate pi to the 100th decimal. Or whether you’ve tried sporn flushing to cure his ‘awful affliction’. And so you trot out the cliches. And the more you trot them out, the more they make you cringe, but perhaps you cringe less than you might if you had to explain it all in your own freshly-minted words every time.

Nathan has experienced similar episodes of societal ignorance and misinformation when it comes to autism, writing:
I’m not sure who said it first, which news agency, which reporter….I don’t know, but whoever reported it was being negligently irresponsible in their reporting. It came out late Friday evening, after the worst elementary school shooting in the nation’s history, that the shooter…may have had Aspergers…some said that he had autism. They could have just as easily said that he was diabetic, had brown eyes, was a New England Patriots fan or had a penchant for sweets…none of it…not a single word of it…had any bearing on what he did or why he did it. To report that it did, as if it DID have any relevance is complete ignorance. Ignorance that will lead the general public to attach a stigma to an already greatly misunderstood and neglected diagnosis.

Everyday life with autism. Everyday life with autism for these fathers included stress related to “normal” family activities or functions that were rendered either difficult or nearly impossible due to their child’s autism. This included things such as attempting a family outing, getting children ready for the day, and even simply trying to have a meaningful conversation with their child with ASD. Stress was created when things that used to go smoothly, or things they felt were a normal part of family functioning, then became a struggle. Charlie shares one such stressful experience, taking his daughter with ASD to a bowling alley:

[Daughter with autism] was not in love with the Alley. The music was too loud. There were too many people. She was visibly anxious, holding on to things to keep her balance and find her place in the noise and bustle, anchoring herself physically. Papa took her outside to wander, but she lost interest and came back inside. I felt really bad about it. I mean, that much...muchness...it was too much for her. But it's the debate we always have with ourselves as parents. Do we push her limits to experience new things or do we exclude her from activities with the rest of the family knowing she'll struggle. [Charlie]

Daniel shared a similarly frustrating experience:

After trying again to “help” [my son with autism] tie his shoes one day and failing again...leaving him almost in tears and me ready to throw a shoe through a window, I took a deep breath and sat back and wondered, why it was so incredibly hard for him?

The fathers expressed that situations that might be handled or dealt with relatively easily in a family with neurotypical children can pose an entirely different set of challenges to a family living with autism. There are more subtleties to take into account; you cannot necessarily tell your child with autism to behave or to allow their sibling to choose an activity because it may simply not be feasible. Jason discusses the stress involved in navigating the needs of multiple children:
One of the things I struggle with is how to make sure that family outings offer both [my son with autism] and [my daughter without autism] the opportunity to have fun and gain important experiences. Truth be told, sometimes we need to react to [my son with autism]’s needs and I feel that [my daughter without autism] does not get everything she needs. I worry about that. I feel that if only I could have thought about every possibility, both kids could get what they want. Of course, it is impossible to plan for everything and sometimes what [my daughter without autism] wants to do means [my son with autism] might miss out on something...

Lastly, the fathers endorsed the all-encompassing nature of life with autism as a nearly universal source of stress. Fathers expressed that practically every aspect of their life now revolved around autism in one way or another; there were no reprieves, and figuring out how to navigate life with a child on the autism spectrum became the centre of their lives, as well as their family life. Bernard writes, “Every minute of every day autism is a huge part of our lives,” and Randall posits that “when [my son with autism] because autistic, we [the family] did too.” This was a sentiment shared by a number of other fathers as well:

I don’t know of a single day the past four and a half years where there wasn’t something to worry over or obsess about. From the illnesses, doctor appointments and evaluations to crying fits, tantrums and frustration for all involved, I now have a hard time imagining a time or a place where autism was not in my life or a part of my everyday thinking. [Leon]

Sometimes I feel like autism is everywhere I look. I talk to parents, teachers, therapists, and doctors about autism. It fills my Facebook feed, podcast feed, e-mail, and a good portion of my thoughts. I am a little pleased that only about half of what I read is autism-related. All this information forms a network that exists in my head/computer/iphone/cloud. It’s my 2013 mental model of the world. It’s not very orderly, but rarely am I surprised when things get added to it. [Harris]

The stress of this all-encompassing identity was further exacerbated in that fathers did not feel understood by others. Relationships that had once been important and close-knit were now drifting apart, as the fathers identified that things that used to interest them or were important to them paled in comparison to their current situation. Patrick recalls:

A friend once said to me "Not everything is about autism, [name]." I apologized and started talking about a movie or some music or an old friend or something... the entire time thinking in my head: "It is for me."

Interestingly, the fathers made it evident that autism had become so central and pervasive to their existence that it even permeated their very identity. When they once may have referred to
themselves as simply “dad” or by their proper name, a number of fathers in this sample called themselves “autism fathers,” and referred to them and their spouse as “autism parents.” It is clear through reading and analyzing these blogs that the father-authors are not as removed from the stresses of life with autism as previous literature would suggest.

Coping

In order to handle the everyday stresses that seem to accompany fathering a child on the autism spectrum, the bloggers in my sample evidenced a number of coping strategies. For the purposes of this thesis, coping refers to strategies employed by the fathers (whether consciously or not) to deal with, nullify, and/or overcome the stresses that accompany being an autism father. These have been divided into coping strategies that “reach out” and those that “reach within.”

**Reaching out.** This subcategory of coping involves the fathers engaging with others as a means to reduce stress, seek out advice and assistance, and generally to absorb the knowledge of others in order to improve their own situation. There is another side to “reaching out,” as well. While fathers extend the proverbial hand for help, they also extend their hand to support others, creating a reciprocal support relationship between themselves (the blog authors) and their readers. This involved seeking advice from other autism bloggers and/or their audience, and seeking to normalize their emotions and experiences as well as connecting with others who are going through similar circumstances. The father bloggers identified what resources they had found to be helpful (such as iPad apps, weighted blankets, certain local parenting groups, etc.), and also sought recommendations for additional resources for issues they had not felt adequately supported in from other avenues.

The fathers identified their blogs as a platform not only to relieve their own stress and share their own stories, but also to encourage other autism parents and build a sense of togetherness. Harris addresses new viewers of his blog, saying, “...welcome to the autism community...we're on a road less traveled and it can be hard, but there's a lot of joy and good friends to be found and occasionally gold.” Another father reveals that his blog is a source of pride for him, saying:
So I've been doing this blogging thing for a couple years now. I am so appreciative to everyone who has taken the time to read my stuff. And it has been humbling to hear that the things I have written have helped a few people. My proudest moments are when I am told that I inspire someone or give hope to someone who is having a down day, week or year. It is literally the coolest thing I have ever experienced. [Stan]

Fathers are nearly unanimous in citing their blogging experiences as a way to cope with the stresses of parenting a child with autism, finding a purpose and a “mission” that is beyond their own local sphere of influence as well as drawing from the experiences of others. A number of fathers share:

Over the years this blog has been crazy important to me. It's my therapy, my soap box, & my confessional. People e-mail me or facebook message me to let me know how much I've helped or how much just reading has be[en] cathartic for them & I'll be honest I'm not sure how that works!...My point is I'm creepy attached to my readers & the people I meet via this community/subculture of special needs parents! [Tyson]

Having a child with autism — or any serious developmental issue — can be a frightening, isolating experience. Hearing or reading the stories of others has been a source of insight and reassurance for me. By writing this blog, I hope to do the same for others. [Alex]

I shared everything over the past few years. Hopefully I have brought solace, insights, enlightenment [sic], and happiness to parents like me. My goal was to give hope to the parents of the newly diagnosed and struggling. To let them know that it gets better. That there was a silver lining waiting for them around the corner. [Bernard]

The fathers also sought to reach out by identifying resources they had found helpful (or not so helpful), and were also quick to both give and seek advice to their audience. Many of the fathers’ posts, such as one by Lance, took the form of encouraging and advice-offering, emphasizing that as autism parents they were all in “it” together. Lance writes:

I thought I would take a moment and share with you some of the important lessons I have learned raising an autistic child. You may want to tuck these away in the ole memory banks so that you can call on them when need be.

His suggestions include taking ‘me time’ and couple time, “celebrat[ing] each milestone with your child like they won the Superbowl,” recognizing that “the system sucks,” and that “when dealing with rude people in public, kill them with kindness. Use that opportunity to
educate … unless they are assholes. Then screw ‘em.” In a different blog, Ian “...challenge[s] each and every one of you to embrace your life a little more. Today. This moment. Right now.”

Ultimately, the fathers express that feeling overwhelmed is normal and that asking for help is necessary, and that together, the bloggers and readers formed an autism community and a safe space to connect with others experiencing similar circumstances. The fathers’ language was particularly interesting; they often referred to themselves and their spouse as autism parents, themselves as autism dads, tying their child’s autism into their own identity. This went hand-in-hand with the fathers’ labelling of an “autism community,” or disability community; blogs contributed to spreading the fathers’ message that “you are not alone” [Terry].

**Reaching within.** Reaching within refers to more internal coping processes that fathers revealed in their blogs. Two key internal coping strategies evidenced by fathers were optimism and humour. These fathers clung to hopes for a brighter future, and were sure to express when their child had met developmental milestones or exceeded the expectations of the behavioural aide; even when expressing frustration when things were not going smoothly, these “negative” stories were often counterbalanced with a confident statement that things would soon be on the up-swing. Jared excitedly shares that “[my son with autism] has continued to make progress in leaps and bounds. I'm more optimistic than ever that he will eventually find his place in the world where he can be happy, healthy, independent, successful and fulfilled.” Similarly, Terry “...refuse[s] to accept that we are doomed to this pattern [discussing frustrating interactions with child], though. I really do believe there has to be a better way.” Lance exults, “Way to go [daughter with autism]! Daddy is SO proud of you! Here is to the future! Whatever it may hold,” displaying a common hope for a future that is exciting and filled with progress, moving beyond whatever struggles and stresses they may be presently experiencing.

Interestingly, this sample of fathers also used quite a bit of humour when blogging. This was expressed through content (sharing stories involving their child with autism that they found funny/cute), as well as writing style (sarcasm, humourous tone of voice), and was a distinct finding that has not been expressed in previous literature with mothers, pointing perhaps to a unique manner of coping fathers employ to deal with the stresses of life with an ASD child. Some instances of fathers coping with stressful situations through the use of humour are exemplified by the following quotations:
Meltdowns, hand ticks, counting, repetitive tasks, & some of the most irrational fears & neuroses I've ever seen. It all adds up to...me having indigestion a need for Tylenol! [Tyson]

[My son with autism] is a sloppy eater. Very sloppy. Our dog loves that he is a sloppy eater because our dog’s diet consists mainly of whatever [my son with autism] drops on the floor. This works out pretty well in that it saves Mrs. [Name] from washing the floor and I get to share my cholesterol medicine with our morbidly obese dog. [Bernard]

The other day though something seemed different. She [daughter with autism] was talking more than usual. She was particularly attentive to her surroundings and interactions with me. She was answering a lot of questions about what she wanted to eat, drink, etc. throughout the day. So I gave it a shot like I had countless times before...“Hey [daughter with autism]!” I said excitedly. She looked at me dead in the eye right away. “Guess what?!” I asked. “Chick-en-butt” she said back to me with incredible over-annunciation that is just so typical [daughter with autism] speech...It was magical and comical all at once. [Lance]

It would seem that fathers are not only focusing on stories that are objectively funny, but are also reframing situations that could be seen as stressful in a more positive, humorous light.

Crisis

This theme is not dealing with crisis in terms of ambulance rides or medical scares (although these indeed were part of many of the fathers’ realities); rather, this theme refers to more of an “existential crisis” – a crisis of faith. For the purposes of this model, crisis is distinguished from stress as being less transient or “in the moment,” requiring deeper reflection and resulting in a more enduring intrapersonal tension. Although, as previously discussed, the fathers expressed a great deal of optimism and hope for the future, the fathers also blogged openly about the more challenging times dealing with the uncertainty of life with autism.

Despair and mourning. Fathers expressed being overwhelmed by the tasks ahead, especially when their child was regressing, and a very salient theme was mourning the loss of the life they had anticipated. As one father, Randall, candidly reveals, “I mourned for the loss of my ‘normal’ son.” Bernard experienced a similar response upon receiving the autism diagnosis for his son, saying:
When we first heard his diagnosis, it felt like getting smashed with a frying pan to the face. It was as though we were handed a death sentence for a crime we did not commit. And this was all before we even began to contemplate the financial burden we now faced.

This sense of loss often gave way to periods of despair and hopelessness, where the fathers felt consumed and overwhelmed, ill-equipped for what life would demand of them. Terry shares:

Two years ago, I went through one of the worst periods of burnout in my life. It was so bad that I dubbed it The Great Burnout. Everything took enormous effort. I was doing everything badly, I was noticeably overweight, my health was going downhill, and I felt defeated. I sincerely believed I wasn’t strong enough to be a parent anymore.

Although perhaps a bit tongue-in-cheek, Bernard “…was certain that raising a kid with a disability like his would mean day after day of wretched misery. All gray skies and gloom. Decades of emotional pain and agony, here I come.” Mason reminisces about what might have been, writing:

Too much pining for little pleasures like play dates, parties, and knock about care free fun that I’m too feeble to suppress successfully; the consolation that he’s content to miss out, tepid comfort at best. Too many experiences where we just can't brook the dam-breaking tears. Too much time selfishly feeling stultified by the shackles of routine, the hours spent on trains (a treat for [my son with autism], at times a tedium chamber for me) weekends at home spend wondering, What if? [Mason]

In addition to their own personal sense of loss and despair, fathers also had periods of despair and hopelessness when they thought about how their child with autism would now face the rest of his/her life. Some fathers write:

After I try to put myself in his shoes for a moment I stop and think if I really do want to see the world as he does for any amount of time. Would I be afraid of what I saw or felt? Could I ever look at the world the same again as I would constantly feel sorrow and pain for what my son experiences on a daily basis? Would I ever be able to stop worrying about him? Who am I kidding? To some extent, all of that is already true. [Leon]
I’m so frustrated, overwhelmed, burned out, scared and feeling utterly hopeless. I simply can’t explain how worried I am about [my son with autism] :’( [Ryan]

It hurts that I can't talk about these things with her. I want so much to be able to help her, support her, guide her through the emotions she is discovering. I know the hugs and the fact that I am always there for her makes it better, but I could do so much more. [Ian]

It is clear that although the fathers may believe in a bright future for their child and their family, at another level they truly appreciate the life-altering potential that can accompany an autism diagnosis. This seems to contradict some disabilities research with mothers, who seem to suggest that fathers minimize or fail to recognize the seriousness and implications of an ASD diagnosis (e.g., Ludlow et al., 2011; Nealy et al., 2012). It would seem, therefore, that fathers are actually much more in tune with the realities of family life with autism than the literature would imply.

**Questioning.** Along with this sense of mourning and grief, fathers inevitably felt guilty for even allowing themselves to be pessimistic and frustrated. Despite all of their efforts to parent to the best of their abilities, these fathers still questioned whether they were doing enough. Ian illustrates this, when he writes:

> It hurts that I can't talk about these things with her. I want so much to be able to help her, support her, guide her through the emotions she is discovering. I know the hugs and the fact that I am always there for her makes it better, but I could do so much more. I want to do so much more.

Leon has similar questions, wondering:

> What happens when you become so involved with autism and helping your child that you have a hard time connecting with others that are not affected? Is that something that other parents of children on the spectrum are concerned with? Does that make me a bad son, brother or husband if I fail to connect with family because I am too focused on special needs?

Jared also questioned whether he was doing enough as a parent, questioning his abilities and expressing uncertainty as to how to best champion his child in a blog entry designed as a letter to his daughter with autism:
...we didn't know if public school was better for you than an autism center. We had just found out a month before that your mother was pregnant again, which brought a whole different kind of stress. We had no idea how to communicate with you, or how to help you reach your fullest potential.

In a separate blog entry, Ian also wonders, “Autism?!?! What the *&$% does that mean?? How do I fix this? What the hell did I do wrong? Or was it my wife? I told her not to eat McDonalds during pregnancy...,” questioning even how autism came to enter their lives and whether he or his wife were somehow to blame.

Some fathers, like Jason, questioned whether they were being a good enough parent to not only their child with autism, but also to their other, neurotypical (“NT,” as some fathers put it) children; the fathers often expressed that they felt their non-ASD children were neglected in favour of paying more attention to the needs of their child with autism. Jason shares:

One of the things I struggle with is how to make sure that family outings offer both [my son with autism] and [my daughter without autism] the opportunity to have fun and gain important experiences. Truth be told, sometimes we need to react to [my son with autism]’s needs and I feel that [my daughter without autism] does not get everything she needs. I worry about that. I feel that if only I could have thought about every possibility, both kids could get what they want.

These fathers also questioned what the future would hold for their child, and wondered whether the ground gained would be maintained, and whether any additional advancements could be expected. Leon “wonder[s], how will [my son with autism]’s speech continue to develop? What other tactics can we use to help him with his echolalia? Will he continue to make positive strides in spontaneous speech?” Fathers expressed needing to re-evaluate their hopes and expectations for their child, which was not identified as an easy or seamless process. One father, Ian, declares, “My child is supposed to be a superstar, remember? Not someone who will need care for the rest of their lives, in and out of doctor's offices, therapy clinics, and stuff. This is bullshit!” Similarly, Ryan reveals that “every day it seems like there is something new to worry about.”

Many fathers, like Leon, also found themselves despairing when they allowed themselves to question or wonder what life must be like for their son or daughter on the autism spectrum, often leading them to question the quality of life their child would enjoy as they grew older. Leon shares, on two separate occasions:
After I try to put myself in his shoes for a moment I stop and think if I really do want to see the world as he does for any amount of time. Would I be afraid of what I saw or felt? Could I ever look at the world the same again as I would constantly feel sorrow and pain for what my son experiences on a daily basis? Would I ever be able to stop worrying about him? Who am I kidding? To some extent, all of that is already true.

I fear that as [my son with autism] matures and his behavioral issues continue people will become even less tolerant of any stimming activity or tantrums.

Existential crises were evidenced in the fathers’ worries and questions regarding their larger family: Would their marriage survive the stresses? Would their child with autism live a long, fulfilled life? Would their other children resent them for the increased attention paid to their sibling? Would they be parenting/caregiver for their child well into the child’s adulthood? These questions were often accompanied by the aforementioned sense of loss and mourning, as evidenced by the following excerpts:

When a doctor looks into your eyes and tells you all bets are off for your child... life as you planned it is over... it has a way of rearranging your priorities a little. In an instant, everything you envisioned parenting to be is thrown on the floor like a jigsaw puzzle... Play dates, Little League, kindergarten, prom, girlfriends, weddings, career... none of it is a given for your child any more. Sure, you mourn the demise of your "typical" life. You cry (a lot). You curse God (guilty). [Stan]

Our obsessing of [my daughter without autism], [my son with autism]’s sister, lands a heavy blow to any beautifying of autism anyway. At six months old, assessing any signs of the condition is perhaps futile. Still, we struggle to not put an autism filter over every tiny thing she does or doesn’t do. Eye contact, eating, initiating gestures. Poring over pictures of [my son with autism] at the same age, looking for clues, doing detective work like some sort of a crank doctor. It’s driven by an oppressive fear that if not tamed, could override everything we do, feel or think. So far, so controlled. But when I can’t halt my darker trains of thought of imagined missed developmental cues and subsequent similarities with [my son with autism], I hurtle to a precipice. [Mason]

These excerpts make it quite evident that fathers are not simply glossing over an autism diagnosis with unbridled or unbefitting humour and optimism; rather, the presence of such deep questions and sense of loss would suggest that the fathers are very much in touch with some of the tougher realities of autism.
Resilience

While the fathers’ own narratives indeed described times of feeling deep grief and loss, the trajectory of the blog content was largely one of resilience; what were seen as “negative” or challenging experiences were bookended with an overarching sense of resilience, or bouncing back, which this theme captures.

The “bright side” of autism. The fathers, like the mothers in the existing literature, often focused on the unique joys and experiences that accompanied the autism which made their life richer; experiences they may not have fully appreciated with the ASD diagnosis. These revelations largely encompassed their own growth as a father, husband, and person, as well as the small victories their child was experiencing.

They discussed uncovering and developing personal strengths that had been dormant (such as being a “butt kicker” and advocate for their child), as well as “autism lessons” – life lessons, “morals of the story”, etc., that they felt they may not have learned if their child did not have a developmental difference. For example, some fathers expressed learning that “different is okay, because normal isn’t real” and felt they were able to be more empathetic to the situations of others; less prone to “judging a book by its cover”. Some fathers, like Leon, discuss the emotional growth they have experienced due to their experiences as an autism father:

My experience these past four years as a father of a child on the spectrum has done something rather unexpected. It has completely destroyed the wall I had built around my feelings. I now allow myself to experience as well as show others a full range of emotions and I have moved past the notion that I should show indifference or stoicism. [Leon]

In addition to emotional awakenings, the fathers also shared how their worldviews had been altered and expanded through autism; they were able to appreciate the potential of autism to nurture their own development as a parent, person, and member of the disability community:
I know I’m getting better at this as time goes on. I am learning new things every day. I am getting wiser. I am figuring myself out. I am growing into my own skin. I am slowly but surely becoming the kind of parent I want to be. And I have two really good little teachers running around the house to help me. [Terry]

I have a secret: I’ve always been uncomfortable around people with disabilities. Obviously, that’s changed a lot over recent years. [Jared]

The fathers also discussed their transition from mourning the loss of normalcy to accepting and celebrating the uniqueness of their child with ASD and family, highlighting the ability of these fathers to bounce back to a place of optimism in the face of the stress and crises that can accompany raising a child with an ASD. Randall is but one example of this, revealing that:

...I still am a little disappointed with myself, though. I mean, I only found out about the normal kid when we went to the doctor after he was born. The kid I wanted, the kid I was hoping for, the extraordinary kid, was there the whole time! I just couldn’t see him because I listened to everyone except him. So now I celebrate my son. I love him for who he is, not who I think he should be...I love the way he expresses himself, because his communications are uniquely his and nobody else’s. I treasure his smile, because I can often get him to share with me what he smiles about, and I smile too. [Randall]

As mentioned previously, a considerable demonstration of the fathers’ resilience comes in their descriptions of their child’s accomplishments or milestones. Rather than dwelling on the thought that their child was lagging behind their peers in whatever skill, even the smallest of achievements was recognized, appreciated, and used as fuel for the journey of living with new normal. Below are just some of the many exultations the fathers gave of their children:
[My daughter with autism], upon her second to last sled run got to the bottom of the hill and said, "I bit my lip." RIGHT?? RIGHT?? Oh, you don't understand. (or maybe you do, but I'll explain anyway, or it's my shortest post ever and I do love to drag things out). We never really know how aware of her own body [my daughter with autism] is... ...Minor pain. Awareness of where it was on her body. Understanding that she was okay. All that stuff seems mind-bogglingly complex to me when I break it down and try to "think through" what the brain has to do in order to process it all, and yet it all seems so ridiculously trivial when I think that it's typically something just taken for granted. [Charlie]

...During this wonderful interaction about the candy another little boy walked right into the conversation and hit [a female classmate; pseudonym Molly]. Yep. Socked her right in the face (this is a Gen Ed class, full inclusion contains some awesome characters, doesn't it?). Molly started to cry and the aide instantly dealt with the little boy. So, as Molly is crying, [my son with autism] asked her why she was crying. "Johnny hit me." "Are you sad?" he asked. Hooray! My son recognized an emotion in another! "Yes." [My son with autism] placed a hand on her shoulder, sweetly. Yes! Joint attention and empathy! "You want me to fuck him up?" Yep. That's what he said. She tearfully shook her head "no". I don't think [my son with autism] knows what "fuck him up" means. I think he's scripting, but not sure. But I do know he recognized emotion in a classmate, I do know he felt empathetic, and I do know he problem-solved. Take the word "fuck" out of the equation and it was the greatest conversation he's ever had. Guess what? I was silently proud. Yep. I was. [Patrick]

It may seem like little thing, but he's never said "really" before to me. It's like he's not been engaged enough in a conversation to express surprise or to question a statement. That's changing...Last week on a trip to the park with his therapist, [my son with autism] saw a bunch of kids playing tag. He ran up and touched one, saying "tag you're it" and joined in the fun. That's huge! [Harris]

The fathers reflected that what many parents of neurotypical children might overlook as normal development and not give a second thought to, were seen by autism fathers as milestones worth celebrating, no matter how seemingly inconsequential. This finding is consistent with previous literature looking at how mothers often choose to frame experiences with autism, focusing on what the autism adds to their lives rather than detracts from it.

*Discovering “new normal”.* A central idea that emerged was that of “discovering new normal.” This emerged out of contemplating whether “normal” existed, and if this was even something worth striving for. By and large, the fathers concluded that society’s ideas of normal are overrated, and that they prefer their unique, if somewhat challenging, family dynamic to a boring, “cookie-cutter” life. Alex speaks about his child’s lack of “normal” social interactions,
saying, “I no longer see these moments of separation from social action as problematic; I’m coming to appreciate his ability to know his limits and find a little bit of calm.” It would appear that he is no longer anxious that his child is not fitting the typical pattern or model of how children are “supposed to” engage socially, but is accepting this “new normal.” Mason alludes to a similar emancipation from society’s constructs of normal child development, blogging:

Then the diagnosis of autism. One mammoth milestone. The confirmation of a lifelong condition that would deposit many a milestone into a morass of maybes. Yet forlornly foraging around in the mental fallout from the diagnosis - after the shock, the tears, the reassurance, the genesis of readjustment - I did discover a perhaps perverse positive in this. A relief even. That maybes and milestones are ok. I broke free from the tyrannical mindset of ‘things must happen’ or ‘things must not happen’ ‘at certain times’. The anxiety ebbed somewhat.

Although they certainly acknowledged the additional and unforeseen burdens and trials they had been dealt through autism, many fathers expressed that although they are overwhelmed, they would not necessarily remove the autism from their lives if they were given that choice. Tyson declares that “…I'm thankful for the odd ball crew I've been blessed with! They are unlike any other & that's A-OK with me!” Likewise, Stan shares:

You start to appreciate the tiny victories in your child's life... victories that neurotypical parents very often take for granted, barely notice and certainly don't rejoice in like we do: His first eye contact with you, the first time he seeks you out for a hug, the first time he shows genuine excitement for an upcoming holiday, the first time he shows disappointment when the Christmas decorations start to come down, the first time he tells you a joke, the first time he shows interest in playing with his sister...I will never forget [date]. We were driving by the beach with my parents. My son screamed from the back seat and pointed out his window, "Look! Fireworks!" My wife broke down in tears. I stopped cursing God and began thanking Him.

A key element of being able to live with “new normal” is acceptance of a different path, recognizing that although their child’s life, their life, and the life of their family would be different from the trajectory experienced by most people but that the difference is not necessarily a bad one; their child and family are no less important and full of potential than anyone else’s. Several fathers reflect on this idea:
Several years ago I stopped trying to “fix” my autistic son and decided to accept him as-is...we realized how unique, funny, beautiful and one of kind [my son with autism] was. Repairs were put on the back burner...[separate blog entry]...Most of the time inadvertently, but occasionally on purpose, the funniest things would come out of his mouth. Life with him didn’t become easier. But it certainly became better. Acceptance and appreciation of my son was fantastic. His autism was no longer a curse. It was merely a part of him that made him quirky and interesting and wonderful. [Bernard]

What I want for my son is what I want for all of my children: a life of ever-increasing independence. I do not want that because he is autistic: I want that because he is an individual. I accept that his path will be different because the path is different for all of us. The path is his to chart and my job is to guide and step back. [Jason]

We are stronger than we give ourselves credit for. I answered the question, How long can I carry a panicked, incredibly strong, 7-year-old, 55-pound child? As long as I had to. We had to make a lot of adjustments. September was very stressful. We were already close to burnout, and this obviously didn’t help. But we made it. We figured out what we had to. [Terry]

If the diverse and complex experiences of these fathers could be neatly wrapped up into a singular phrase or idea, the picture that emerges is one of a never-ending journey, one that not only involves valleys (times of despair, hopelessness, questioning, frustration, and stress) but also affords one marvelous mountain views (celebrations of milestones, newly discovered talents and aptitudes, optimism, humour, and a close-knit community). I conclude this section with a quote that sums up the essence of the model of Living with New Normal:

Are there challenges? Of course. Are there trials, bad days, meltdowns, frustrations, and pain? Absolutely. If you don't grab hold of the positives in your life more fiercely than you do the negatives, then you allow the negatives to define you. [Ian]

Discussion

I turn now to a more in-depth discussion of some of the key findings from this thesis research. Research Question #1 (“What are fathers expressing in their online blogs? How do they describe their experiences and emotions?”) has been thoroughly outlined in the preceding section, ‘Findings and Interpretations.’ I will now discuss Research Question #2 (“What, if any, differences exist between the experiences and perspectives of these fathers when compared to the
experiences of mothers in the autism literature?”) and Research Question #3 (“What, if any, similarities exist between the experiences and perspectives of these fathers when compared to the experiences of mothers in the autism literature?”) in greater detail. I will also discuss the possible implications of mismatched parental perspectives, will address the fathers’ disability-first language, and will conclude with a discussion of the study’s limitations and how this research can be advanced in the future.

**Fathers’ uniqueness**

Two key insights into fathers’ coping behaviours gleaned from this study are consistent with previous research relating to paternal or male patterns of coping. As in the literature, the father bloggers sampled for this study utilized a great deal of humour in their postings, as could be seen in the Coping theme in the previous section. Humour is not a theme or coping strategy that has been endorsed by mothers; in fact, mothers sometimes report that fathers seem to not take the diagnosis of autism or disability seriously (e.g., Ludlow et al., 2011; Nealy et al., 2012). This may point to differences in coping styles that may contribute to a strained marital relationship; if one parent does not understand how the other is dealing with the stresses of life with autism, it is unlikely that they will be able to respond accordingly and may feel isolated. Decreasing this dissociation and increasing awareness of differences in coping between mothers and fathers may serve to alleviate a portion of the tensions that inevitably arise, hopefully improving feelings of support.

Fathers also tended to emphasize proactivity. This often took the form of activism, working tirelessly on behalf of their child with autism to ensure their rights were being upheld and that they were able to have the highest quality of life as possible. A number of fathers share:
Many of us want to write, blog, and advocate. We want to raise awareness about our children’s challenges and make the world a better and more accessible place for them. We want to teach, learn, and grow as parents and adults. [Terry]

I LOVE my child intensely. I will fight harder than you could possibly know and will break through any barrier in my way. [Ian]

This is what makes autism awareness so important. The issue needs to be brought into the mainstream so that people are able to recognize the early signs of autism and to also create a better overall understanding of the disorder. Most people know about cancer, AIDS, diabetes and other serious medical conditions, but how many people who are not directly affected by autism know much about it? Not many. That has to change...[separate entry]...Going forward as we continue to advocate on our son’s behalf we will be faced with a whole new set of challenges. [Leon]

By and large, the findings and interpretation of the present study are consistent with the key assertions of previous research (e.g., Davis & Carter, 2008; Hastings, 2003) that there are likely more similarities than differences when it comes to the reactions, coping, and resilience of mothers and fathers raising a child on the autism spectrum.

**Comparison between mothers and fathers**

When conducting research on mothers or fathers, comparisons to the other member of a parenting duo is inevitable. In consulting the literature that surrounds mothers and “parents,” a number of themes that were identified in those studies were also found in this sample of fathers. Three key themes that were endorsed by both parents were the all-encompassing nature of autism, the need for support and sense of belonging to a community, as well as a journey of “coming to terms” with autism.

The sample of father-bloggers accessed for this project, as discussed in greater detail in the theme of Stress, often recounted that upon diagnosis (or the emergence of ASD-related behaviours) their lives were completely altered. The fathers were no longer just dads, and their families were not “normal families;” rather, they now labelled themselves as autism fathers, parenting an autism family. These same shifts in parental and familial identity were also reported by mothers (e.g., Nealy et al., 2012), who recounted that once the diagnosis of autism was reached, their life became inundated with autism research, attending support groups, following
local and international autism news, and so on. Autism became, for both parents, a central tenet to their family life and to their own existence.

Both mothers in previous research and the fathers in this sample also discussed the importance of resources at length. They identified an initial hunger for any and every autism parenting resource they could access. After the digestion of this initial influx of knowledge, parents identified a strong need for support resources—both for their child, in terms of educational assistance, behavioural therapy, and accessibility, as well as for themselves in terms of social connections to other parents facing similar situations. In this sample of bloggers, the fathers used their online platform to seek advice on which services to access or which products to try, and also served as an informational resource for other parents, sharing what therapies, interactional approaches, and tools had found success in their situations. The fathers also took an active role in being a support to and resource for others, supporting the contentions in previous research that fathers may be more likely to take proactive approaches to dealing with autism. Interestingly, in previous research, parents (mostly mothers) reported a lack of connection to a support system apart from their immediate family (Nealy, O’Hare, Powers, & Swick, 2012). The blogging fathers in this study, though, seemed to feel a strong sense of autism community and garnered a great deal of support from their readers and other bloggers. This suggests that the internet may be seen by parents (particularly mothers) as simply a tool of information rather than a tool of connection and community, and that its function as a “connector” needs to be highlighted to this population in order to bolster and supplement their external support network. It is recognized, however, that the fathers in this sample may be particularly unique in their use of the internet as a tool of communication and connection; further research exploring internet use by autism parents is needed to further clarify these possibilities.

Another notable similarity between mothers in other studies and the fathers in this study was in their descriptions of a journey from worry and struggle to a position of acceptance and resilience. Both the fathers in this sample and mothers in other research (e.g., O’Connell, O’Halloran, & Doody, 2013; Ogston, Mackintosh, & Myers, 2011) reported worrying about the future of their family and their child with autism (often in the form of future well-being and adjustment for child and parent). Despite these challenges, though, resilience was evidenced very often, commonly taking the form of focusing on the silver lining of autism, unique experiences
and perspectives that would not have been as momentous or special without an ASD diagnosis. Mothers in the autism literature (e.g., Bultas & Pohlman, 2014; Kuhaneck et al., 2010), like the fathers in this sample, often expressed hope and optimism in the face of the adversities that can accompany parenting a child on the autism spectrum. Although they acknowledge the stresses, parents seem to prefer to focus on the contributions that autism has made to their family and their lives.

Consistent with the existing literature, the fathers in this sample seemed to present an optimistic attitude regarding the diagnosis of autism and life thereafter (Brody & Simmons, 2007; Cashin, Small, & Solbert, 2008; Flynn, 2012). Both mothers and fathers are committed to reframing life with autism—turning challenges into triumphs, and focusing on the small victories that may be experienced by parents of neurotypical children as a normal or everyday occurrence (e.g., Kuhaneck et al., 2010).

**Clues to mismatched perspectives**

An interesting and important dichotomy identified between the mothering literature and the present study is found in mothers’ and fathers’ perceptions of the other spouse. Mothers have reported feeling inadequate in their roles as both spouse and mother (Nealy et al., 2012). However, the fathers sampled for this study raved about the strength of their wives, and admired them outright. To them, their wife was the champion of their family and someone who was greatly respected and appreciated. Some examples of these sentiments are shared below:

So, since I know she’s going to read this, this is what I want to say to my wife... to my bride, to my friend, to my son's champion, to my daughter's heart and soul, to my legal counsel, to my harshest critic, and to the one that holds my pure admiration. Baby Love, life is a series of choices; some good some bad. Some made by us, some made by others. Our family is the result of a series of good choices, with hopefully many more to come. [Patrick]
But what I really want to say is that this has been an inordinately tough year at the Burrow and my Cheerleader has been right beside me the whole time...not silently, mind you, but beside me none the less. And I really appreciate that. I love her dearly. She is the cream in my coffee, the light to my fire and the bestestest friend I’ve ever had. She takes care of us on a minutely basis, [my son with autism] and [my daughter without autism] and me—and the Twenty-One year old too, when he comes around. She is the backbone of our family and the heart too…and she should probably be more of the brains too, cause I screw stuff up all the time. [Daniel]

It would seem, therefore, that a disconnect exists between what fathers are feeling and what they may be expressing, or what their wives may be interpreting. Being able to bridge the gap between these views may serve to strengthen the marital bond between the mother and father, which has been cited as a key social support network related to positive adjustment in the face of an autism diagnosis (e.g., Nealy, O’Hare, Powers, & Swick, 2012). In this study, the fathers also expressed at times feeling inadequate to the task of parenting and partnering; it may be useful in clinical settings to appreciate that although both members of the parenting dyad feel as though their efforts to be a good parent and a good spouse are insufficient, their efforts are, in fact, recognized and valued by their partner.

There are a number of somewhat contradictory findings between the present study and the existing literature pertaining to mothers and autism. What seems to be somewhat incongruous with the literature is that the fathers in this sample did indeed discuss at length their experiences and emotions surrounding periods of stress, and times of existential crisis, which would suggest that fathers are not as disconnected from the everyday realities of life with autism as mothers in previous research have suggested (e.g., Nealy et al., 2012). Mothers reported that the father struggled with denial over the initial diagnosis—even to the point of ignoring the issue—and were also less accepting of the severity and long-term prognosis of the disorder (Ludlow et al., 2011). These mothers also suggested that fathers were less patient when tolerating ASD behaviours, because they did not spend as much time with the child as the mothers. The results of the present study, on the other hand, paint a picture of fathers who struggle with worry and questions but accept the reality of the autism diagnosis, and respond with optimism and resilience. There was no evidence in this sample to suggest that fathers were impatient in tolerating ASD behaviours. In fact, by so often expressing their deep pleasure and pride in their
child, it would seem that these fathers are much more understanding and supportive of their child with ASD than might be suggested by previous research.

This mismatch in maternal and paternal coping may be heightened by fathers’ humorous approach to dealing with the difficult circumstances that can accompany life as the parent of a child with autism. As previously mentioned, mothers have expressed feeling that their spouses are not as attuned to the stresses of life with a child on the autism spectrum. Perhaps because humour has not been identified as a method of coping employed by mothers, wives may feel that their husbands’ joking approach invalidates their own struggles, and makes light of the potential life-altering implications of an autism diagnosis. However, from this study it is clear that fathers are indeed respecting the gravity of an autism diagnosis, and experience many of the same emotions surrounding grief, loss, questioning, and frustration as mothers have previously reported. Rather, it would seem that humour is one of these fathers’ strategies for overcoming stress and crisis and is not indicative of a flippant attitude towards parenting a child on the autism spectrum. This dichotomous approach to coping may serve to alienate husband from wife, instead of drawing them together to form a spousal support team that has been identified as key to surviving and thriving in this circumstance (Nealy et al., 2012).

**Language and identity**

Of further interest is the language used by these fathers, referring to themselves as “autism dads” who are part of an “autism family,” drawing upon the larger “autism community” for support. In helping professions, there has been an increased focus on the use of person-first language (e.g., person with autism vs. autistic person) as it is felt to empower individuals, reduce stigma, and foster dignity and hope (Jensen et al., 2013; Lipscomb, 2010; Titchkosky, 2001). This practice operates under the notion that a person is not defined by his or her disability; rather, people have various identities (e.g., father, brother, husband, teacher, volunteer, artist) that come together to create the whole person, and that having a disability should not be expected to carry greater “definitional weight” than any other identity (Lipscomb, 2010).

What is interesting in the present findings is that the fathers in this sample often chose to refer to themselves as “autism fathers,” flying in the face of accepted discourse and using a disability or difference to serve as their salient identity marker; it could be interpreted that the
identification of “autism” is more salient to these fathers’ identity and experience than even the identity of “dad.” What is most fascinating is that this primary descriptor (autism/autistic) does not even refer to a disability or difference the fathers themselves have—they are taking on an aspect of their child’s identity as their own. This speaks to the extent to which autism permeates these fathers’ lives; one can certainly not assert that fathers are out of touch with the impact of autism when they have taken on what could be described as someone else’s disability as a key component of their own identity. While some person-first language proponents (e.g., Snow, 2008) have stated that one’s difference or disability is no one’s business but their own, these father-bloggers have gone out of their way to reveal this identity marker to the public. They are sharing their personal experiences and identities, inviting others into their autism reality and reclaiming the language of disability as an important, empowering, and motivating identity of which they are unashamed.

Helping professionals should therefore not assume that “autism fathers” or parents invariably appreciate person-first language and/or are offended by difference-first language; rather, clinicians should ask parents what language they feel most comfortable with moving forward. Indeed, some fathers may refer to themselves as autism fathers but would feel uncomfortable being referred to as such by someone else, or may feel comfortable with that label for themselves but be offended by someone referring to their child as an “autistic child.” The use of language surrounding disability and difference continues to be nuanced and complex, and open discussion on the topic at the outset of a therapeutic/helping relationship is necessary to reduce ambiguity and build rapport.

Family-centered caregiving

The increase in the recognition of paternal involvement in parenting a child with a disability bears some clinical implications. The likelihood that fathers are much more keenly aware of the various emotions and experiences—both positive and negative—that accompany parenting a child with autism would point to the increased importance of a family-centered caregiving/helping approach (FCC). This approach to disability management focuses on the involvement of all family members in developing a management plan, and “...involves ensuring that parents have ultimate control over decision making, treating parents respectfully and supportively, and providing parents with needed information” (King, King, Rosenbaum, &
Goffin, 1999, p. 41). Although the FCC is a model of medical caregiving, it can reasonably be extended to components of family care beyond the medical, to include behavioural aides, educational professionals, case workers, etc. FCC emphasizes a partnership approach between both parents and the existing healthcare team; whenever possible, both parents (and other family members relevant to treatment, such as siblings) attend meetings and appointments so that one parent is not the sole receiver of information, thus reducing the burden of having to pass on this information to their spouse. In this study, fathers expressed that one source of stress was a poor fit between the caregiving team and their family, and also that stress is reduced with access to resources and information. A wider implementation of the FCC model in the care of families of children with autism can increase the father’s role and responsibilities related to caregiving, appreciating that they are not as disengaged to the stresses and challenges that accompany life with autism. It has been reported that families are more satisfied with services utilizing a FCC approach (King et al., 1999) and report greater wellbeing (Kuo, Houtrow, Arango, Kuhlthau, Simmons, & Neff, 2012), but despite the apparent benefits it remains underimplemented (Kuo et al., 2012). Highlighting fathers’ engagement in day-to-day life with autism may bring into clearer focus the need for helping teams to engage both parents equally in processes of medical and educational decision-making, utilizing an FCC system for fullest benefits.

Limitations

Sample and generalizability. Although this study serves to illuminate some unique elements of the paternal experience of raising a child on the autism spectrum, I recognize that this research is not without its limitations. I understand that fathers who blog do not necessarily represent the majority of fathers; indeed, most fathers appear to keep their experiences more private. It cannot be concluded, therefore, that this sample of blogs captures a universal reality espoused by all fathers, or that the authors represent the “average” North American father raising a child with an ASD. This is in large part due to the homogeneity of the sample accessed. The authors of the blogs were all Caucasian men with a nuclear family structure—father, wife, and child(ren)—and it can be assumed that these fathers were not economically disadvantaged given the statistics available for individuals with consistent internet access (Bimber, 2000).

Furthermore, it is possible that the sample of fathers accessed (i.e., those who blog) may be more involved in the day-to-day parenting activities and more engaged in life with autism
than fathers who choose not to blog; after all, one does not keep a travel blog if one does not indeed travel, enjoy travelling, and wish to share this passion with others. There may also be other distinct personality characteristics present in those who blog which differ in some way from individuals who do not use online forums to publish their thoughts and experiences. For example, some research has suggested that individuals who blog score more highly on ‘The Big Five’ personality measures of ‘openness to new experiences’ and ‘neuroticism’ when compared to non-bloggers (e.g., Guadagno, Okdie, & Eno, 2008); however, other studies have suggested that the personalities of bloggers are not significantly different from the personalities of a normative sample (e.g., Li & Chignell, 2008). For these reasons, it is certainly worthwhile for future studies to include a more diverse, non-blogging sample of autism fathers.

In addition to the fathers being very similar to one another, there was also a lack of diversity in the children with ASD. The vast majority of children that the fathers wrote about were young boys (aged 3-10) with relatively high-functioning autism or Asperger’s (when such demographic information was made available by the blog author). Considerably less is known about the experiences of fathers parenting girls with an ASD, those parenting children with lower-functioning autism, or those parenting a child over the age of 10 with an ASD; there is very little data in the autism literature in general that looks at the experiences of parents with a teenager on the autism spectrum, or even parents or caregivers looking after adults with ASD. Given that many autism diagnoses are severe and may require parents to continue hands-on parenting their child with ASD well beyond what they may have expected (e.g., into the child’s adulthood), research exploring this niche of autism fathers—and indeed, parents in general—is sorely lacking but very much needed.

Control of data. Another consideration to be made is the lack of control I, the researcher, had over the data set itself. While it is certainly of great value to be able to analyze information the fathers shared without provocation (as it can be assumed that these represent the experiences and emotions that are most salient and important for the author at time of writing), there are some challenges that accompany the use of such an organic data set. Firstly, I am limited in regards to what information I can gather about the father and their family situation as I cannot simply hand them a demographics questionnaire. Because of this, there are holes in knowledge in terms of the age and autism severity of the child, as well as certain family characteristics, and I
had to rely on deduction and inference in some cases (e.g., if the father was discussing the Toledo education system, I made the assumption that the blogger was located in Ohio, USA), or the information was lacking entirely.

**Filtering.** It is worth noting that while blogs are an “organic” data source, they do not necessarily provide accurate representations of the fathers’ experiences. Instead, it is likely that a filtering process occurs prior to posting a blog entry: fathers will experience or feel something, may dwell on it for a while and/or wait to calm down, may run their post by their wife, write a draft, edit and refine this post (perhaps removing the rawest expressions of crisis) before publishing it to their blog. It is likely that fathers allow themselves time to process events occurring in their life, or may be using the blog as a method of reflection and processing. Additionally, fathers may take breaks from blogging during periods of intense crisis or even during seasons of relative calm; this may result in blog entries only representing middle-ground experiences and emotions. However, this degree of filtering is not solely a potential issue in blog research; indeed, it is likely that some degree of self-censorship also occurs in the classic qualitative research methods of interviews and focus groups. A future study, employing mixed methods, which examines fathers’ and parents’ motivations behind creating a blog, the timing of blog creation and individual posts, and choosing what content to include in blog entries, can further illuminate what role these blogs are playing in parental coping and what purpose they are serving for this population.

**Canadian context.** Lastly, the lack of a Canadian context limits the extent to which the results can be extended to represent autism father-bloggers from Canada. Given the differences between the healthcare and education systems in Canada and the United States of America, there may be sources of stress that are very relevant for American fathers that have less impact on Canadian fathers, and vice versa; similarly, there may exist different resources (and differences in the availability/accessibility of these resources) that alter the autism parenting landscape between the two countries. Using a Canadian sample, situated in a Canadian context, will make future research more applicable for parents of this country.
Moving forward

This study serves as a first step in utilizing qualitative research methods and father-authored blogs to specifically address the experiences of fathers who are actively involved in raising a child on the autism spectrum. Because this study was quite novel and exploratory, it serves to lay a foundation for future work examining this population. It would be ideal to gain additional support for the themes that were identified in the present research by conducting in-person, in-depth interviews or focus groups with autism fathers. Being able to sample from more diverse backgrounds (e.g., socioeconomic status, ethnicity, age, family structure, etc.) is also necessary to more fully represent this population.

Additionally, it is intended for this research to inform service provision in the autism parenting community. As it stands, parents may believe that their experiences are quite distinct from that of their spouse, when this may not actually be the case. Being able to highlight areas of convergence (i.e., similar experiences and coping processes that parents may be able to work through and engage in together) as well as pointing out potential divergent experiences (e.g., humour, father’s perspective of mother’s role) will ideally allow couples to feel increasingly validated, supported, and understood by their partner, leading to a stronger and more harmonious marital relationship, and in turn creating a stronger family unit that is better able to support their children. Therefore, it would be helpful for clinicians (e.g., couple and family therapists) to be aware of the identified patterns and trends in maternal and paternal expressions of stress, coping, crisis, and resilience to be able to provide the most nuanced, beneficial, and non-marginalizing care possible. Being able to bridge the gap between the perceptions and experiences of mothers and fathers is key to creating and maintaining this mother-father support dyad, which has previously been identified by mothers as the most important support relationship (Kuhaneck et al., 2010). Additionally, helping professionals may realize that disability-first language may be used by parents of a child with ASD to represent their salient experiences and identity; to automatically use person-first language may invalidate this parental identity, so a discussion of the parents’ preferred language is be necessary.
Conclusion

The main goal of this research was to give fathers a stronger presence and voice in research, which was accomplished through focusing exclusively on fathers’ organic expressions of their perspectives and experiences as a father of a child on the autism spectrum. This thesis examined what fathers were expressing in their online blogs, and a model of “Living with New Normal” was formed to capture and “normalize” these experiences of stress, crisis, coping, and resilience. The uniqueness of fathers’ experiences were highlighted, and the similarities between this sample and previous research with mothers was also explored. With fathers continuing to take a larger role in parenting activities (Pleck & Masciadrelli, 2004), it is imperative that this population does not continue to be overlooked in research pertaining to parenting a child with a difference or disability. Getting the perspectives of both participants in a parenting duo is imperative to improve family functioning, and it is unwise to assume that the experiences of one parent will mirror those of the other. Moving forward, researchers need to take care to ensure that the voices of all parties are given space and respect, to contribute to a more holistic understanding of situations facing today’s families. Further research examining fathers’ motivations behind creating and maintaining a public, online blog may point to ways in which autism professionals can better use the internet as a source of support, resources and information.
References


