

The lived experience of mothering a child with autism:
a hermeneutic phenomenological understanding

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This manuscript is dedicated to mothers with children with autism. It is with many thanks for their participation in this study. I look up to the women in this study as examples of strong mothers where their voices have not only become the voices of the mothers in this study, but they have also become the voices of *my* mothers.

Abstract

Autism Spectrum Disorder is a complex developmental disorder with increasing prevalence. Despite the significant role of mothers, often seen as primary caregivers, there is limited understanding of this experience. The purpose of this study was to explore the everyday experience of mothers with children with autism. Accounts of lived experience were collected through research conversations with six mothers and analyzed using van Manen's (1990) orientation to hermeneutic phenomenology. The main themes include: It Can't Be Autism, The Womb is Extended, The Locus of Other, and The Womb is Now and is Forever. The findings suggest that mothers experienced a transformation from mother to mother with a child with autism; one that mirrors the transformation from woman to mother (Bergum, 1989). In this transformation, mothers move from suspicion of the potential diagnosis to acceptance that they are mothers with children whose needs define them and potentially, mothers whose wombs are forever extended.

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“Beyond mountains there are mountains”—Haitian proverb (Kidder, 2009, p. 36)

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Chapter 1: Introduction

A Contextual Background

Holding the vessel of life in their belly, women prepare for the change that pregnancy offers. Through pregnancy, a new culture of becoming mother is born (Nelson, 2007). As a new beginning for both woman and baby, the woman transforms into mother with the presence of a child (Bergum, 1997). Viscerally connected by the life of the mother, the deep and relentless connection of the umbilical cord beats in tandem with the life of the child (Bergum, 1989, 1997; Duden, 1993; Rabuzzi, 1994). After giving birth, the “quintessential rite of passage,” mothers have their own stories to share and through sharing these stories with other mothers, they seek validation (Nelson, 2007, p. 93). The stories of others who experience a similar phenomenon, such as birth, loss, adoption, teenage pregnancy, older mothering, as well as experiencing a different kind of mothering children who are unique or different, we as others can begin to see into the world of mother through the dialogues that we share and create (van Manen, 1990). Turning to Max van Manen’s (1990) orientation to hermeneutic phenomenology, we uncover what this experience is like by uncovering the stories of mothers through conversation.

The childhood period is a time of growth and change for developing children, but for parents of a child newly diagnosed with a developmental disorder, the time between birth and diagnosis is often turbulent and characterized by some as a time of uncertainty because of a noticeable lack of development (Mulligan, MacCulloch, Good, & Nicholas, 2012). Autism Spectrum Disorder (ASD), or simply autism, is a complex developmental disorder and phenomenon with an abstruse etiology (American Psychiatric Association

[APA], 2013; Lord, Kim, & Dimartino, 2011). The prevalence of autism spectrum disorders is increasing and, especially with the newest additions and changes to the fifth edition of the APA Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the landscape of autism is changing. Because children with autism often do not show any outward physical characteristics of a developmental disorder, new moms and dads often describe their experience of coming to know that “something is different” (p. 316) with their child as a time of confusion (Mulligan et al., 2012). Differences in behaviour and missing developmental milestones prompted these parents to clarify their suspicions through formal professional supports and informal supports, such as reading literature online. Obtaining the official ASD diagnosis was a lengthy, unclear, and uncertain process, where these parents were often in flux not knowing what to do between the time of suspicion and when they obtained the actual autism diagnosis (Mulligan et al., 2012).

Mothers are often cited as the primary caregiver of the child (Fletcher, Markoulakis, & Bryden, 2012; Gill & Liamputtong, 2009, 2011; Gray, 2003; Kimura, Yamazaki, Mochizuki, & Omiya, 2010; Markoulakis, Fletcher, & Bryden, 2012). Many studies on autism, such as Mulligan et al.’s (2012), focus on the experience of parents, rather than on mothers or fathers specifically. The significant role of mothers reminds us of the orientation to the mothering relation (Bergum, 1997) that we take within this phenomenon.

When we listen to the stories of mothers, such as those in phenomenological studies, we question, what makes the phenomenon of mothering a child with autism essential to the story of mothering (Bergum, 1997; van Manen, 1990)? Even further, we question what is it that makes this phenomenon the very nature of itself (Dahlberg,

2006)? The story of ourselves as mothers and mothers with children with autism help us to understand what it is about the experience of some phenomenon that distinguishes it from something else (van Manen, 1990). In hermeneutic phenomenology, our understanding of essence, as van Manen (1990) points out, comes from the structures of meaning of a phenomenon. This is to say that, when we look at an object, no matter the multiplicity of variations of that object, there is something that makes this object known to us in a universal way (Dahlberg, 2006; van Manen, 1990). This philosophical notion of the essence of a phenomenon emerges from both Husserl and Merleau-Ponty and has subtle hints of the ontological notion that the essences of phenomena or objects have been in the world around us to begin with (Dahlberg, 2006).

The choice of our methodology calls us back to the use of literature as a component of phenomenology where the stories of mothers can be captured in various ways (van Manen, 1990). Looking to other phenomenological literature, we develop an open conversation with the text, such as other phenomenological sources, poems, novels, popular literature, stories, or larger literary works, and extend our understanding of the phenomenon beyond the stories in peer reviewed journals (van Manen, 1990). Other literary works may have already contributed to the discussion of the phenomenon and by having our own conversations with the phenomenon while consulting existing literature, we add to and develop the phenomenon, propelling us forward and reflecting deeper on the phenomenon (van Manen, 1990).

In this hermeneutic phenomenological research, I question, what is the story of mothers' experience of mothering, caring for, and being with a child with autism? When we tell the stories of women, mothers, our mothers, and other mothers (Nelson, 2007), we

have the opportunity to see a world that is otherwise hidden, silenced by the voices of others. By telling the mother's story of autism, we can begin to understand the experience as both an essential and universal phenomenon (Dahlberg, 2006; van Manen, 1990); an understanding that is always coming. In this way, understanding lived experience is both of "the ordinary and the extraordinary, the quotidian and the exotic, the routine and the surprising, the dull and the ecstatic moments and aspects of experience as we live through them in our human existence" (van Manen, 2014, p. 39). Through the explication of the meaning of mothers' experience, we can begin to understand, as fathers, sisters, friends, and others (Bergum, 1997), what it means to mother and what it means to be a special kind of mother as we live *through* this experience (van Manen, 2014).

Within the telling of mothering stories, the exploration of mothers' lived experience is to understand that what we are researching is regarded "as a possible human experience" (van Manen, 1990, p. 58). Using Max van Manen's (1990) approach to hermeneutic phenomenology, the purpose of our endeavour was not to recount the experience as one precise truth, but to understand what it is like to be mother "as an aspect of the possibilities of our being human" (van Manen, 1990, p. 62). We do not imply that there is only one essential reality, rather, that understanding is "a complex and constant interplay between showing and hiding" (van Manen, 2014, p. 343), where *showing and hiding* refer to uncovering what it is about the phenomenon that is always in transit, always covering and uncovering itself to us. Listening to mothering stories, such as in the conversations we have in phenomenological research, helps us to better understand what an experience is like for mothers (van Manen, 1990).

Using a storytelling approach to tell the lived experience of mothers with children with autism, we begin to enter the world of mother in a unique and situated way, in which our detached ability as naïve knowers and unknowers of a phenomenon enables us to enter in the world of Other (Bergum, 1997; van Manen, 1990). It is as if looking through a crystal, our perspective of the phenomenon is meaningfully influenced by the light of our position in the world (Bergum, 1997). As we move towards the experience of mothers with children with autism and through the conversations that we have with these mothers, we can begin to see the spectrum of colour, prised through the unique sides of our mother participants. In this way of constant turning and returning of the crystal, we see this as the essence of the universal and the particular (Bergum, 1997; van Manen, 1990) and this notion of universality and particularity is reflected in Husserl's and Merleau-Ponty's philosophical notion of essence as essentially one view of the phenomenon (Dahlberg, 2006). It is with this tension between the paradoxical nuances of universality and particularity in hermeneutic phenomenology that we discursively turn the crystal and palpate lived experience (Bergum, 1997; van Manen, 1990). It is with van Manen's turn from essence as essentially one view to the idea that we also see beyond the deductive nature of Husserl's essence, which creates the distinction that there are multiple possibilities of experience. It is with the dialogues that we have with mothers in this study that we begin to understand the tension, not relieve it (Bergum, 1997).

Coming to the Question

Perhaps a bit eagerly, I became interested in the experience of mothering children with autism because of the relation to what it means to care for a vulnerable other within a phenomenon whose definition and etiology is historically difficult to ascertain

(Feinstein, 2010; Lord et al., 2011). This difficulty is evident in terms of its prevalence (Ouellette-Kuntz et al., 2012) and criteria for diagnosis, which has undergone significant change in the fifth edition of the American Psychiatric Association's DSM. With the publication of the newest version of the DSM, the DSM-5 attempts to bring together four previous definitions and diagnoses under the term "Autism Spectrum Disorder," which highlights the broad band of disorders to be included, both in differing type and severity, of a number of disorders previously individually classified in the fourth edition of the DSM (APA, 2013). Despite wavering definitions in the literature, several studies have attempted to articulate the family experience of autism. Differing terms of 'autism' in previous studies include *Pervasive Developmental Disorder* (Kimura et al., 2010), *Autism Spectrum Disorder* (Mulligan et al., 2012), *Asperger's syndrome* (Gray, 2003) and autism as a continuous spectrum of disorders (Ryan & Runswick-Cole, 2009).

With the latest revisions of the DSM and a miscellany of definitions in the scholarly literature, clarity in the definition of terms was offered. It is within the obscurity of the phenomenon that we wish to understand mothers' experience of autism, not as a purely definitive definition based on scientifically rigorous diagnostic criteria, but rather, based on how the mothers in our conversations experience autism as a phenomenon as lived (van Manen, 1990). Therefore, variations of the phrase "mothering a child with autism" will be used throughout this thesis. The mindful wording of this phrase attempts to make reference to an orientation to mothers' experience of autism based on their self-identified description or definition of autism as an encompassing word in everyday language (Dahlberg, 2006; van Manen, 1990).

Coming into the research with an orientation to the landscape of previous and current literature (van Manen, 1990) and a contextualization of my own assumptions about the phenomenon (McNamara, 2005), it is important to maintain the integrity of mothers' language of the experience of autism while still sensitive to the literature and a strong orientation to the methodology (van Manen, 1990). The collaborative aspect of the research conversation (Cotterill, 1992; McNamara, 2005; van Manen, 1990) carries a commitment to being oriented to the language of our question (van Manen, 1990). Although our purpose is not to validate the diagnostic criteria of autism, we also cannot simply ignore the language of the DSM (APA, 2013; McNamara, 2005). The delicate balance between prescriptive sources and the interpretive sources of our participants reflects the collaborative and dialogic nature of the research conversations, as well as the inter-subjectivity of experience (McNamara, 2005; van Manen, 1990).

The language within this research thesis is a result of listening to and for mothers' own linguistic descriptions of her lifeworld, her experience as lived (van Manen, 1990). Furthermore, autism, as a vernacular, is used to describe the miscellany of terms used by mothers with children under the autism spectrum. By maintaining a conscious orientation to the language of mothers' experience, we are consistently reminded of the purpose of this research, as we seek experience as lived, not as prescribed (van Manen, 1990).

Within this research, I use the pronoun "we," which is an extension of the notion of hermeneutic phenomenology "as a possible human experience" for both researcher and participant (van Manen, 1990, p. 58). Conjugates of the *we* pronoun are used throughout as both a confession of self-experience and as a self-reflexive tool to investigate and understand the meaning of the lived experience within a co-created dialogue between the

researcher and the participant (Cotterill, 1992; van Manen, 1990). The use of the “we” pronoun is an offering of my own reflexive understanding and a statement of my position of how I view knowledge as a socially constructed creation among multiple perspectives. I do not, and cannot, have sole ownership of the dialogue between the phenomenon and me. It is only through relation with the mothers experiencing the phenomenon that I can develop conversation of what that experience is like within that phenomenon. There must be acknowledgment that both parties are in the conversation, in that there is a partnership as “we-partners” between the speaker (myself) and others (mothers with children with autism) (Spiegelberg, 1975, p. 223). Therefore, use of “we” throughout the research is reflective of the constant orientation to the belief that the conversation is built as a co-created partnership.

Orienting to the Phenomenon

Coming to the phenomenon, I question: How does it mean to be the mother of a child that is both poorly understood because of the often intrinsic features of an autism diagnosis (APA, 2013) and because of an ambiguous diagnosis or no diagnosis at all (Feinstein, 2010; Lord et al., 2011)? In the search for meaning of mothering within this phenomenon, I am situated in a tension, not between what I bring to the phenomenon, but I propose, it is perhaps what I do not bring to the study of this phenomenon (van Manen, 1990). Because I am not mother to a child with autism, I am, paradoxically, situated in a tension (Bergum, 1997) between defining what it means to be mother and understanding what the experience of mothering a child with autism is like when I am not a mother, nor have I, in time, space, or body, mothered a child with autism.

Perhaps my own interest and subsequent orientation to the phenomenon of mothering a child with autism emerges from an ineffable inquisitiveness of what it means to care for a child with a disorder that is often unknown in the very first few months and even years of the child's life (Lord et al., 2011). There is vulnerability felt as we move through life transitions, never certain that our expectations of what we want or imagined for ourselves will be fulfilled by the reality of what life transitions offer us. How do we transition through life changes, never fully certain that what happens next will be what we want? Being vulnerable can mean being open to change, positive or negative, and in my own experience, understanding that it is okay to be vulnerable. In being human, and being women, we open ourselves to the experience of vulnerability as a shared experience that transcends beyond the boundaries of a particular person or phenomenon.

In coming to the question and orienting to the phenomenon, it is the universality of vulnerability as a human experience that is shared in the experience of life transitions. For women, as Bergum (1989) suggests, there is a significant change seen in the transformation to motherhood. Is it possible to know and understand, and even relate to the phenomenon in a way that transcends the defining elements of motherhood, such as having a child? How do we, and more so, how do I, listen to mothers' stories? As a naïve knower, which van Manen (1990) suggests comes through previously reading both scholarly and literary (fiction and non-fiction) sources, my orientation to the phenomenon has been shaped in a way that has been presented as both as a knower and an unknower.

The position or view that I take in my grounding, orientating, and coming into the phenomenon is influenced by my assumptions and thoughts as a nurse, researcher, and my own sensitization to how the phenomenon is presented in the public. Propelled by a

consciously heightened representation of autism in the media and fictional literature, my interest in the stories of mothers with children with autism has become a part of my growing interest as both a nurse and a researcher.

Therefore, researching mothers with children with autism seems particularly relevant, given the presence of children with autism in the media, such as in stories highlighted in the *Toronto Star*'s multi-part feature titled *The Autism Project* with exclusive features on mothers, exploring the often silent voice of the mother, family, and child with autism (Green, 2013). Most recently, the story of Jacob Barnett, a child with autism from Indiana, is told through the perspective of his mother in the non-fiction book *The Spark: A Mother's Story of Nurturing Genius* (Barnett, 2013), which highlights the mothering role of caring for a child with autism from the lived first-person viewpoint. Other fiction works, such as Lisa Genova's (2012) work entitled "Love Anthony" shares the story of Anthony who was diagnosed with autism at three years old. Written from the perspective of both Anthony and his mother, Olivia, Genova's (2012) book offers a rare glimpse of mothering and autism from the eyes of both mother and child. These public pieces of writing (Barnett, 2013; Genova, 2012; Green, 2013) place mothers with children with autism at the heart of more accessible literature while creating awareness and sensitivity to the phenomenon from a first-person perspective.

The turn to the question of mothering a child with autism is prompted by a curiosity about a phenomenon that is encumbered with ambiguity. This very ambiguity is reflected in debates regarding the definition of autism as a spectrum of disorders and the changing criteria for diagnosis. By implication and evidence, there is a lack of understanding about mothering in the face of ambiguity. With mothers often as the

primary caregiver, there is a significant need to understand the mothering relation with implications for nursing practice, research, education, and policy.

The choice of phenomenology as the methodology enables the exploration of the lived world of these mothers as a relation to a different kind of mothering. Through phenomenology, we collect accounts of lived experience to not only describe the life way of the mother, but also to interpret the meaning for these mothers, and what it is like to be this mother. Through van Manen's (1990) orientation to hermeneutic phenomenology, we bridge description and interpretation, exploring the lived experience of mothering a child with autism by curiously asking, "what is that like?" (van Manen, 1990, p. 46).

Chapter 2: Literature Review

The purpose of providing a landscape of past and current literary sources, and especially of other hermeneutic phenomenological literature, in hermeneutic phenomenological research is to become oriented to the phenomenon by understanding what conversations with this phenomenon are taking place, as well as those that have already taken place (van Manen, 1990). By reading phenomenological texts on mothering children with autism or explications of this phenomenon, we become sensitive to the interpretive orientation of the dialogues in our own research (van Manen, 1990).

The question in phenomenological research is not that we should or should not consult other research *a priori*, but that we do so with a scrutinous curiosity that enables us to further understand our own meaningful interpretations in latter phases of our research (van Manen, 1990). Hinting at Husserl's notion of bracketing and being mindful that much is still unclear as to what is truly meant by the term *bracketing*, it is important to be aware of how we have, in body, time, and space (van Manen, 1990), encountered or not encountered the phenomenon of discussion (Dahlberg, 2006; van Manen, 1990). A discussion of reflexivity and the researcher will be offered in the discussion of the research approach and methodology (chapter three). For now, this chapter offers a landscape of the current literature as a dialogue between the current and past conversations with the phenomenon (van Manen, 1990).

Mothering

What does it mean to mother and to be mother? With Old English and Proto-Germanic origins of the word *mother* (Hoad, 1996; Stevenson, 2010), the relation between the mother and the child is described as one who has given birth to the child or children

(Stevenson, 2010). As a tender verb, *to mother* means to “bring up a child with care and affection,” (para 4) and has specific relational undertones, such as the female who has “given birth” (para 1) to a child or children (Stevenson, 2010). Can we, in any sense, pin down what mother means or define it in such a way that signifies the difference between a woman and a mother (Bergum, 1997)?

Bergum (1997) expresses that “mothering, as life, is a journey that blurs the distinction between separate, autonomous individuals—mothers and children” (p. 169). Between these two autonomous individuals, along the journey, is the mothering relation (Bergum, 1997). This relation between mother and child is the journey and “the mothering story is the relational story by its very nature” (Bergum, 1997, p. 169). Cyclical and discursive, the mothering relation is the very basis of the relationship that Bergum (1997) proposes when women experience mothering as a thoughtful consciousness, such as that of “a child on her mind” (Bergum, 1997, p. 14). In this way, we experience mothering as a relational commitment to the self and to the Other (the child) and it is the very essential nature of being born to woman that we experience this relational commitment, because, as Bergum (1997) proposes, this phenomenon is the “primordial experience of relationship. It is *the* relationship of which all other experiences are built” (p. 136). Not only is it this primordial relationship, but it is also, as Bergum (1997) points out, a “body/mind experience” (p. 13) in which we mother and come to be mothers different than that of fathers. When women decide to have a child or give life to children, “the desire is to experience what our mother, our grandmother, and a line of women before us did” (Robb, n.d., para 10). There is significant tradition in the mother and mother relationship to be explored and uncovered.

Not all women are mothers. Women become mothers through pregnancy and with the birth of the child, a mother is born (Bergum, 1989, 1997). In practice, this transformation may not be simply distinguishable; the line of woman and mother may not be clear. At what point in pregnancy does the woman become a mother? At the beginning? At the end? What about adopting mothers who may never experience pregnancy, but experience the presence of the child? What about women who miscarry or women who choose to “give up” her baby through adoption or abortion? It is with these questions that literature is born of the experience of women, pregnancy, and mothering. Mothering literature in multiple facets has explored the experience from the woman’s perspective. We look to literature on mothering, sometimes for reference, validation, reassurance, perhaps advice, or to see if what we are doing is *right* (Nelson, 2007).

Looking at Chesler’s (1998) *Diary of Motherhood*, we peer into the sincere thoughts of a woman struggling with the transformation from woman to mother. Phenomenologically a lived description of motherhood, Chesler (1998) tells us what it is like to be pregnant and to become a mother through the conversations that she has with other mothers, describing being a mother as part of her identity, “Yes. Never will I be a ‘mother first’ or a ‘mother only.’ How strange that I regret that this is so” (p. 219). Nelson (2007) describes the culture of motherhood and the significance of sharing birth stories after the baby is born. It is within the stories that Nelson (2007) describes and the way in which Chesler (1998) tells us about mothering that goes beyond a factual account of what mothering is and what mothering could be. Through these stories of mothering, we see a unique phenomenon that cannot be experienced by another unless lived in the first-person perspective.

Mothers and Not Fathers

Why is it the experience of mothers, and not that of fathers, that we wish to understand? What is it of mothers that makes the experience different in a way that is different than the experience of the father (Bergum, 1997; Engel, 2003; van Manen, 1990)? Within the literature on mothering and caring for children with long-term illness and/or disability, mothers are frequently cited with the role of caregiver outside of the normative mothering ideology of care with both internal (at home) and external (external employment) duties of care (Leiter, Wyngaarden Krauss, Anderson, & Wells, 2004).

Landsman (1992) describes the ideology of mothering children with disabilities as a reconstruction of what it means to be a mother, when mothers were expecting the ideological *perfect* baby, exemplifying this experience of birthing a child with disability as “the “death” of the perfect child” (p. 73). Of course, fathers can experience the psychological heartbreak associated with the birth of a child different than what was expected, but it was mothers who conceptualized their relationship with their babies as the “producers of defective merchandise” (Landsman, 1992, p. 77). Within the spectrum of conducting research about mothers and thereby, research about women, we aim for “research that is beneficial for women, not only *about* women” (Gill & Liamputtong, 2009, p. 313).

Although mothers and fathers experience the presence of a child differently (Bergum, 1997), researching for and about women is beneficial for both men and women. Mothers experience the child differently than fathers and others because of the physicality and embodiment of pregnancy and childbirth (Bergum, 1989, 1997; Duden, 1993; Rabuzzi, 1994). Even further, there is a budding relationship being nurtured

between the physical presence of the child in the woman's womb and the connection that the experience of the child in one's life transcends all facets of the woman and mother's life. This experience "penetrates the heart, the soul, and the spirit" (Bergum, 1997, p. 14). More than just a baby in the womb, the presence of the child and what the child means is what distinguishes the woman from the mother (Bergum, 1989, 1997; Duden, 1993; Engel, 2003) and the mother from father.

Autism

Historically, the definition and etiology of autism has controversial origins (Feinstein, 2010). Beginning in the early 1930s, the lines of work of two early autism pioneers, Dr. Hans Asperger and Dr. Leo Kanner, appear to blur somewhere in the proposed "autistic psychopathology" disorder definition (Feinstein, 2010, p. 17). The bumpy early days of both Asperger and Kanner were that of defining children with atypical patterns of behaviour (Feinstein, 2010). Kanner's early writings on autism were on "early infantile syndrome" (Feinstein, 2010, p. 37) and sparked much research on the syndrome after the publication of his writings in 1943 (Feinstein, 2010). Kanner's early papers hint to the allusion of parental contributions to the origin of the disorder, much beyond that of solely a biological or genetic etiology (Feinstein, 2010). Here, the precipitation of the notion of parental blame was conceptualized by Kanner and further clarified by Bruno Bettelheim (Feinstein, 2010). The "refrigerator mother" persona was a pervasive theory that would influence others working in the field of autism theory and research (Feinstein, 2010). Because the definition or cause of autism had not (and has not) yet been pinned down in otherwise diagnostic terms, the cold mother characteristic is still rife throughout later literature.

At this time, there is still change amongst the clinical definition and diagnosis of autism (APA, 2013). Tidmarsh and Volkmar (2003) suggest problems with the fourth edition of the DSM, which lacked rigour in the diagnostic criteria. With the convergence of four previously individual diagnoses, the newly revised and published version of the DSM attempts to create a harmonious definition and diagnosis of autism as a spectrum of disorders, now cohesively termed *Autism Spectrum Disorder* (APA, 2013). The new ASD diagnosis definition attempts to establish the basis for a clearer diagnosis and pathway toward treatment, suggesting that, with a clear and accurate diagnosis, clinicians are better able to prescribe a treatment plan (APA, 2013).

According to the recent changes in the DSM-5, ASD presents in children uniquely and along a spectrum of features, in which the child may present with communication difficulties and may display characteristics of patterned behaviour, where the child has difficulty adapting to change in the environment, often dependent on a strict routine (APA, 2013). The new diagnostic criteria established a move away from the DSM-IV's previous trio of categorical features to only two categorical features (McPartland, Reichow, & Volkmar, 2012) that include "social/communicative defects" and "atypical behaviours," which refers to "restricted, repetitive behaviours, interests, or activities (RRB)s" (McPartland et al., 2012, p. 369). Problems in communication can include "responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age" (APA, 2013, para, 4). Although many children with autism are considered to have normal IQ, Mayes and Calhoun (2011) describe a reciprocal relationship between age and IQ and autism symptoms, where "a decrease in IQ and/or age was related" (p. 754) to an increase in items on the Checklist

for Autism Spectrum Disorder, such as fixations, communication difficulties, and a high tolerance to pain, among other symptoms associated with developmental ability (Mayes & Calhoun, 2011). The latest revisions of the DSM also include more universal criterion for the timing of the onset of symptoms, which must be present during early childhood, even if the diagnosis is not made until later (McPartland et al., 2012).

Although Swedo et al. (2012) describe multiple limitations of McPartland et al.'s (2012) study, McPartland et al. conclude that the changes to the DSM diagnostic criteria for autism spectrum disorder may change the number of children diagnosed with ASD, because many of the children who had previously been diagnosed with Asperger's syndrome or pervasive developmental disorder may no longer meet the DSM-5 criteria. Without such diagnostic labeling, these children may no longer be eligible for services or research inclusion (McPartland et al., 2012). This suggests that parents of those children, who once were eligible for these services, will have to secure alternatives because of the change in the diagnostic criteria, leaving a potentially large pool of children without these services. If services are shortened and tightened, then much of the responsibility may fall to the informal caregiver, who is frequently the mother. A change in diagnostic criteria, as well as the usual burden ascribed to the mother, which falls out of the residue of social blame, as well as the shortfall in services, lends even more urgency for understanding what it is like to mother children with autism and, therefore, what the needs of these mothers might be.

In an updated review of the prevalence for autism and other pervasive developmental disorders (PDDs) analyzing 32 epidemiological surveys from 13 different countries, Fombonne (2003) suggests that the estimated prevalence of autism is

10/10,000. Described as “conservative estimates” (p. 373) of the prevalence of autism and other PDDs, Fombonne (2003) describes the limitations of the prevalence rate of autism, suggesting various possible discrepancies between the 32 articles from 13 different countries included in the review. Fombonne (2003) concluded that, because the studies included in the review differed in methodological design, “the prevalence estimates must be seen as underestimates of ‘true’ prevalence rates” (p. 369). In Ontario, the prevalence has increased from 1 in 189 in 2003 to 1 in 77 in 2010 (National Epidemiologic Database for the Study of Autism in Canada [NEDSAC], 2012, p. 21). In Southeastern Ontario, the prevalence of children diagnosed with autism in both boys and girls is climbing rapidly, with a 142% increase for boys, and a 161% increase for girls between 2003 and 2010 (NEDSAC, 2012, p. 15). With an increasing prevalence of children with autism, there is a compelling need to understand what this means for mothers as the often predominant caregiver for a child with autism.

What does this mean for the child with autism? The DSM criteria suggest characteristics of what autism *may* look like and children with autism may present with diagnostically similar characteristics, but autism is not a single, universal, experience (APA, 2013); the experience of living with autism is uniquely exclusive, as experience is uniquely different for another (van Manen, 1990) even within the same autism phenomenon. Beyond the limits of a diagnosis, what does it mean to have autism and to live with and care for a child experiencing these symptoms?

Mothering Children with Autism

The mothering stories that Bergum (1997) describes of being and becoming mother are proliferative in the literature of the story of mothering and caring for a child

with a disability. In her interactive narrative study interviewing mothers with children with a variety of complex and chronic disabilities, Green (2003) shows that the experience of mothering a child with a disability transcends the disability diagnosis. As a mother with a daughter diagnosed with cerebral palsy, Green dialogues with a mother with twins, where one twin is diagnosed with autism. The experience of mothering a child with a physical or developmental disability had both very similar characteristics, and too, there were divergent features of what it is like to be the mother of a child with a disability (Green, 2003). In their own ways, these mothers share a universal experience that transcends beyond the particular, where both mothers' stories reflect a particularity of a phenomenon within the universal term of disability. Although Gill and Liamputtong (2009, 2011) discuss caring for a child with autism and Asperger's syndrome directly, Green (2003) compares and contrasts the experience of mothering a child with cerebral palsy with another mother's specific experience of mothering a child with autism.

The literature has described the mothering experience of a child with autism in a miscellany of ways, including mothering within the context of the primary caregiver role (Fletcher et al., 2012; Gill & Liamputtong, 2009, 2011; Kimura et al., 2010; Markoulakis et al., 2012) and a few studies (Farrugia, 2009; Gray, 1993, 2002) have explored the perception of stigma among parents with children with autism. Somewhat contradicting the notion of stigmatization, a semi-structured qualitative research study by Gray (1993) found that although parents may have felt stigma, many families did not perceive "as being stigmatized" (p. 118), and fathers more than mothers, affirmed a weak link between the experience of stigmatization and their child's autism. Here, various facets of being a parent to a child with autism are described that challenge the notion of stigma perception,

such as being the mother or father of the child, the severity of the child's diagnosis, and the child's differing behaviour (Gray, 1993, 2002).

Gray (1993) describes stigma perception as the negative feeling of difference felt by parents of a child who is different. More specifically, in a sample of 33 families of children with autism, Gray (2003) looked at the gender role differences that parents displayed in the coping strategies that they used to come to terms with their child's high-functioning autism or Asperger's syndrome diagnosis. Mothers in this study voiced the disparate struggles they faced in caring for their child with Asperger's syndrome, such as the intention to work outside of the home, but had the inability to do so because of the immense demands that their family life places on their responsibility inside of the home (Gray, 2003). Contrastingly, fathers felt less impacted by their child's autism than the mothers of their children, especially because of the fathers' often indirect role in the care of the child (Gray, 2003). Corroborating with this notion, Gray (1993) suggests that it is the mothers who take on more responsibility for the family care, where fathers are more on the peripheral, as "reserve source of support for their wives" (Gray, 2003, p. 635).

Using discourse analysis in a qualitative study of stigma as experienced by 16 parents with children with autism spectrum disorder, Farrugia (2009) found that parents often described the change in perception of their child's autism after diagnosis. Through a medicalized notion of the language used to describe their child's behaviour, parents were able to change the perception of normality in various ways, such as by joining support groups or preparing others through letter-writing (Farrugia, 2009). Although much of the literature reviewed has attempted to include both mothers and fathers of children with autism in the research process, when both parents were invited to interview, many fathers

did not participate or participated in lower numbers than mothers (Farrugia, 2009; Mulligan et al., 2012; Woodgate, Ateah, & Secco, 2008). Despite that these studies offer no explanation for this occurrence, many studies such as those by (Fletcher et al., 2012; Gill & Liamputtong, 2009; Kimura et al., 2010; Markoulakis et al., 2012) interviewed only mothers because of the conviction to explore the mothering experience.

A hermeneutic phenomenological study by Woodgate et al. (2008) looked at the family experience of parenting a child with autism where the child's autism created a separate world for the entire family, rendering the family's feeling isolated socially, from their own child, and from a larger support system. The experience of the family in this study places the locus on the mother and the father, thereby questioning what is the experience of being a *parent* with a child with autism? Here, the experience of mothering is embedded within the family experience and the parenting experience, rather than focusing on the specific mothering experience.

In a Canadian phenomenological study, Posavad (2009) described "the day to day lived experiences of mothers who are raising a child with autism" (p. 7). In this study, the 'everyday' experience of mothers with children with autism/developmental disorders was described in terms of how mothers experience the *procedural* caring for a child with autism. Through analysis of mothers' journals and focus group discussions, Posavad (2009) illuminated what it was like for these mothers to experience a child that was *different*, summarizing the mother role in the family with a child with a disability as, "mothers must be everything for everyone, forced in many situations to give most of their attention to the child who rarely returns the same sentiments" (p. 81). Posavad (2009) described mothers' existential experience of lived body, time, space, and other, through

Foucault's concept of disciplinary practices and Wendall's ideas on the rejected body, where the tension of motherhood is displaced with the notion of disability. Mothers' day-to-day negotiations within the challenges of presenting within the world as 'normal' were illuminated in the narratives of how mothers experienced others in their private, public, and social world (Posavad, 2009).

From a feminist perspective, Jackson and Mannix (2004) explored the experience of mothers in the context of *mother blaming*, where *mother blaming* refers to "mothers being held responsible for the actions, behaviour, health, and well-being of their (even adult) children" (p. 150). This exploratory descriptive study, which included 15 mothers between ages 30 and 50 years, who had at least one child, explored the experience of blame when mothers encountered health care professionals, including nurses. While the study included mothers vaguely and not exclusively mothers with children with autism, mothers experienced feelings of blame when their child experienced acute presentations of illness when encountering healthcare professionals for treatment. Significant findings from this study suggest that women experience judgment from health care professionals, which further exacerbates the feeling of mother blame when the child is sick (Jackson & Mannix, 2004). Important findings from this suggest that the experience of blame is perpetuated from a variety of childhood and older adolescent (up to 17 years of age) illnesses, not specifically on any one kind of phenomenon (Jackson & Mannix, 2004).

In addition to the burden of being blamed for their child's behaviour or diagnosis, women and mothers are more likely than fathers to provide a significant amount of care for their children (Fletcher et al., 2012; Gray, 2002, 2003). They are also more likely to encounter blame and shaming from others, such as members of the public, at critical

points in time with their children because they have failed to meet the expectations of being an *ideal* or *perfect* mother (Gill & Liamputtong, 2009; Gray, 2002, 2003; Landsman, 2009; Jackson & Mannix, 2004). The stigmatization of the “bad mothering” persona has been previously described in the literature, describing Goffman’s (1963) concept of stigma and “social identity” (p. 1), where mothers are viewed by external others, such as strangers (Gill & Liamputtong, 2011; Gray, 1993, 2002; Ryan, 2010). Gray (1993) discussed Goffman’s (1963) idea of “courtesy stigma” (p. 104), in which it is not the mothers experiencing direct stigma, but experiencing stigma because of their child’s presentation of autism behaviours that differ from what is perceived as *normal*.

In Gill and Liamputtong’s (2011) qualitative feminist methodological study, mothers of children with Asperger’s syndrome associated their child’s behaviour with “bad” parenting, where the diagnosis of the child’s developmental disability resulted in mothers feeling relief. This finding is consistent with other studies by Farrugia (2009), Gray (2002), and Mulligan et al. (2012) where the parents in these studies shared feelings of relief after their child’s diagnosis. The diagnosis is considered both a positive and negative event and tends to resolve some of the stigma of a *bad mother* because the diagnosis offers a label even though parents foresee the label of the child’s diagnosis as a struggle for the child in the future (Gill & Liamputtong, 2011; Gray, 2002), and perceived a diagnosis as a confirmation of parents’ feelings (Farrugia, 2009; Gill & Liamputtong, 2011; Mulligan et al., 2012).

Mulligan et al. (2012), in a phenomenological study of eight mothers and two fathers, described the experience of the diagnostic process for parents with children with autism in the greater Toronto area. Often parents described the validation of the child’s

behaviour through diagnosis as ranging from “grief and shock to relief, validation, and empowerment” (Mulligan et al., 2012, p. 319), and parents described this relief in the form of confirmation that the child’s behaviour was as a result of the developmental disorder and not something caused by the parents (Mulligan et al., 2012). Ryan (2010) describes a similar form of relief in a study of parents (five fathers and 29 mothers) of children with autism spectrum disorders. In this study, parents felt relief when they could give out cards that indicated that the child had autism, so that when their child acted out of the socialized behavioural norm in public, they could quell any stigma, judgment, or negativity from strangers towards their parenting style. Parents felt that explaining the child’s diagnosis was a strategy to help strangers understand that the child’s different and unsociable behaviour was not a culpability of the parents (Ryan, 2010) or a result of something the parents had done wrong (Gill & Liamputtong, 2011).

Similar to parents in Mulligan et al.’s (2012) study, other studies have suggested that parents felt that their parenting style was a form of blame for their child’s behaviour disruption from the normalized behaviour of children (Gill & Liamputtong, 2011; Ryan, 2010) and that this impacted parents before receiving the official diagnosis (Mulligan et al., 2012). “Bad mothering,” also described by Gill and Liamputtong (2011), Mulligan et al. (2012), and Ryan (2010), was relative to the child’s behaviour, the diagnostic process, and the diagnosis of autism as a confirmation that their behaviour was a result of the child’s developmental disability, rather than of parenting style (Farrugia, 2009).

The effects of autism on the health of mothers with children with autism have been described in the literature. Mothers face challenges as the caregivers of children with long-term disabilities or illnesses, such as physical and developmental disabilities,

which are not specific to autism (Leiter et al., 2004; Yantzi, Rosenberg, & McKeever, 2007). Fletcher et al. (2012), in the context of mothers with children with autism, described that the burden of care on mothers is often experienced as physical and psychological responses in the time after the child's diagnosis, such as "depression, anxiety, weight gain, and sheer exhaustion" (p. 57) and parents often "put the needs and health issues of their children above their own health needs" (p. 57).

Although this described *cost* of care giving (Fletcher et al., 2012) can be experienced by both mothers and fathers, the experience of maternal care giving, or mothering, is a unique human experience and a pivotal relationship in the care of a child (Bergum, 2007; Chesler, 1998; Robb, n. d.). Mothering is an experience and way of being that moves away from a traditionally passive medical aspect of care (Bergum, 2007). Bergum (2007) describes "the way of the mother" (p. 3), in which it is the relationship between the mother and the child that reflects a kind of mutuality "in person interest (both self and other), engagement (between one and another), and embodiment (integration of body and mind)" (p. 3). It is between these stories of interest, engagement, and embodiment in which the relationship between the mother and the child grows, even before a physical embodiment in the world (Bergum, 2007).

Parents in both Farrugia's (2009) and Mulligan et al.'s (2012) studies described the notion of coming to understand that something may be different or has changed in their child's communication or behaviour. This change led parents to feeling relieved by the diagnosis of ASD or Asperger's syndrome in their child. Perhaps this disruption in the relationship between parents and the child, and, especially between mothers and their

children is because mothers often have increased difficulty coping and experience the child with disability to a greater extent than that of fathers (Gray, 1993; Gray, 2003).

I am curious specifically about the mothering experience and the relationship between the mother and the child with autism, wondering if there is a disruption or change in the relationship at any time after the baby's birth and noticing that something may be different with the child. Despite the assertions of many of the studies reviewed here which describe the mothering experience, few actually focus on the mother's experience, but rather focus on the mothering experience in comparison to the fathering experience. Other studies embedded the mothering experience within the family experience or mothering within the context of disability, as compared with mothering specifically in relation to autism.

Summary and Significance

In the literature on parenting and mothering children with developmental disorders, including autism and autism spectrum disorder, parents often describe an early feeling that "something is different" (Mulligan et al., 2012, p. 36) in the ways their child is acting, behaving, or *not* responding (APA, 2013). Parents often describe feeling unknowing, uncertainty, and disconnection in relation to their child's diagnosis (Mulligan et al., 2012; Woodgate et al., 2008). Children with autism often do not present with any physical features (APA, 2013) of difference from typical development and this feature of unknowing often puts strain on the caregiver role (Gray, 2002, 2003; Mulligan et al., 2012). Described as "metaphorically akin to being on the edge of an "abyss," "cliff," "precipice" or being set adrift in an "open sea"" (Mulligan et al., 2012, p. 320), receiving a diagnosis of autism often decreases feelings of ambiguity and in the literature, this

parenting experience appears to change in its uncertainty over time (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009; Mulligan et al., 2012; Woodgate et al., 2008).

Phenomenological knowledge, which is intended in this study, is significant because of its deep orientation to the phenomenon. “[I]t is what stands iconically behind the words, the speaking and the language” in which the production of knowledge is truly embedded within the values behind the interpretive paradigm (van Manen, 1990, p. 46). Knowing and understanding the language of the lived experience of mothers with children with autism is helpful for other mothers who are in a similar situation thereby creating an open community of sharing. For healthcare providers, understanding the experience of mothers through phenomenological inquiry sensitizes us to the phenomenon, which is seen as a human experience that could be encountered in practice (van Manen, 1990). By knowing and understanding the experience, we as others who perhaps do not or cannot experience the unique phenomenon (Bergum, 1997) can begin to orient ourselves to the phenomenon by keeping it on our minds (van Manen, 1990).

A very limited number of studies in the literature present the hermeneutic phenomenological understanding of the experience of mothering a child with autism. Studies tend to focus on the mothering experience compared to the experience of fathers, and even within these studies, there is limited consideration of autism and the dialogue between it and mothering. Using hermeneutic phenomenology as a methodological tool to understand lived experience as a human experience, research about mothers with children with autism can create a community of sharing and potentially, a network of understanding for mothers who are in a similar situation. Phenomenology helps us to begin the journey of understanding, especially because our current understanding is so

limited. The current, growing prevalence of autism (Lord et al., 2011; NEDSAC, 2012; Ouellette-Kuntz et al., 2012) and limitations of diagnosis and funding, as well as the heavy burden of primary care that is placed specifically on the mother (Gray, 2002, 2003) create a significant need to better understand the mothering phenomenon with children with autism. There is a local and recent need to share the voice of mothers with children with autism, that is both supported by the evidence that has been generated as well as by the lack of evidence that enables us to understand the needs of these mothers and a calling from mothers to return back to the essence of our primordial purpose (Bergum, 2007; Van der Zalm & Bergum, 2000).

Chapter 3: Methodology

Philosophical Grounding

Between the tensions arising from the philosophical origins of this methodology, we understand that we are ontologically and epistemologically tied to, and grounded in, the ideas of our position within the phenomena we study as researchers (McConnell-Henry, Chapman, & Francis, 2009). Traditionally, phenomenology is primarily divided by two distinct ideologies (McConnell-Henry et al., 2009). Although stemming from Husserl, where Husserl's notion of intentionality and objectivity persists in Transcendental Phenomenology, this tradition of phenomenology is juxtaposed with Heidegger's concept of *Dasein*, which lies at the crux of interpretative, or hermeneutic phenomenology (McConnell-Henry et al., 2009). Heidegger's concept of *Dasein* refers to how we are within the world or "what it means to be" (McConnell-Henry et al., 2009, p. 9) and reflects how we have meaning in the world. Dueling Husserl's Cartesian split between the mind and body, Heidegger rejects this notion of intentionality and objectivity (mind/body) from which we cannot take ourselves out of how we mean to be in the world (McConnell-Henry et al., 2009), and this reflects the highly interpretive nature of Heidegger's position of being attuned to, and looking for, meaning in phenomenology.

With both different nuances of these coteries of philosophical phenomenology, each having distinct and diverging theoretical underpinnings, we are situated in this tension both as a researcher of the phenomenon and, too, as a person situated on the outskirts of the phenomenon; me, not a mother, and too, not a mother with a child with autism. van Manen takes us on a journey of hermeneutic phenomenology, attempting to unravel lived experience in every sense of our own orientation to the phenomenon as a

deep orientation to a kind of philosophical being that is both descriptive, nodding to Husserl, as well as toward the interpretive, an inclination towards Heidegger (McConnell-Henry et al., 2009; van Manen, 1990).

Methodology

With broad and varied philosophical roots (Liamputtong, 2009; van Manen, 1990), phenomenology attempts to untangle the contextual lived world of participants (van Manen, 1990). Lived experience is embodied as a “temporal structure” (van Manen, 1990, p. 36), which is socially constructed, ontologically (Tracy, 2013). Based in this co-created interpretive paradigm, “phenomenology is the systematic attempt to uncover and describe the structures, the internal meaning structures, of lived experience” (van Manen, 1990, p. 10). Although the phenomenon could be discovered and uncovered in a multiplicity of ways, the uncovering of the meaning and the essence of the phenomenon within phenomenology is a reference to how the phenomenon is *lived* by the researcher (van Manen, 1990). Through interpreting the question and meaning of the experience, we understand that we explore the possibilities of the phenomenon in multiple ways because “the essence of the question is the opening up, and keeping open, of possibilities” (Gadamer, 1975, p. 266). It is not only ubiquitously asking a question, but “that we “become” this question” as a unique and subjective researcher in an attempt to deeply understand the phenomenon (Gadamer, 1975; van Manen, 1990, p. 43).

Within the interpretive or constructionist paradigm, Tracy (2013) references Heidegger’s concept of *verstehen*, or the understanding of, which refers to “first-person perspective that participants have on their personal experience as well as on their society, culture, and history” (p. 41). van Manen (1990) describes this understanding to be rooted

in the very essence of what qualitative research aims to find; “the *ti estin* question” (p. 33). This question begins with phenomenological research in finding the “whatness” of a phenomenon; “what is it?” (van Manen, 1990, p. 33). In finding out *what it is*, van Manen’s (1990) turn to hermeneutic phenomenology opens up the possibility that we do not need to find one universal truth of *what something is*, but rather, that we open up the multiple possibilities of what it could be. Phenomenological research is often historically divided into two separate perspectives of methodological position (van Manen, 1990) and these will be compared here.

First, followers of Husserl’s tradition take the position of “subjectivity and discovery of the essences of experience” (Moustakas, 1994, p. 45). Often described as descriptive phenomenology, which refers to “pure description of lived experience” (van Manen, 1990, p. 25), Husserl’s tradition of *Transcendental Phenomenology* (Moustakas, 1994) “adheres to what can be discovered through reflection on subjective acts and their objective correlates” (Moustakas, 1994, p. 45). This means that what we see within the structure of the world is what is produced in our consciousness (Moustakas, 1994; van Manen, 1990). Husserl described this conscious experience of a phenomenon to be *Lebenswelt* (van Manen, 1990) or lifeworld. In phenomenological research, the lifeworld asks us to look at the tension between the scientific reality and the abstract qualities of everything else, where “the lifeworld is the concrete fullness from which this abstraction is derived; science constructs, the lifeworld provides the materials out of which the construction arises” (Carr, 1977, p. 206). The description of the lifeworld, which Husserl describes, is more than the reality of what we see, and Husserl focuses specifically on the present and immediate action of the world around us (Carr, 1977). This tension between

the scientific and the immediateness of the lifeworld is resolved in our perspective, where “the pre-scientific life-world in which we always *live* but to which our theoretical reflection has been blinded by our scientific prejudices” (Carr, 1977, p. 206).

The second perspective within phenomenology as a methodology is referred to as hermeneutic phenomenology, which refers to the interpreted experience of our participants, and is described by philosophical proponents such as Silverman and Gadamer (van Manen, 1990). The difference between hermeneutic phenomenology and that of describing the lived experience of a participant is that, within hermeneutic phenomenology, we begin to understand the phenomenon “from the inside” (van Manen, 1990, p. 8). The “whatness” of the conscious experience that is lived by the participant is the conscious experience that we seek to understand (van Manen, 1990, p. 33). Because hermeneutic phenomenology is based in the interpretive perspective of a phenomenon, the meaning of experience is related to the description of an object or phenomenon in a reflexive way that is lived only by the person that perceives the phenomenon (Moustakas, 1994; van Manen, 1990).

van Manen (1990) suggests that in order for us to do phenomenological research, we must first have experience of a phenomenon for ourselves and this phenomenon must be reflected within our consciousness. Husserl saw the world of phenomenology through subjectivity, which “utilizes *only* the data available to consciousness—the *appearance* of objects” (Moustakas, 1994, p. 45). Similar to the way that Tracy (2013) describes paradigm perspectives in that she states “the type of glasses you wear affects the world you see” (p. 38), Husserl saw that experiences are perceived and in contrast to other forms of science, phenomenology through Husserl-coloured glasses would describe the

physicality of the lifeworld in which it “brings the person into focus as the necessary source for explicating experience and deriving knowledge” (Moustakas, 1994, p. 48). The perception of the consciousness and physicality of the world is described in the existentials of the *lifeworld*: lived space, time, body, and other (van Manen, 1990).

Tradition. Although perhaps controversial, phenomenology as a methodology in qualitative research is often contested on the basis of its perceived inability to produce fruitful or pragmatic knowledge (van Manen, 1990). It would be naïve to assume that phenomenology has no pragmatic use, without immediate summations of findings and tangible interventions to employ (Moustakas, 1994; van Manen, 1990). Rather than produce these pragmatic findings, inconsistent with the philosophical underpinnings of the methodology, in a very holistic sense, phenomenology seeks greater depth in understanding a particular phenomenon (van Manen, 1990).

Engendering a uniquely created engagement towards knowledge, phenomenology is evolving as a traditional, yet divergent form of research. In phenomenological research methodology, the theoretical constructs and methodological procedures strive toward a philosophically rooted basis of a consciously experienced phenomenon (Moustakas, 1994; van Manen, 1990). Traditionally, Husserl described phenomenology as a “discovery of the essences of experience” (Moustakas, 1994, p. 45) and focused primarily on “the appearance of objects” (Moustakas, 1994, p. 45). Contrastingly, the works of Gadamer and Dilthey employ a much more interpretive and hermeneutic approach, described as “the art of reading a text so that the intention and meaning behind appearances are fully understood” (Moustakas, 1994, p. 9). Within the hermeneutic approach, we approach our consciousness and our experiences amidst the foggy of

tradition, but accept a broader understanding of meaning and interpretation (Moustakas, 1994; van Manen, 1990). Similarly, the approach of van Manen (1990) is much less traditional in the approach to tradition, where he views phenomenology and phenomenological research as a form of knowledge “scholarship” (p. 29) and method between the structure of traditional human science (Moustakas, 1994), where the rigidity of historical convention is reduced in an effort to “animate inventiveness and stimulate insight” (van Manen, 1990, p. 30).

The Role of the Researcher and Reflexivity

The role of reflexivity within the research process will begin with and align with van Manen’s (1990) discussion of including “personal experience as a starting point” (p. 54). The role of reflexivity within this hermeneutic phenomenological research is to both remain what van Manen terms oriented to the phenomenon, but also to be able “to be reflectively aware of certain experiential meanings” (van Manen, 1990, p. 57). Although not necessarily placing boundaries around the researcher’s own experience (Roulston, 2010) or “bracketing” (Liamputtong, 2009) experience aside, for the purpose of this research, I aimed to follow the guidelines of both van Manen (1990) as well as Dahlberg’s (2006) notion of “bridling” (p. 16). Unlike the varied interpretation of Husserl’s mathematical concept of *bracketing*, where the researcher suspends “one’s various beliefs in the reality of the natural world” (van Manen, 1990, p. 175), which is to say that one can only understand the natural world once these experiential beliefs of the researcher have been cast aside, Dahlberg’s (2006) concept of “bridling” makes possible the idea of the researcher as an interpretive and reflective being (van Manen, 1990).

In gathering phenomenological knowledge, we often question, how is it that we know that what we are describing is not a taken-for-granted reflection of our own self-narrative experience of the phenomenon? Dahlberg's (2006) concept of *bridling* acknowledges that we cannot separate ourselves from the world in which we experience the phenomenon, which honours our ability to be both attached to the world and at the same time, be distanced from the created meaning of the phenomenon. By "bridling," we relax the tight boundaries of our brackets in the world "...in order to give us that elbow room" to fully understand the phenomenon as a created meaning (Dahlberg, 2006, p. 16). Compared to Husserl's concept of *bracketing*, Dahlberg's (2006) concept of *bridling* encourages us to become *we*; it is not that we only suspend our pre-understandings, but that we do so as an "understanding of the whole" (Dahlberg, 2006, p. 16). This means to be consciously aware of how we come to research the phenomenon and also that we understand how we move within the phenomenon as researchers.

van Manen (1990) makes it clear that closing off the experience of the researcher is to close off deep and conscious meaning, for the purpose of the research is not to provide an objectivist account of the participant's tangible experience (Moustakas, 1994; van Manen, 1990). By placing the researcher's experience within the realm of the phenomenon and by confessing these experiences, we can attach our own meaning as a curious explorer of the phenomenon (van Manen, 1990). For this very purpose, this research was conducted in a tone that reflects both the researcher within the first-person perspective within the relationship between the researcher and the participant (Finlay, 2002; van Manen, 1990). The experience of the researcher is an act of the ability to share in the experience as a view of the world from the conscious experience of that person;

how I view the world is different from how my participants view the world (van Manen, 1990). The very act of the conversations we have with mothers places the researcher in an often unintentional and unacknowledged power relation where we tend to question in a way that is subordinate to our conversational other (Cotterill, 1992). It is important to understand that, because our conversations are created in meaning between our participants, *bridling* gives us the ability to acknowledge ourselves within the phenomenon within the dialogue between the researcher and the participant (Dahlberg, 2006; van Manen, 1990) allowing us to see past the abstracting features of that phenomenon, shaped by our own pre-understandings as researchers, into something that shows the phenomenon for what it truly is (van Manen, 1990).

How does one separate from the intense want to conduct the research when our desire and pre-assumptions coming into the research are unclear, unacknowledged, or unaware to us? Not only do we need to critically question our own internal stimuli, but also to do so in a way that reflects the very nature of the essence of what it is that we wish to seek (Finlay, 2002; Tracy, 2010; van Manen, 1990). When we question our position as a researcher, it is not that we wish to throw away these presuppositions that we already come into the study of the phenomenon with, but that we wish to harness them in a way that allows us to acknowledge our naivety (Dahlberg, 2006; van Manen, 1990) as well as our own pre-understandings. Through journaling, we acknowledge how our presuppositions influence or not influence the way in which we see, and subsequently, explore the phenomenon (van Manen, 1990). Further, acknowledgment of my own assumptions coming into the research within the writing of this thesis, as well as the open conversations I have had with my supervisor and committee members about my own

previous experiences as well as my experience within this research project have opened the dialogue of how I situate myself within this phenomenon. Being aware of how I situate myself as a listener and re-teller of mothers' stories, I begin to harness my own pre-suppositions through journaling and writing down key aspects about the research as I progressed through the stages of this project.

Hermeneutic phenomenology is the philosophical tradition and research orientation that guides this research study. Phenomenology is historically divided into two philosophical traditions, one more descriptive and the other, more interpretive. Borrowing from both traditions, van Manen (1990) attempts to bridge descriptive phenomenology with interpretive or hermeneutic phenomenology. Through van Manen's (1990) orientation to hermeneutic phenomenology we seek to collect accounts of lived experience, noting that our writings are only one interpretation of the experience of that phenomenon. Through these interpretations, we open up the possibilities of multiple interpretations (Gadamer, 1975) and begin to understand the phenomenon in a deeply situated way. Being cautious of how we present and place ourselves within the research and within the phenomenon, the role of the researcher is to honour the meanings of the mother participant's lived experience in re-telling her story, but being cautious that we cannot cut off our own perspectives and (pre) assumptions of how we perceive and view the phenomenon (van Manen, 1990).

Collecting Accounts of Lived Experience

Study Purpose

The purpose of this study is to understand the lived experience of mothering a child with autism using a hermeneutic phenomenological design. The lived experience of

mothers with children with autism was explored with a desire and a curiosity to be *within* the phenomenon (van Manen, 1990). Ultimately, the purpose was not to validate the experience as truth, but to be able to share the experience with a community of others.

Research Question

Max van Manen's (1990) orientation to hermeneutic phenomenology and the study of lived experience was used to guide the research process, where van Manen professes, "to truly question something is to interrogate something from the heart of our existence, from the center of our being" (p. 43). The research question navigating this study is, "what is the lived experience of mothering a child with autism?" Following a hermeneutic conversational and relational research approach to the research conversation (van Manen, 1990), subsequent questions used included:

- When did you know that you wanted to be a mother?
- When did you first begin to suspect that you were a mother of a child with autism?
- How did you come to know or think that your child had or may have autism?
- What has your life been like since first *knowing*?
- How has the recognition of yourself as a mother of a child with autism changed the perception of yourself as a mother?
- What did we not discuss that you wish to share?

Because phenomenological conversations are a collaborative conversational process between the researcher and the participant, or co-researcher (van Manen, 1990), rather than a structured exchange of information, our conversations were guided, rather than directed by these open-ended guiding questions. Probes, such as "ok..." "yeah..."

“can you tell me a bit more about that...” and “how were you feeling...” as well as rephrasing and clarifying statements, were used within the conversation to elicit deeper meaning into the expression of mothers’ experience and to move the conversation in a way that was meaningful to that mother.

To clarify meaning or to gain a deeper understanding of the context of the discussion, as well as to penetrate further into a thematic thread of the discussion, follow-up questions explored salient points of discussion. Early in the conversations, mothers described a similar phrase or notion of a child who was “constantly” on her mind, a phrase that Bergum (1997) captured in her work. After discussion with my supervisor, this phrase was explored in subsequent conversations. The intent was not to pre-suppose or dictate the mothers’ experiences, but rather to tease out whether or not this was also the experience of other mothers by asking a question phrased similarly as, “some of the other moms have talked about this idea of their son or daughter always being on their mind, is this something that rings true with you?”

The phenomenological research question acts as a guiding orientation to the phenomenological conversations and grounds the conversation in purpose. With open phenomenological conversations, it is often easy for the researcher to become lost in the dialogue, unsure how to get back to the original research question (Liamputtong, 2009; van Manen, 1990). Although the purpose of phenomenology is for the participant to guide the research with a conscious and reflected experience of the phenomenon (van Manen, 1990), it is still important to remain true to the aim of the research; straying too far away from the intent of the research has implications on the trustworthiness and quality of the research (Liamputtong, 2009; Tracy, 2010).

Recruitment of Mother Participants

Explicit throughout this study, the definitions of mothering and autism are described in a way that reflects the co-created nature underpinning the foundation of this study (van Manen, 1990). Therefore, recruitment of English speaking mothers who were of any age, with a child or children of any age with any type of autism under the autism spectrum (with or without diagnosis) and thereby, with any characteristic or demographic within the autism population, were eligible to participate in this research study. In order to recruit mothers, I displayed recruitment posters (see Appendix A) across one Canadian post-secondary campus. Although other locations would have been utilized to display the posters, such as support groups and community agencies, the recruitment posters and word-of-mouth snowball sampling were effective in recruiting mothers whose sharing of the experience of mothering a child with autism yielded a repetition of themes.

The recruitment poster described details of the study, details of the researcher and how to contact the researcher, as well as the benefits or perceived harm that will be incurred as a result of participation in the study (none perceived). I also recruited at an autism program at a post-secondary campus, where I met and connected with mothers, and handed out letters of invitation (see Appendix B). The majority of the mothers in this study were, at one time, connected or involved with this autism program, even if they were not recruited directly from this program. In order to reach as wide a community as possible, I also attempted to utilize snowball sampling to help recruit potential participants through informal connections and strategies because the mothers were more likely to know someone experiencing the phenomenon (Liamputtong, 2009) than I was. Using this snowball sampling technique, it was hoped that mothers would have networks

within the autism awareness community and would be able to recruit other mothers with children with autism. These connections were quite informal, mostly maintaining connections between the mother support groups that were mentioned during our conversation. Although secondary letters of invitation were proposed, snowball sampling occurred much more informally through word-of-mouth and mothers contacted me on their own if they were interested in participating.

Mother Participants

Qualitative research is often contested because of sampling issues, as well as sample size (Coyne, 1997; Higginbottom, 2004; Sandelowski, 1995). Sample size in various qualitative methodologies differs depending on the aim of the research and the theoretical underpinnings of the methodology (Sandelowski, 1995). Similar to the type of sampling, the sample size in phenomenological studies often varies, but ideally, should remain true to a small sample size (Creswell, 2013; Dukes, 1984; Sandelowski, 1995). Sample size will also vary depending on when conversational redundancy is reached (Sandelowski, 1995).

Higginbottom (2004) suggests that the type of sampling varies depending on the type of methodology and the purpose of the research study, whereas Coyne (1997) suggests that most qualitative research is a type of purposeful sampling and ascertains that variations of purposeful sampling exist. Purposeful sampling refers to the considerations a researcher must make before selecting his or her research sample, where participants are selected because of an identified criterion that is shared between the participants (Creswell, 2013; Higginbottom, 2004). Sandelowski (1995) expands the notion of purposive sampling in phenomenology by advocating phenomenal variation,

where participants are recruited based on criteria directed by the phenomenon of interest. For this phenomenological study, participants were included in the study if they were English-speaking mothers with a child with any diagnosed or undiagnosed disorder (perceived) under the autism spectrum disorder.

Mothers were considered volunteers because there was no incentive to participate. Using participant volunteers allows the researcher to maintain distance from potential participant coercion, where participants do not feel obligated to participate (Liamputtong, 2009). Potential mother participants were instructed to contact the researcher via email to inquire about the research. At the first point of contact, mothers were emailed a letter of invitation and asked to read the letter of invitation and contact the researcher with any questions or comments, which could be addressed at this time. If the mother was still interested in participating in the research after reading through the letter of invitation, a date, time, and location was negotiated to ensure the mother's choice was maintained.

The majority of mothers chose to meet on the university's campus, whereas others chose a more public location, such as a coffee shop, and two offered her own home. When mothers offered to meet at a public location, such as a coffee shop, I reminded them that whatever was shared could be potentially overheard by others and that strict confidentiality in this manner could not be maintained. Informed consent forms were completed on the day of the phenomenological conversation and this process was explained at the beginning of the digitally recorded phenomenological conversation. Before proceeding with the conversations with mothers, participants were given an opportunity to ask any questions relating to the research or informed consent process. Although there was potentially concern for bias or coercion, as mothers were asked to

read through the informed consent process on the day of the conversation with the researcher there, this concern for coercion is minimized because these mothers (seemingly) voluntarily initiated contact with the researcher, who, in turn, sent the letter of invitation. All mothers responded positively to the letter of invitation and, subsequently, a time and place for the research conversation was arranged.

All six mothers had children with disorders that had been clinically diagnosed along the autism spectrum (please see Table 1 for a summary of the characteristics of the mother participants). Each of the mothers spoke English and was able to articulate their experience of mothering a child with autism and therefore, met the criterion for inclusion. Although exact ages of the mothers were not asked, the mothers appeared to vary in age.

Table 1

Summary of the Characteristics of the Mother Participants

Name of Mother*	Name of Child with ASD	Type of ASD	Number of Children	Partner Status of Mother
Helena	Lily	Autism	2	Married
Sarah	Toby	Autism	1	Single
Kate	Adam	Autism	1	Married
Emily	Graham	Autism	3	Married
Victoria	Nathan	Asperger's syndrome	2	Married
Erica	Matt	Asperger's syndrome	1	Single

***all names are pseudonyms**

Mothering stories. The language of another is embedded in the writing process of hermeneutic phenomenology. Within the writing process, the stories told by mothers

reflect the sharing of stories within phenomenology because, as van Manen (1990) suggests, we ask participants to offer “personal life stories” (p. 67). Through our guiding questions within the methodology, we share stories, which become our writing through listening, telling, and re-telling of these stories. Like the birth stories that Nelson (2007) describes, the story of becoming a mother is deeply embedded in a woman’s life. The mothers of this study illuminate the experience of mothering a child with autism in a deep, visceral, and sometimes in an indescribable way.

Vignettes of the six mothers in this study describe their lived moments in their lived environment and are a reflection of the conversational space between the mother participant and me. By presenting the mothering stories as vignettes here, it is hoped that meaning is provided to the individual experience, whereas the presentation and discussion of the findings in chapter four reflects the possibilities of multiple perspectives and experiences as an orientation to the phenomenon and the methodology (van Manen, 1990). The stories of the mothers from this study are presented here.

Helena. The conversation was held at Helena’s family home, where she offered coffee and cookies. Our conversation lasted approximately 30 to 40 minutes with Helena telling many reminiscent stories of her daughters growing up, and breaking up these stories with affirming questions (*you know?*). Helena is the mother of two children, Amelia and Lily. Her second daughter, Lily, has autism. Although Helena laughs with the stories she tells of Lily, there is a tension in Helena’s voice reflected by her timid descriptions as she tells me about her life with Lily’s autism; she asks me if she is answering the questions correctly. Tension is also seen between her description of Lily

and their life after Lily's diagnosis; tension that she knows that Lily has autism and she cannot change this fact. Lily's autism will never go away, the tension is never resolved.

One of the most powerful stories that Helena shares is the process of preparing for Lily's first communion. Because Lily will not willfully eat something that is round, be it a cookie or a cracker, and knowing that the Host for communion is a round cracker, it was important that Helena broke it down for Lily so that she could eventually take her first communion. In taking her first communion, Lily was able to share an experience with her typically developing sister by wearing the same communion dress. Helena states that she recognizes that these shared experiences are few and far between, but she is always willing to *try* with Lily.

A community of sharing is deeply present in Helena's life. This is not only the sharing of experiences between Lily and her older sister; Helena relishes in her mother's group as a *saving grace*. Having what she describes as a *good circle of friends* has been important to Helena. Although she has lost some friends along the journey, she has long-time friends that have been supportive. Helena compares herself to the other mothers, rejecting a *super mom* persona, in that she is not working alone; she commends her family for their involvement and thanks God for the presence in her life. The moms group of which she is a part is much more a shared circle of people that understand what she is going through than a social group that celebrates holidays and meets regularly on Thursday nights during their children's life skills programming nights.

Helena often compares her life to others, in a *it is what it is* sort of way, although I cannot help but be curious about the comparisons Helena makes, perhaps as a longing for something else in her life, something *easier* for Lily, she states. Although it is apparent

from her dialogue that she is thankful that she is Lily's mother, there is still an empty feeling reflected in the tension between what her life was before Lily's autism diagnosis and what it could be or what it could have been, especially within the dialogue that she describes between a sharing of normalcy between her daughters and other children.

Helena describes that she was consciously guarded, wanting to believe that Lily will meet her milestones, but protecting herself from disappointment if she does not. Helena states that even though Lily met many of her early milestones and is accomplishing new goals, there is still a tendency for Helena to feel as if Lily's achievements are not possible.

Sarah. Sarah sat crossed-legged during our conversation, where she spoke optimistically, and positively about her life and the future with her son, Toby, who was diagnosed early with ADHD (Attention Deficit Hyperactivity Disorder), OCD (Obsessive-Compulsive Disorder), anxiety issues, and autism. Even though Sarah and her family have an extensive history and experience working with children with a range of developmental disorders, she admits that she really did not suspect autism in the beginning; maybe, it was something else. Toby is Sarah's only child, *one and done*, she states with laughter. Laughing, Sarah admits to me that before she was pregnant with Toby, she wanted to be like "Kate Plus Eight" and have multiple children, because she always knew that she wanted to be a mother, but life is busy as a young mom completing a second university degree. Sarah had great expectations for herself to be a mom, stating that, even from a young age, she knew that it was her purpose to be a mom. Sarah talks endearingly of the relationship she has with Toby, who is at the centre of her life.

Sarah described her situation as *a little different* when asked about her experience during pregnancy and what that meant to her. Multiple times within our conversation,

Sarah explained that she did not get to enjoy the pregnancy as much as she could have, referring back to how she saw her troubled situation with Toby's father.

She, too, has a community of others. The community of others that Sarah describes is important to herself as a mother with a son with autism because it redefines what it means to be around others who are in a similar situation. Sarah is constantly aware of the perception of others. This community appears to make Sarah resilient to the comments made by others, as she seems to shrug off the negative perceptions and comments made by those around her. Although Sarah has the perception of resiliency, there are still times in the conversation, in which it is clear that Sarah faces challenges, especially when dealing with others. It appears that Sarah struggles with the comparisons made by herself with other children outside of autism, thereby trying to redefine normalcy within the community of other children with autism. She often described an empathetic communal understanding by other mothers who have children with similar diagnoses. The ability of other mothers being able to *get it* was expressed positively. Although she states that she has support from other friends with typically developing children, there is a kind of empathetic communality shared when others are able to *get it*. The perception of others was expressed as a perpetual challenge.

Through Sarah's responses and her outward demeanor, it is apparent to me that she has a vibrant and positive outlook on her life. She explains that she has a supportive group of people around her and is highly involved in her autism mom's group, where she identifies herself as an *autism mom*. She recalls the moment when she finally felt comfortable out in public with her son, a time when other mothers with children with autism reached out to ask her if she needed any help at an autism organization barbeque.

The social aspect of the *autism moms* group is balanced with the need to not have to worry about the stigma or public perception of other mothers with normally developing children. Furthermore, Sarah describes this feeling of redefining the normalization of the mothers groups as a community that is not just for the benefit of the mother, but Sarah also sees it as a community for the children as well.

Kate. My conversation with Kate was held at her home. Kate is a married woman with short blonde-hair. This is the second marriage for both Kate and her husband. Adam is Kate's only son, although she stated early in our conversation that she would have liked to have had two children. There were reasons. Kate explains that she had a *terrible pregnancy* and a *terrible labour*. Further, Kate describes an overwhelming feeling with Adam and an intuition that she only wanted to have one child after the early health problems that she experienced with Adam and the physical exhaustion she experienced after his birth.

Kate and I had many sidebar conversations before and after the tape-recorded conversation. I distinctly remember Kate's suggesting the differences that she sees between herself as a mother and her husband as a father. She explains that, because she spends so much time with Adam as a mother who works inside the home, her husband struggles to make the same connection that she has with Adam. She tells me that he will never be able to communicate with Adam in the same way that a father would with a typically developing child; he will never be able to sit around and watch a football game with Adam like a father does with a child who is verbal, one who can communicate.

Reflecting on her experience of mothering a child with autism, Kate states that she tries to remain positive, but there are times when she needs to cry. She describes her

eight-year old son as a *demanding baby, happy but demanding*. Because Adam is Kate's only son, she is able to focus her time on him. Adam is now eight and had met most of his milestones before Kate first suspected that Adam had autism. Kate showed me a picture of her family: her supportive husband, herself, and their son, Adam, smiling with curly blonde hair.

Emily. Emily is a tall, thin woman with three children. Her youngest son is Graham, she discloses, who is a tall, muscular boy with low-functioning autism. Emily describes Graham as a challenge. Graham is non-verbal, self-injurious, and needs constant, 24/7 care. Many of the challenges that Emily describes with Graham come from the acuity and severity of Graham's diagnosis, as well as from his increasing age, his growing body, and his reoccurring self-injurious behaviours in public. Emily tells me that Graham takes medication to help calm him down and to control his self-harming behaviours. Although Graham is not violent towards others, he is physically violent towards himself; and, because he is mostly non-verbal, he cannot tell you if he has a headache, stomachache, or toothache, which exacerbates Emily's uncertainty. Emily calls this *a guessing game*. Matter-of-factly, Emily says that Graham has an obsession with drinking water and could drink a whole case of water, if allowed; one of the family's unique challenges is that everything in their home is locked up.

He has an obsession with drinking water so he can drink a whole case of water at once if you let him or left it out. So everything in my house is locked up. Food is locked up. Drinks are locked up. But he runs to the neighbour's house and will grab water out of their fridge [laughs]. But I have great neighbours, they let him take it and I will replenish it.

Emily's experience of coming to know that Graham has autism was a realization that Graham was starkly different than her two older sons; Graham was not meeting the milestones that her other two boys were. At eighteen months of age, Emily states that *Graham was not playing with his other siblings, he was not giving any eye contact. He would line things up, he wouldn't parallel play and he wouldn't respond to his name.* Emily describes encountering others in the community asking her if Graham had autism. Emily would brush off these comments, not knowing what terms such as stimming or flapping meant. Emily's story of finally recognizing that Graham had autism came when a woman at a bakery blatantly asked her *does your son have autism?*

For Emily, the process of coming to know about Graham's autism was not linear. Furthermore, she considered herself to be a very athletic and healthy woman. The perception of external causes of autism was a persistent idea against the idea of herself as, what she terms, the mother of a special needs child. Emily could not believe that Graham *could* have autism because she never smoked or drank or did things that she previously believed could cause autism. In some way, Emily's expectations did not meet reality. She considers herself to be a very proactive person and mother, especially at that moment at the bakery when she first recalls starting to come to know about Graham's autism.

Emily's meeting with me is efficient; she tells me frankly about Graham's autism and raising a boy with severe autism. Graham is twenty years old and will be finishing up high school within the next year. Graham is much older than the other children in the study, and Emily describes her experience of mothering an older child as an experience that has changed over time. The flux of her lifestyle has always been a process of being both proactive and guessing at the same time. Emily also describes herself as being in a

sort of “motherly” role with the other mothers in the groups that she belongs to. Here, she describes herself within a group that she terms *autism moms* where a group of moms meet while their children participate in recreation groups. By paving the way for other more ‘younger’ mothers, Emily sees herself as being much more laid back; she has experienced a lot of the uncertainty and change in the beginning of the diagnosis process.

The way that Emily describes her experience is much more reflective. When Emily describes her experiences, these are much more present/future-oriented, in that, she describes her challenges with Graham as *current challenges*, rather than looking to the future to describe potential future uncertainty. There is a very real and very visceral experience of *now-ness* that Emily describes, and it feels as if you are living these moments with her, in tandem as she describes them in detail.

Victoria. Victoria is a soft-spoken woman with two children. Victoria speaks of her children in a reflective, storytelling way. Victoria’s son, Nathan was diagnosed with Asperger’s syndrome when he was around three years old. Victoria spoke in a charming, casual way, laughing and pausing between the lines of her short stories. Victoria became tearful during our half hour conversation and she confessed to me that she specifically left make-up off of her face because she sensed that she would become emotional discussing Nathan and their life within autism/Asperger’s syndrome.

Victoria spoke lovingly when describing Nathan, his likes and dislikes, his unique behaviours, and what she does not want to change about Nathan. Nathan loves dinosaurs and the computer. Victoria also spoke about Nathan’s current preoccupation with skipping. Although Nathan is currently twelve years old, Victoria fears that someone will eventually come along and tell Nathan that he cannot or is not supposed to skip.

Although, she has this realization about Nathan's skipping, she explains that she does not want to be the one to tell him that he cannot skip. In this realization, Victoria has rediscovered skipping for herself and now embraces it as part of her exercise routine.

Erica. Erica met me with hesitation and reservation; she was worried about the potential implications that meeting me would mean for her social relationships. Erica was expressive in her discussion and emotive when describing her life with her son, Matt, who has Asperger's syndrome. Although Erica states that she never initially wanted to have children, she describes a very deep connection with Matt. Erica repeatedly described her relationship with Matt as something different that she *did not know how to put into words*. Erica explained that, because she was so close with Matt, she has difficulty working outside of the home and while he is in school, her work hours are restricted to the hours that he is in school. Erica e-mails me to add to her verbal transcript. Her writing is fluid, cautious, and centered around Matt as the sole purpose of her life, and even through the challenges, they find a way to persevere.

My son is my life. He is the reason why I get up in the morning and continue to try to find ways to make our life work. My son is my hero. He is continually being told "no, stop, don't do that," and he still tries. He lives in a world where he is the exception and tries very hard to fit in everyday, without understanding why he is the way he is. But, he shows up, he tries, he cries, he laughs, and shows up again! That's perseverance if I've ever seen it!

Matt is self-injurious and bangs his head when he is upset, and because he is getting older and bigger, he is also becoming stronger. Matt head bangs on things such as a wall or a cement floor and this is increasingly worrisome for Erica. Matt is very literal,

and has difficulty understanding abstract concepts. For Matt, the figurative expression “running to the bank” literally means putting on his sneakers and running to the bank.

Things like, “come on, Matt, I have to run to the bank. Let’s go.” So we get in the car to drive to the bank and he’s upset and yelling at me, “why are we driving to the bank? “I told you I had to go to the bank.” “Yes, you said we were going to run to the bank.” “We are running to the bank.” We weren’t running. We were driving.

Erica and I have conversations off the record and chat casually over tea and coffee. Erica questions me in a way that I was not expecting, curious about the themes in the study. Erica was one of the only mothers who asked me for specific reassurance, asking if the other mothers in this study had described similar experiences and, perhaps questioning if what she was doing as a mother with a child with Asperger’s was *right*.

The Phenomenological Conversation

We need to find access to life’s living dimension while realizing that the meanings we bring to the surface from the depths of life’s oceans have already lost the natural quiver of their undisturbed existence. (van Manen, 1990, p. 54)

Although various styles of interviewing exist within phenomenological research (Kvale & Brinkmann, 2009; Liamputtong, 2009), the phenomenological conversation was utilized in this research study (van Manen, 1990). The term *phenomenological conversation* is used to describe the method of phenomenological conversational “interviewing,” where the term “conversation” reflects a partnered method of collecting accounts of lived experience (Crotty, 1998; Tracy, 2013; van Manen, 1990).

Data collection methods are rooted within the purpose of the phenomenological conversation (van Manen, 1990) where the overall purpose is to create a textual representation of the mother participant's lived experience through analysis and writing (van Manen, 1990). It was essential to the development of these textual expressions that the guiding questions be rooted in what van Manen (1990) describes as the "phenomenological question" (p. 42). By always having this question on our mind and circling back to it during the conversation, the orientation to the question was preserved so that it was difficult to stray from the purpose of the research (van Manen, 1990) and that we could remain authentic to the experiences of mothers with children with autism.

In addition to the guiding questions (van Manen, 1990), communication skills, such as active listening, reflection through silence and long pauses, and being attentive to non-verbal body language and gestures, were utilized to emphasize the participatory nature of the conversation (Liamputtong, 2009; Oberle & Raffin, 2009) rather than the researcher "taking over" the conversation. Active participation in the conversation bridges the values and underpinnings of the phenomenological conversation (van Manen, 1990), and silence, especially "ontological silence" (van Manen, 1990, p. 114), was often used as a tool of reciprocal vulnerability while listening to the participant. Ontological silence provides space for deep reflection in understanding the experience of that phenomenon (van Manen, 1990). As is often true with literary work, *reading* and *seeing* between the lines of writing within the silence of the researcher was important in the sincerity of the phenomenological conversation (Tracy, 2010; van Manen, 1990).

The close of the conversation is often marked with a spiraling downward progression towards *silence* (van Manen, 1990). At the end of the phenomenological

conversation, as suggested by Liamputtong (2009), participants were asked to share any final thoughts that were not discussed during the conversation by asking, “what did we not discuss that you wish to share?” Many participants utilized this space to share short anecdotal stories with the researcher and then were thanked by the researcher for her time in participating in the research conversation. The purpose of this question as an ending statement, encourages mothers to offer their experience as a co-investigator of the study (van Manen, 1990), which echoes the theoretical underpinnings of phenomenology and the values inherent in the ethical relation, such as that of feminist ethics and relational ethics within the tradition of hermeneutic phenomenology.

Because the conversations are a collaborative process, multiple conversations were thought to be beneficial for some mothers, with the premise that mothers will be able to leave the initial conversation and have time “to reflect on their experience...in order to determine the deeper meanings or themes of these experiences” (van Manen, 1990, p. 99). Although it was proposed that one to two conversations would be had with each mother, only one conversation was held with each participant, with a total of six conversations between six participants. The number of mother participants and the number of conversations with each mother was intended to be flexible and to be determined by silence and/or redundancy between transcripts (van Manen, 1990).

The Ethical Relation and Ethical Procedures

Within the phenomenological design of this thesis, and too, within the phenomenological conversational method, the research participant is holistically a co-creator of knowledge and van Manen (1990) warns that, because of this intrinsic nature of being, the participant’s lived world must not be questioned in a way that would exploit

his or her experience with or within the phenomena. Because of the first-person nature of lived experience, the participants' lived experience is written as a raw conscious narrative of the phenomena where "writing objectifies thought into print and yet it subjectifies our understanding of something that truly engages us" (van Manen, 1990, p. 129).

Although the research conversations were not completely confidential, the identity of each mother participant is protected by utilizing pseudonyms, thereby maintaining anonymity while transcribing the conversations; during discussion of the transcripts throughout analyses with others, such as my supervisor and thesis committee members; in the written thesis document; and in potential future publication(s). Initially, I discussed the use of pseudonyms with mothers before the phenomenological conversation. Mothers were reminded of the use of pseudonyms in the transcript return email and were asked if they wished to choose their own pseudonym or to have one arbitrarily selected by the researcher. Although some mothers stated initially during the research conversation that they did not care if their actual name or a pseudonym was used, actual names were changed for all the mothers and a pseudonym was chosen by the researcher to respect and maintain anonymity. Although this may be seen as overriding the mothers' wishes, the autism community that these participants are gathered from is quite small. The writing within the vignettes of mothers as well as the written discussion of the findings and implications reflect a mindful orientation that, due to the nature of the phenomenon as a small community, very specific details of these mothers' lives may be identifiable to others within the same autism community. Therefore, pseudonyms were used to respect the sensitive nature of the phenomenon and these sections were written with this in mind.

An informed consent form (see Appendix C) was signed by the participant at the outset of the research conversation in an effort for the research participant to be aware of the research process; by signing the informed consent form, the participant indicated that she understood the research process as much as she wished and understood her role within the research process. The informed consent form detailed the purpose of the study, perceived risks and benefits, issues of confidentiality, data collection and storage, and the ability to withdraw from the research study at any time without loss of potential benefits (none) to the study (Brock University, 2010; Liamputtong, 2009; Oberle & Raffin, 2009). The informed consent form was based on the template provided by Brock University. The informed consent forms were signed by the participant and kept in a locked drawer in the student researcher's office. Mothers were given a copy of the letter of invitation and the informed consent form on the day of the actual conversation.

As per the Tri-Council Policy Statement (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada [CIHR, NSERC, SSHRC], 2012) and institutional research ethics at Brock University (Brock University, 2010b), the research required clearance for research with human participants. Full ethical review was completed and cleared within the Social Science Research Ethics Board (SREB) at Brock University in September 2013 (see Appendix D). Due to the confidential nature of the informed consent forms, signed consent forms remain in a secured and locked drawer in the student investigator's office to ensure privacy, confidentiality, and protect participants' identity.

Potential concerns about disclosure or observation of maternal and child abuse were addressed early in the research process were addressed within the informed consent form and outline the procedures to take in the event of such disclosure (Liamputtong, 2009; Oberle & Raffin, 2009). These potential concerns were also addressed within the informed consent form, which outlined the procedures to take in the event of such disclosure (Liamputtong, 2009; Oberle & Raffin, 2009). Not only does the reporting of child abuse fall within ethical guidelines of the signed informed consent form (Oberle & Raffin, 2010; Tracy, 2010), but it also complies with Canadian law (Oberle & Raffin, 2009). No instances of child abuse were disclosed or suspected; if there had been, the researcher would have had a professional and lawful obligation to report.

Mothering is both about the mother and the child. Bergum (1997) suggests that that pregnancy, and perhaps mothering by extension, is an experience of “one with the other (two in one)” (p. 144). When we ask mothers to participate in research, do we need consent from the child, as the mothering experience and the stories shared by the mother are that of *both* the mother and the child? Suggesting the mother and/or parent would provide assent, we can perhaps assume that the mother would need to provide assent for the child with a developmental disability in any research study. The mothering stories shared here are perhaps the mother providing both permission and assent because these are *her* stories. It is not that the voice of the child does not matter, nor that we wish to ignore the child, and we cannot because of the relationality of the mother/child relationship (Bergum, 1997), but it is the experience of the mother that we wish to pursue in this research study. Although this may, at times, include specific discussion of the child, she offers her perspective in *her* story of mothering.

Ethical considerations in relational inquiry require special attention when conducting research with participants because of the vulnerability of the participant, here both because of the small sample size and because of the sensitive nature of the phenomenon as a special kind of mothering. The relational aspect of the research conversation can, at times, create a close space between the researcher and the participant, and developing rapport with participants is essential to the dialogic nature of the conversation (Eide & Kahn, 2008). Yet the vulnerability of the participant may increase when the lines of rapport are poorly delineated, especially when the sensitive and vulnerable nature of the phenomenon presented (Eide & Kahn, 2008).

The boundaries of the researcher-participant relationship were tested when I encountered a research participant in public, many months after our initial research conversation. I was hesitant to approach the topic of this research project, yet did not want to ignore the mother and how we came into each others' lives, I in a researching role, and she, as a participant in this research project. Although the role of the researcher has been discussed as a co-creator of knowledge (van Manen, 1990), I am the investigator in this research and she was the participant. Yet, how do I meaningfully address our relationship outside of the research role? With discussions from my supervisor, guidance was offered as to the relationality of this researcher-participant relationship, which respects the participant's privacy, and yet responds to the invitation for dialogue with this mother, and other mothers, if the situation arises. The relational aspect of this research brings to mind the relation between mother and child; the relation of nurse to patient; and the relation of one to another. With a new relationship and relation to Other, a sensitive

moral shift (Bergum, 1997) brings to the forefront the importance of the relational and ethical commitment to our participants.

Analysis of Lived Experience

This research used van Manen's (1990) guidelines in the approach to the analysis of the transcribed conversations. To produce a rich phenomenological text, the digitally recorded phenomenological conversations were transcribed verbatim (Liamputtong, 2009; van Manen, 1990) into a word processing program by the researcher. Mothers were given an opportunity through email to review the transcribed conversations to add, clarify, or change any details of the conversation. The content of the emails showed enthusiasm for the research process, because the majority of these mothers responded to the email, thanking me for sitting down to talk with them about their experience. The majority of the changes to the transcripts can be attributed to transcription errors and errors in grammar and/or punctuation. Only one mother chose to add a lengthy paragraph to her transcript. After these final changes were made, the transcripts were reviewed, read, and re-read in an effort to remain deeply seated within, and oriented to, the phenomenon (van Manen, 1990).

Contextually, the way that the phenomenon is perceived and interpreted varies by each individual participant, as well as with the researcher (van Manen, 1990), and we understand that the phenomenological descriptions from our transcribed conversations cannot be separated from the interpretive nature of the writing process (van Manen, 1990). The representation of our conversations in text is a rigorous process and nonetheless, a discursive relation between writing, dialogue, and re-writing. The research does not begin and end with the transcribed phenomenological conversations; rather, this

process is always in tandem with our writing, our curiosity, and our scrutiny towards the research process (van Manen, 1990). We cannot simply present our findings; we must deeply interpret the text in a way that bridges the text with the interpretation of the researcher in a holistic sense (van Manen, 1990).

In reviewing the phenomenological text in the writing of this thesis, we understand that, although van Manen (1990) makes it clear that there is no one true method of data analysis, he does propose several ways in which our textual conversations can be phenomenologically analyzed. Using van Manen's (1990) approach as a guide, data analysis in the study proceeded along four steps.

Thematic Analysis

Thematic analysis was done concurrently with data collection, where conversations were held while completed conversations were in the process of being transcribed. The discursive reading and re-reading process of data collection, analysis, and writing (van Manen, 1990) aided in developing and pulling together of similar lines of inquiry within individual transcripts and then later between subsequent transcripts.

van Manen (1990) suggests that there are three ways we analyze the text thematically: the wholistic approach, the selective approach, and the detailed approach. Wholistically, we look for salience within the entire text; through the selective approach, we look for certain phrases that appear to tell us something essential about the phenomenon; and, in the detailed or line-by-line approach, we look at every line of the transcript and ask what is it about this line that helps us to understand the phenomenon (van Manen, 1990). Thematic analysis allows us to concurrently have conversations, transcribe, reflect, go back to our participants, and to develop and refine the themes with

the purpose of untangling the essence of the conversation, rather than creating or developing the theme (van Manen, 1990). The discourse we use to approach the data analysis comes from the orientation to the language of our methodology, and thus, the term “theme” rather than the term “code” establishes the approach to data analysis as a co-created process between the researcher, the text, and the research participant (van Manen, 1990).

The process of thematic analysis was not linear and included integration of van Manen’s (1990) other three suggestions for data analysis. Because the researcher transcribed the conversations, it was impossible to have a true “first read” because the conversation was first heard during the transcription process. Although it would have been ideal for a third-party to transcribe the conversations, this was not possible given the time and cost. The transcription process was found to be beneficial in the initial process of listening to the mothering stories and hearing the nuances of each conversation in the development of themes and sub-themes.

Preliminary themes were developed early in the analysis process. These preliminary themes were “It Can’t Be Autism,” “The Locus of Other,” “Shared, Sharing, and Redefining Normalcy,” and “Living in the Moment.” These preliminary themes were presented at the Ethnographic and Qualitative Research Conference (EQRC) on February 10, 2014 in Las Vegas, Nevada. After the conference, discussion with my thesis advisory committee and supervisor suggested that the themes be further revised, to develop depth and to reach the core of the phenomenon. To develop and expand the themes, meant starting with the preliminary themes and reading, re-reading, and re-reading again, each transcript individually wholly, selectively, and line-by-line (van Manen, 1990) and then

compare between each transcript once more. The difference this time was that I was aware of my preliminary themes, but I was curious if these identified themes were actually themes or points of salience, or if they were sub-themes or patterns. To further develop the concepts and expand the themes, I questioned, *what does this mean? What signifies this compared to something else?*

To clearly delineate if the discussion was a sub-theme, a component of a larger idea, or its own theme, and given the embodied and intentional nature of the methodology (Dahlberg, 2006; van Manen, 1990), I used markers and coloured pens to visualize and arrange similar notions, concepts, ideas, or points of discussion. Using markers and coloured pens, notes were written in the margins of the transcripts after multiple readings of the same transcript. The notion of sitting with and listening to the transcripts was a process that was extremely important in developing a deep and interpretive orientation to the phenomenon (van Manen, 1990). Each individual transcript was read multiple times before moving on to the next and before reading between each transcript.

Interpretation Through Conversation

The research conversation as a *conversational relation* has been described as a way for the researcher and the participant to come together in a co-created dialogue. Because phenomenology is based in an interpretive paradigm, the co-created nature of the conversation is a two-part process within the data collection and interpretation/analysis process (van Manen, 1990). After each conversation was transcribed, the transcripts were sent to the mothers to review, comment, or revise as they wished. Through conversations with the mothers in this way, I was able to develop the textual transcript from the digitally recorded conversation. Between the emails with these mothers, it was clear that

our conversation was important to them. One participant's willingness to provide a deep and eloquent post-conversation email about the special bond that she shares with her son is evident of the meaningful relation created within between these mothers and me.

Collaborative Analysis

Using a collaborative approach to the text, we look to others to help us identify and strengthen the themes of our research conversations (van Manen, 1990). Looking to friends, colleagues, and other more formal relationships, such as reviewers and consultants, we add strength to the connection of the identified themes by "testing" the research in a way that creates meaning, thereby allowing us to see through and beyond our text (van Manen, 1990). At the ERQC (conference) where I presented preliminary findings, I was able to discuss the preliminary themes with other qualitative researchers, and surprisingly, with many who knew a mother or family with a child with autism. Positive feedback at this conference indicated that the themes resonated with what they have experienced being on the outskirts of this phenomenon.

After I returned from the conference and discussed with my advisory committee and supervisor about exploring the themes deeper, I began a second round of data analysis that was much more embodied and tactile. First, I wrote each of the preliminary themes on separate large sheets of paper and created mind maps of patterns of ideas centralized around the preliminary themes using coloured markers to visualize. The four themes were written in four separate columns on one large sheet of paper and I wrote words, phrases, or quotes that emerged from re-reading the transcripts to relate to each theme. These were phrases that differentiated one theme from another theme.

During this process, I met with my supervisor twice a week, where I brought in these large pieces of paper and taped them to the walls of the nursing conference room. In collaboration with my supervisor, we worked and re-worked the themes by moving ideas around, renaming concepts, adding quotes, sharing stories and ideas, and by doing so, this allowed us to develop the major themes and the sub-themes within each. Talking through ideas and concepts allowed for clarity in the expansion of the themes. We looked for resonance and repetition, which gleaned from several “aha” moments where we knew we needed to “write *that* down.” These *aha* moments suggested salience and contributed to the outline of the developed and expanded themes and sub-themes.

Existential Analysis

In existential analysis, the text is analyzed within “the four fundamental existentials of spatiality, corporeality, temporality, and relationality” (van Manen, 1990, p. 102). Using the large-scale mind maps created out of the large pieces of paper that were used to visualize the themes from the transcripts during the second round of data analysis, van Manen’s (1990) fourth concept of data analysis, *existential analysis*, was intuitively used to align preliminary themes in the early process of data analysis. Within the development of the four preliminary themes, there was a strong orientation to two existentials by the mothers within their experience: *Lived time* and *lived other*. Analyzing the text, we can begin to construct the living phenomenon as oriented to the participant within his or her uniquely created lived world (van Manen, 1990).

Lived time refers to the temporality of our experiences, how we live and breathe in the world across the landscape of past, present, and future (van Manen, 1990). Lived time cannot be clearly defined by measurement; it is not the seconds on our watch, nor is

it the minutes on the clock (van Manen, 1990). The effect of time on our consciousness shapes our perspectives and ultimately how we see and act in *our* world, in *the* world (van Manen, 1990). Lived time is the moments in-between; the grey particles of the passing of our experiences. Lived time is the candles on the birthday cake, each year represented by an addition of glowing wax; it is the hurried moments before a deadline.

Lived other refers to the dissonance created between our expectations and our realities and calls us towards a transcendental *Other*, in which we search for the “experience of the other” (van Manen, 1990, p. 105). Lived other is the mother relation we develop during our conversations; it is the way that we perceive another and the grounding that our relationships are built on (van Manen, 1990). We are ontologically always interested in the experience of Other in the pursuit of phenomenological knowledge, as we seek the experience of the phenomenon that is lived by the Other. We seek the particularity of the difference within the similarity of Other (van Manen, 1990).

Lived space, the third existential, refers to the “category for inquiring into the ways we experience the affairs of our day to day existence” (van Manen, 1990, pp. 102-103) and can have different meanings for different persons. Because the phenomenon often has a universal quality, or essence, we can explore the divergence of space between and within a phenomenon (Dahlberg, 2006; Moustakas, 1994; van Manen, 1990). The existential, *lived body*, refers to the physicality of a visceral presence, especially within the company of another where the taken-for-granted response of the body is a corporeal reflection of another’s experience of our body in the physical world (van Manen, 1990).

Within the context of hermeneutic phenomenological research, we can look to how the body is perceived as reflected, and the lived meaning of this (van Manen, 1990).

The lifeworld of a person would not, and could not, be without one of the four dimensions, as their conceptual stickiness interweaves throughout our memories and our experiences, both physically and consciously, as they are dependant on each other (van Manen, 1990). In this study, the relation to *Other/another* and *time* were intuitive because of the rich conversational text and the researcher's deep orientation to the text through reading and re-reading the text multiple times (van Manen, 1990). The mothering relation went beyond the experience of another, where the perception of another for these mothers created a different kind of relation. Even more so, lived time transcended the mothering experience in this study, going beyond the boundaries of traditional time, perhaps in a sense because these were not traditional mothers.

Rigour

In the writing of the research conversations and discussion, it is important that the research remain ethically stringent to the lived experience of mothers with children with autism. To do so, we look for criteria for qualitative quality in research. Tracy (2010) suggests eight updated criteria for quality in qualitative research. For this study, rich rigour and sincerity (Tracy, 2010) will be the focus of this discussion on quality.

Rich rigour refers to the attention paid to the data collected; was the amount of data collected sufficient given the expectations and context of the study? Is the data appropriate for the methodology (Tracy, 2010)? These questions were thoughtfully considered before beginning the conversations with the mothers in this study. The proposed number of research conversations suggested seven to ten mothers or until repeated themes emerged. Being rigorous means that we pay attention to the details of the research process (Tracy, 2010). Research conversations were conducted with an

ethical and a moral relation to the participant (Bergum, 1997); the research conversations were transcribed verbatim and mothers were given pseudonyms early in the process to protect their identity during later data analysis.

Sincerity in the research process is achieved in the vulnerability of the researcher to honestly confess mistakes, biases, or presuppositions in the final conceptualization of the research thesis (Tracy, 2010). Offering my own presuppositions as a naive researcher, believing that I had little in common with the participants or the research was challenged. In this thesis, especially within the reflection at the end of chapter five, I own up to the ‘mistakes’ or ‘hiccups’ that occurred along the way. I confess that the journey of this research project has certainly not been linear, nor has it been easy. The struggles as a researcher, and too, the transparency of this research project gleams from the honest presentation that I present throughout the write-up of this thesis. My own sincerity, honesty, and transparency represent my moral commitment to the research as a graduate student and nurse researcher, keen to provide meaningful text and discussion back to my participants.

Transparency was also significant in the representation of the research findings, where the use of language is especially important in the representation of lived experience (Tracy, 2010; van Manen, 1990). The use of literary language must always be in a delicate balance, as the hermeneutic writing is the overarching purpose of hermeneutic phenomenological research (van Manen, 1990). The use of language in hermeneutic phenomenology is the ability of the lived experience to coil back to the primal research question and the original *orientation* of the phenomenon within the research. van Manen (1990) refers to our sensitivity to the language of the written text,

where we are always mindful of the context of the conversation; it is only by using the language of our participants in which we can enter and represent their experience (van Manen, 1990).

Authenticity within the research process reflects the idea of remaining oriented to the question and creating a meaningful coherence within the research purpose; thus mirroring socially constructed research (Tracy, 2013; van Manen, 1990). Rather than using specific questions, such as those in a semi-structured interview (Kvale & Brinkmann, 2009; Liamputtong, 2009), the conversational relation proposed by van Manen (1990) is specifically important to phenomenology, because it helps to ground the researcher in a sense that remains true to the orientation of the phenomenological research question, and subsequently, true to the research participant (Tracy, 2010; van Manen, 1990), and as such, the conversational relation was a means to collaborate with the mother with a child with autism. The rootedness of the chosen method of data collection within hermeneutic phenomenology as a methodology within an interpretive paradigm allows us, as researchers, to co-construct meaning, where “the interviewee becomes the co-investigator of the study” (van Manen, 1990, p. 98). This shared and co-created knowledge, perhaps would not flourish without the selected paradigm, methodology, or method as described (Finlay, 2009; Tracy, 2013; van Manen, 1990).

Finally, resonance refers to how the text reads and feels with the reader (Tracy, 2010). For the text to resonate, it must impact the reader through an evocative voice, not only making the reader think about the text, but allowing the reader to feel in a way that was perhaps unexpected, resonating with something about the text (Tracy, 2010). The impact of the text comes through the writing of this thesis, maintaining a fluid and

readable text that others outside of academia would be able to relate. Writing the findings in chapter four, I approached the text with the knowledge that literature adds a vocal presence to the text (van Manen, 1990) in such a way that we would not be able to accomplish salience in the findings without integrating literature throughout. In addition to the multiplicity of literature within the findings section we add aesthetic merit (Tracy, 2010) as an evocative narrative to the text.

In addition to the quality criteria outline by Tracy (2010), van Manen (1990) also suggests that the text of our phenomenological research be oriented, strong, rich, and deep. To be oriented to the text means that we have a clear and distinct focus that we cannot separate the content of our research (the mothering relation) from our theoretical curiosity as researchers. In this sense, we are oriented to the mothering relation. In being oriented to the mothering relation, our strong relation to the phenomenon means that our research, our phenomenological interpretation and writing of the text is one understanding of that phenomenon, exclusive to that phenomenon. In a strong orientation to the text, we understand a universal quality (van Manen, 1990) of the mothering relation that transcends beyond the mothering relation of children with autism.

A rich text explores the multiple possibilities of the interpretation of the stories of the transcripts (van Manen, 1990). Interpreting the stories of the mothering relation, we offer rich and thick description of the phenomenological description (van Manen, 1990) of mothering in relation to autism. The descriptions of the vignettes of the mothers in this study and the evocative textual descriptions of the findings and discussion offer a vivid picture of what the experience of mothering a child with autism is like.

Finally, we should always strive for depth in our phenomenological texts, as depth is what van Manen (1990) suggests provides meaning to the description of the experience. Without depth, the experience of the phenomenon is flat; the possibilities of the interpretation of the text, lifeless. Think of the narrowness of digging a deep and beautiful hole in the universe; carving a place for the phenomenological descriptions of our research through the stories of our participants. It is through the depth that reflects the orientation and the strength, and richness of the text, which holds together the contextual lived experience of the phenomenon (van Manen, 1990) we are looking to look at, and perhaps, dig at more clearly.

Summary

Phenomenology, grounded in its philosophical origins, is used to create a conversational relation between the researcher and the mother participants. Accounts of lived experience were collected from six English speaking mothers whose children were diagnosed along the autism spectrum, although they did not need a diagnosis to be included in the study. The embodied and intentional nature of phenomenology creates an understanding of the phenomenon as a human experience. By remaining oriented to the phenomenon, we never stray too far from our purpose or our research questions in collecting accounts of lived experience (van Manen, 1990).

The final stories of the mothers are presented both as vignettes of the conversations that I had with each mother and a description of the child. I met with each mother once, without the child. The child's presence during all conversations was nearly visceral, almost tangible. The fluidity that these mothers spoke with, especially when talking about their child, was remarkable. The concept of love was hardly talked about,

but between the mother's space, the tissues, tears, laughs, and recollection of memories, there was something remarkable and perhaps lovely about the space that the mother and child created.

Chapter 4: Findings

The Experience of Mothering a Child with Autism

The question that orients this collection of lived experience is what is it like to be the mother with a child with autism? How is it different to be a mother than it is to be a father with a child with autism? How do mothers experience living within this phenomenon, one of which she had little say or control over? When mothers live this phenomenon, we question if their experience is similar or different to how other mothers experience the phenomenon. Even more so, we question if the experience is qualitatively similar or different to how other mothers without children with autism experience mothering. Reflecting a universal experience within the particularity of the phenomenon (van Manen, 1990), the inter-subjectivity of mother voices within this study are shared here through listening to, interpreting, and re-telling their stories.

It Can't Be Autism

Leading up to a diagnosis of an autism spectrum disorder, the focus of the mother and the family is often centralized on the child with suspected autism. In the process of coming to know and acknowledge that something has changed with the child, and too, before the family has a chance to accept an inevitable change, as with the label of a diagnosis, the dynamic of the family focus starts a quiet, sometimes subtle, evolutionary change. In a 'calm before the storm' kind of way, like the slow bubbles of volcanic magma beneath the Earth's surface, the process of coming to know that the child has autism was a time defined by hesitation and uncertainty. The phrase 'it can't be autism' comes from a salient and overwhelming expression that these mothers hoped that the child did not have autism, yet ultimately knew that something was not quite right.

Maybe He Has It, It *Could* Be Autism

Coming to know about the child's autism was a laboured process of constant hesitation and often placed these moms, and their families, including husbands and parents/grandparents, in a state of uncertainty, moving back and forth between knowing and unknowing. Tension was heard in the process of mothers questioning, "*Is this autism? Could this be?*" "No," they were told, it is just something else, and they were dismissed for a few more months. This tension of unknowing created a flux of emotions, especially with and around uncertainty, in which many of the mothers reached a breaking point. Uncertainty often emerged from a discussion between "*is it?*" and "*is it not?*" where there was an inconsistent back forth emergence of *what it could be*. This back and forth hesitation was most explicitly expressed by Sarah, the mother of Toby, where Sarah uses a very hesitant voice to describe this feeling of her back and forth-ness of coming to know, and coming to terms about Toby's autism diagnosis.

I think...because we were so focused on the ADHD and the OCD and the anxiety issues that we weren't willing to look at the autism issue because, um, I think...I don't think I wanted to look at it...I wasn't...I don't know, like, I would say, "maybe he has it," and it would kind of occur to me, like, "maybe he has it, it could be autism" but I would be like "no, no" and I don't know if it was more denial or more if it was the fact that we were so focused on the diagnoses that we already had and we were attributing the behaviours to that and not looking at the bigger picture. (Sarah)

Sarah's suspicion of autism was often quieted by her own internal thoughts that *no, it's not autism, it can't be autism*. Sarah indicated that she did not really suspect autism early

because Toby had previous diagnoses of *ADHD, OCD, and anxiety issues* and was attributing many of his behaviours to these previous diagnoses. Sarah's mother who works with children with developmental disorders (psychometrist) recognized certain qualities in Toby and encouraged Sarah to explore autism as a possible diagnosis.

With other mothers, there were other significant people in the mother's life who were not as acutely aware as the mother was in suspecting, thinking, or feeling that *something was different* in the child. The feeling that "something is different, but what?" was also described in the literature where parents laboured over a child that was noticeably different, unsure why the child was different (Mulligan et al., 2012, p. 316). Prior to receiving a formal diagnosis, these mothers and fathers described consulting others in their social networks who knew the child, with concerns that maybe they too would recognize what the mother or father was seeing. Unsure what to do next, these concerns were quelled and dismissed, increasing the uncertainty these families experienced (Mulligan et al., 2012).

Despite her early investigation of autism through a project she had completed in high school, Helena suggested that she questioned autism naively, acknowledging that autism *can* present differently and uniquely. Helena explains that the movie *Rain Man* had a significant effect on her own and others' perception of autism and how it *looks*. Like Helena, often mothers were in tension between their previous assumptions and understanding of autism and what they experienced with the child.

So, like, I guess, I suspected that maybe something might have been off, but I didn't really suspect like, autism. (Helena)

Although Helena recognized something may have been *off* or different, there was nothing that stood out to her. Despite having some understanding of autism, Helena and her husband, especially, did not notice anything that blatantly suggested autism.

It wasn't anything that really slapped you in, like, the face, but it was like a lot of little things that, when you put them together, would add up. (Helena)

Most mothers had a difficult time explaining the differences that they saw in their child; but it often was the woman's instinct in understanding that the child was not meeting his or her milestones that pointed her intuition to *something else*. In the process of coming to the realization that *it could be autism*, these mothers cycled through a process of acceptance and forgiveness; acceptance of the diagnosis, and forgiveness that there is nothing that they could do to change the diagnosis. It was as if autism has always been in the back of their mind, but they refused to let the words surface.

Playing it off as *just a late talker*, Helena's own mother encouraged and persuaded her to accept Lily's *late talking* deficit, but Helena's instinct had her holding on to Lily's subtle, other *odd* behaviours; things that, with the experience of having a first daughter who is typically-developing, seemed *different*. Mothers hoped for *something different*, something other than autism.

I thought, "maybe she's just going to be...for a lack of a better statement, maybe she's just going to be like slower in developing...like her speech, maybe she might be a little behind, maybe a little bit delayed, like, you know? It's possible, like, you know?" (Helena)

Referring to the point of diagnosis as *frozen in time*, the pediatrician and/or specialist appointment was often a significant moment in time for these mothers. Stuck

and fixated in the process of allowing the child's autism surface like the slow, bubbly volcanic magma that is preparing to seep through the Earth's surface, most mothers knew the significance of the appointment with their pediatrician and/or specialist. The specialists had asked similar questions that these mothers had asked themselves multiple times, internally, and sometimes externally to close family and friends. But these quietly nagging questions were not something that would go away, no matter who asked. Beneath the surface of the brewing eruption, the force of her questions were stronger than her efforts to quiet her feelings of *what it could be*; she could no longer attribute the child's behaviours to being something else.

...as he [pediatrician] was talking to me, like I knew then, something was up from what he was saying because I was saying "no" to too many questions, you know? (Helena)

"one of those moments that's frozen in time...it's one of those memories, you know? 'cause then, like, I knew when I was going to that appointment that everything was going to change and it did..." (Helena)

Many mothers experienced this frozen-ness where the diagnosis is fixated as a reference point and a point of change for both the mother and her family; not only did the child have autism or Asperger's syndrome, but the diagnosis meant a shift in a way that centered the family's life on the diagnosis. Previous hesitations and reservations regarding *what it could be* that worried these mothers turned into a truth in which they were stuck, frozen in the news that was going to forever change *something*, even if they did not know what that *something* was, because it could be *everything*.

Coming to know about the child's autism was an upsetting experience for many of these mothers, who often *knew* before their partners or family, with the actual diagnosis solidifying what was already known. A woman's intuition of knowing she is pregnant is often confirmed by the advancement of technology (Bergum, 1997; Duden, 1993; Sandelowski, 1994); no longer does she have to wait for her physician to confirm the presence of another. Much like the mothers in this study, women come to know (about pregnancy and autism) through various ways. A woman can suspect she is pregnant by taking at-home pregnancy tests (Bergum 1997; Sandelowski, 1994), and the pregnancy becomes confirmed through technology, such as a fetal ultrasound. With mothers suspecting autism, there is much more sensitivity in coming to know about the child's autism. Although it is suggested that the women in this study begin to understand and know about autism through a long and laboured process of questioning and asking friends, relatives, and others about the child's odd behaviours and if they too see what the mother sees, there was a strong pull towards the diagnosis as a confirmation or a validation that the mother was correct in suspecting autism. Even though the women and mothers in this study were correct in their assumptions, as confirmed by the child's "official" diagnosis, there was a common feeling with the mothers in this study that, no matter how many people she asks, nor for women suspecting pregnancy, how many at-home pregnancy tests she takes, there will never be true certainty.

One of the greatest signifiers for Kate and her husband that Adam had autism was the comparison to other children without autism. When Kate brought Adam to an *Early Years* center, the contrast facilitated the process of knowing, such as when Kate saw Adam's minimal interactions with the other children at the center. Kate describes this as

an *Aha* moment, where her husband finally agreed that *oh my God...he has autism*. The process of coming to know was intuitive but was marked by a back and forth of hesitation and uncertainty. Kate's story of *coming to know* is much like Emily and her husband's process of hesitation in coming to know that something is *different*.

I knew something wasn't quite right. I knew it and my husband...didn't take us long to figure out he wasn't like the other two boys. (Emily)

Helena describes the process of coming to know about Lily's autism as a process of stepping outside of *your own world*, where the features of Lily's autism were more stark and noticeable when she was with other children her own age, rather than a comparison with her older sister. Perhaps this is because of the entangling *world* that Helena was wrapped in; she was so close to the phenomenon, woven into the lives of her daughters, that her perspective became unfocused. There is a popular expression that because you are so close to something, you "can't see the forest through the trees," meaning that it is difficult to see the whole or bigger picture when we are looking too closely at the details. Perhaps it is when Helena stepped back, and stepped *outside of her own world*, that her perspective shifted and she could more clearly see the definition of Lily's autism more sharply, free from the distraction and clutter from the outside world. Adding to the diagnosis, Lily was also diagnosed *at the severe end of the spectrum*.

I think if she would have been my first born, I wouldn't have suspected as early...but it's never kind of how it looks like and what you see in the books and stuff...(Helena)

I think we were able to get a diagnosis so early because, you know, she scored more at the severe end of the spectrum too, so and then it's more like, then it's

probably more clear, you know? But...when they're little like that...you just kind of get in your own world, like you don't see that they're that different. And then when you're around other kids that are her age, that's when it really kind of hit me that I'm like, 'yeah...she...you can really tell' you know? (Helena)

There was a haze that clouded these mothers' perceptions of their child's behaviours. They did not want something to be wrong or different, as Kate exclaims, *'cause who wants anything wrong with their child, right?* The perception that something was different was a reflection of a discrepancy of what the mother was expecting and what was known. In their hermeneutic phenomenological study of sixteen parents of children with autism in Canada, Woodgate et al. (2008) found a similar feeling that they were "living in a world of *our own*" (p. 1078). Woodgate et al. (2008) describe the parents' *own world* as a separate entity from the child as living in his/her *own world* that was distinct from the parents' because the parents experienced social isolation.

The experience of mothers in this study appears to be rooted in the locus of the child. Rather than having two separate worlds, one of the child and one of the mother, these mothers were often so focused on the child's *odd* and different behaviours and living in a foggy space *with* the child, that they were unable to surface out of their own world to notice a contrast with the outside, social world.

Could It Have Been Me? The process of coming to know about the child's autism was marked by a deep uncertainty and questioning of *how could this happen to me?* There is a strong sense that the child's autism was linked to something caused by the mother, internally or externally, either in something that she did or did not do during pregnancy or leading up to birth, rather than an accident of biology. The self-reflective

stance that several mothers took was that of apprehension, questioning *was this my fault?* Self-blame riddled these mothers' narratives, torn between a tension knowing that autism has no known cause or cure, but still feeling as if, somehow, for some reason, her child's autism was her fault. Historically, women and mothers have been at the centre of blame when something goes wrong, which has included being at the heart of the cause for the accidents of biology (Rabuzzi, 1994). Such blame is seen in the Greek mythology of Gaia (Mother Earth) and Ouranos (Father Sky) and their children, the Titans (Hard, 2004; Rabuzzi, 1994). After giving birth to the Titans, Gaia gave birth to two sets of monsters, of which Ouranos disliked, as he "hated his offspring;" loving all her children equally, Gaia set out to take action against Father Sky (Hard, 2004, p. 67). Ouranos' fixation of the children as monsters born of Gaia is reflective of the perpetual blame placed on mothers for having children who are different and is reflective of the self-blame internalized by the mothers of this study. The fixation of the mothers' loci on internal or external causes significantly influenced how these mothers saw themselves within the worlds of their children. Emily experienced uncertainty and reservations in Graham's diagnosis, questioning herself as the cause of Graham's autism in relation, and perhaps in comparison, to herself as the woman and mother with two typically developing children that she was before Graham.

I thought there could be some kind of thing we could fix this...right away 'cause there's no way I thought I would have a special needs child. No way. I'm very athletic. I didn't drink. I didn't smoke. I just thought, "I'm the healthiest person, there's no way I'm having a special needs child, but that means nothing...that you didn't drink or smoke...or..." (Emily)

This reflection on Emily's experience knowing Graham's autism could not be related to her own behaviours is intuitive and bittersweet for Emily. In an unpublished online essay on the experience of giving birth to a stillborn baby boy, *Nice Baby Boy*, Kate Suddes (2013), too, naively questions *was it me?* Suddes' (2013) worries and fears about internal and external factors are reminiscent of the fears expressed by Emily and Helena. Vulnerability is reflected in the experience of Emily, where there is blurring between curiosity about reasons and causes and a lingering sense that the cause might, in some way, be related to her own failures. Vulnerability is part of the back and forth realization that *it could be autism* and, in being vulnerable and questioning herself, she opens herself to the possibility that autism is more than what she expected as a mother. There is rawness in Suddes' (2013) questions, a vulnerability in which she allows the reality of uncertainty to seep through, and without border, boundary, or blame, she opens herself to a curiosity of *why me?*

Was it all the Diet Coke I drank that summer? Is it because I wrote a short story about a stillborn baby in 9th grade? Was it the positive pregnancy test on April Fools' Day? My fear of handling two kids? My joking about him being a neglected second child? Packing and moving four weeks before he was born? Was I overconfident about how well my first birth had gone? Did I have too much pizza? Watch too many sad movies? Eat too few vegetables?

(Suddes, 2013, para 11)

Although Emily described herself as *proactive*, she resisted early ideas that Graham's behaviours *could* be autism. Emily saw autism as a reflection of either internal or external behaviours or causes, such as smoking or drinking alcohol. For most mothers

in this study, the child's diagnosis challenged the mother's assumptions of autism and herself as a *healthy* mother, where she had to quickly accept it as not a reflection of who she was or what she did or did not do. This tension between knowing and believing that she is a *healthy* mother is contrasted with the confirmation that the child still had autism.

There is a lack of choice in autism and yet a subsequent, prevailing need to take on the responsibility of being a mother with a child with autism. Bergum (1989) describes this responsibility that the mother has for her child as a "pull toward the child" (p. 139), where if something happens to the child, the responsibility falls to the mother. A lack of control reflects a lack of choice; these mothers did not choose autism and they had no say in the diagnosis. Subsequently, the mother must pick up the responsibility of her child's autism. For example, even if Emily did make "bad" decisions, such as deciding to smoke or drink alcohol during pregnancy, would Graham still have autism? Without choice or control, Emily places the responsibility for Graham's autism on herself *because she is the mother* (Bergum, 1989). With the choice to have a child, the mothers become responsible for the child in a way that they were not responsible as mothers before the child. Yet, how does the mother take responsibility for something she is unprepared for or that she has no control over?

How is this responsibility of mother balanced with coming to terms with having a child with autism? Half of the mothers in this study had older typically developing children, and because of this, the reflection of herself as a mother with a typically developing child appears to contrast with these mothers' perception of herself as a mother with a child with autism. Was the decision to have Graham any different than it was to have the other typically developing child or children? There is no choice in either

decision (autism or not), yet, is the responsibility any different? In the transformation of woman to mother, and for Emily, mother with two typically developing children to mother with a child with autism, does the woman lose herself (Bergum, 1989)? Does Emily uncontrollably lose herself as a mother in taking on the responsibility of autism? Along the autism spectrum, is the responsibility of the mother with a child with autism different than the responsibility of mothering a typically developing child?

The choice to mother or become mother, as Bergum (1997) suggests, is a reflection of the knowledge available to us at that time and our responsibility for the child comes at different points in time for different women. For Emily, autism was not a choice that she made or one over which she had control and there is a tingling sense of blame residue that autism was not her choice because she did everything “right.” Despite the ability of some mothers to decide when they can become a mother, there is also a feeling of “being ready” (p. 98) and “getting it right” (p. 134) in Engel’s (2003) study on older mothering. This sense of *getting it right* is a moral tie to being emotionally and physically present for and with the child (Engel, 2003) and for mothers with children with autism, taking on the responsibility of *getting it right* or moral accountability becomes something that, for Emily, is unresolved, unending, twenty years later, and something that she cannot escape.

Coming to know about autism was also a process of exposing mothers in this study as a mother trying to do whatever possible to help her child. The vulnerability of coming to know about the child’s autism is defined by the openness that she might fail to provide the child with the possibilities, such as early intervention services, that the child desperately needs. For these mothers, autism was not something that was stark nor, as

Helena previously described, something that *slapped you in the face*. The mother's ability to provide for the needs of the child was often defined by the child's diagnosis. The mother could not prepare or start early intervention without knowing what was wrong or different with the child. The junction of the mother's internal and external factors in suspecting autism was a reflection of slowly uncovering the child's odd behaviours as autism, and in doing so, the openness of vulnerability becomes greater, the possibility of failure becomes expanded. Helena confesses this exposed self here, where she cannot believe that, even though she did so much for Lily, Lily still had autism.

I had all this time and I did all this stuff with her...but then, you know, I would talk to my parents, I would talk to my mom and she would say well you know, there's other late talkers in the family so you know" but, you know, there was still something that was a bit more than that, you know? (Helena)

Many mothers held a strong belief that negative behaviours, such as smoking or drinking alcohol, were too *risky* during pregnancy, and for Helena, being a mother and having children was important. She expressed that she did everything that she could to avoid *risking* her pregnancy with Lily, even refusing medications that her physician wanted to prescribe her.

He was going to prescribe prednisone. I wasn't going to risk...I wouldn't even take a Tylenol. I didn't have coffee, I didn't have pop, I didn't have diet pop. Like, and I love coffee, that's...and would not take anything. And then said, like "well it might not go away" and I said, "I don't care" I wasn't going to risk anything, like, for either one. With [Lily], I didn't have any, I didn't take any, I didn't drink or anything. I could understand, yeah, if I had done a couple lines of coke or

something or some explanation, there is no explanation, it's all in your head, no there really isn't. (Helena)

There is a sense of a lack of control and unfairness that, even though the mother did everything she could to, perhaps, prevent autism, the child was still diagnosed with a developmental disability. In these moments, there is tension and unfairness because the mother did not necessarily do anything that she could foresee would *cause* autism. Seeing other mothers with typically developing or seemingly 'normal' children out in public was difficult because these other mothers had something that was out of reach. Even though the mothers in this study did not engage in negative behaviours she thought would *cause* autism, it is as if she feels betrayed; betrayed by her body, betrayed by herself, and betrayed by others whose babies are different than hers. Interestingly, Helena described negative behaviours in mothers who are pregnant, unknowing if the growing baby in the pregnant woman's belly will have autism. She sees smoking or drinking, as betrayal perhaps of the sacredness of what, for Helena, is pregnancy and motherhood.

Does it bother me when I see somebody who is pregnant and smoking or drinking? Yeah it does. I don't say anything, but I always think, yeah...you know, in the back of my mind, like why? Why would you be a mom and then like, do this? (Helena)

Pregnancy and motherhood is sacred for many of the mothers in this study; it is something not to be tampered with, but with the child's autism, there was something that appears to have transformed the mother's perspective of motherhood responsibility (Bergum 1989). For Helena, the responsibility of the mother is to be careful and "take care" of her child (Bergum, 1989, p. 87). Although it is uncertain if she felt this way with

her first child, there is a drawn out “cause and effect” notion that is tied to the fantasized compared to real version of what motherhood is like. Women often fantasize about the baby they will have when they become mother (Rabuzzi, 1994) but this fantasy was dissonant for the mothers in this study because they did everything they could to have the fantasy. The reality of *what is* and the fantasy and expectation of *what could have been* is associated with motherhood’s betrayal on the mother, especially for mothers who are also mothers with an older typically developing child or children. Coming to the realization of having a child or children who do not match the fantasy, and for mothers such as Helena, Emily, and Victoria, nor does it match their other world with their typically developing older child or children, is part of the drawn out realization of the presence of autism and coming, perhaps, to terms with their own vulnerability and limitations that they never expected and had not prepared for.

For Victoria, she saw Nathan’s Asperger’s syndrome as a reflection of her mothering, rather than something that was internally or externally influenced during pregnancy. This means that she referred to Nathan’s Asperger’s syndrome as something that she could have potentially groomed out of him as a result of her presence or her behaviours after he was born. Chesler (1998) questions if motherhood should be the workingwoman’s only focus. Victoria alludes to competing demands for her attention after Nathan’s birth and in suspecting his Asperger’s syndrome. Chesler (1998) grapples with coming to motherhood with a life filled with other tasks, which were often a struggle to balance without the responsibility of caring for another life. We come to think of our responsibilities after birth as bridging our life prior to motherhood with the life of the child. No longer separate, the presence of the child is a relationship of “two in one”

(Bergum, 1997, p. 144) of mother and child, rather than two separate individuals paired together. Our demands after birth, and with this transformation lead us to question our involvement with the child: Is the relationship and the connection with the child ever enough, especially with competing life demands?

Despite Victoria being present for Nathan in their relationship, she questions if it were enough given the focus she had with her older daughter. Was there something different that she did or did not do between her two children? Further, Victoria confesses that she has always been hesitant of her own perception of herself as a mother. Is doing the best that you can *enough* when your child is *different*?

I mean, I think you always question yourself as a mother no matter what your child is or does, like, "did I do the best I could with what I had?" I tried to get there with my mother [laughs] and I tried to do the same to make sure I'm doing the best that I can for the two of them. (Victoria)

False Start

For several mothers, the diagnosis of the child's autism or Asperger's syndrome seemed to be a starting point. The period in *coming to know* about the child's autism as a foginess and a haze, in which, although the mother may have a suspicion that her child has autism because of the child's *odd* or *different* behaviours, the mother is distanced from the label of the diagnosis because she hoped that it was not autism. The diagnosis of autism is presented here as a metaphor of the starting block in a running race. Coming to know is the mother's heels in the starting blocks; the mother is preparing herself for the gun to go off and to run out of the gates at full speed ahead. It is not a race, suggesting that there is an end point and a winner and it is definitely not a sprint; there is no end

point, there is no winner or loser. Hurdling through the starting blocks, the diagnosis is not presented as a setback and neither is it considered negatively, but the mothers explained the moments after the diagnosis as sounding as if the starting gun went off. There was a loud bang and the aftermath of the remnants from the explosion hung in the air. As the dust began to settle, the false start seemed distant, but the end, the finish line, was out of sight.

This point, the sounding of the starting gun, appeared to be the moment that a shift in the mother's perspective occurred. Pregnancy places the mother and child in a unique relationship that moves the woman into motherhood by the very notion of "being with" the child because the woman cannot be a mother without the child (Bergum, 1989, p. 52). When mothers are faced with the challenge of *something different*, is the motherhood perspective also *different*? Sitting in the pediatrician's office, waiting, *frozen in time*, such as Helena's *frozen* moment waiting for Lily's diagnosis after the physician asked too many questions, Helena knew that she could not give the right answer or the answer that she *knew* would place Lily outside of the autism spectrum. Toby's diagnosis was overwhelming for Sarah, even though Toby had already been diagnosed with *ADHD, OCD, and anxiety issues*.

I...bawled my eyes out. I cried for two days because we went and saw the child psychiatrist at [organization] and he said that...he asked all these questions, and then was like, "ok, now we have a diagnosis of autism" and it was really overwhelming for me because you don't want to hear that...And it's a very overwhelming diagnosis no parent wants to hear, "well, your child is special needs...your child has autism." (Sarah)

For Sarah, Toby's other diagnoses were something that she had previously accepted and something that she felt that she could handle. With Toby's diagnosis of autism, Sarah experienced a hesitation that was different. Hesitant, perhaps because the word autism hung in the foggiest, more than a label, but a life sentence. A whirlwind of emotions erupted, and Sarah began to question what life would be like from this point on. The diagnosis, that word, "autism" hung in the air at the starting blocks. Was this the false start? Like a caption without words, and much like the other mothers in this study, Sarah and Toby's life hung in the balance. Sarah was at the brink of Toby's diagnosis; the gun went off. She had to push off out of the starting blocks whether she was ready or not.

Leading up to these frozen moments, the hesitation that these mothers experienced had built up into a pressurized uncertainty. The point at which the mother would explode out of the starting blocks was unknown; *is it enough to know?* For all of the mothers in this study, there was a certainty in that they needed all the information that they could get from anyone to be able to move forward with the diagnosis. Some mothers explained that the diagnosis was necessary to be put on waiting lists for Intensive Behavioural Therapy (IBI) or for funding. For the parents in Mulligan et al.'s (2012) phenomenology, the diagnosis offered both an explanation for the child's behaviours, which led to a sense of relief, as well as a starting point to getting the help that they need for the child in terms of funding and services. The parents in Gill and Liamputtong's (2011) and Mulligan et al.'s (2012) studies expressed a similar sigh of relief that, indeed, the child's behaviour stemmed from something much greater than typical development, such as *temper tantrums* or *meltdowns*. There was validation knowing that it was not just the mother or the father who was noticing something different in the child (Mulligan et

al., 2012). At the same time that Sarah explained that the diagnosis of Toby's autism was overwhelming, she also felt that this diagnosis was truly something that she could use to clearly explain his behaviours.

But then at the same time, I was really relieved because then I knew what was the cause of all of his behaviours, which had been, like, driving me crazy and I was crying every day about and, so it kind of made a lot of sense to me, and I was like, "Ah, it makes so much more sense." So I kind of had, like, two days to, like, grieve about it, and then I was like, "Okay, now I know, let's start and let's get working with it. (Sarah)

Before Toby's confirmed diagnosis, Sarah stated that she had cried each day when Toby acted out; she felt isolated at home because his behaviours had increased and he became more physically aggressive. Feeling that she could not leave the house because of the overwhelming nature of Toby's *meltdowns*, Sarah expressed a feeling that his behaviours were not a reflection of herself as a mother but a result of Toby's autism. At the same time that the diagnosis meant that her life would change, there was relief in understanding that she finally had an explanation for Toby's behaviours and a relief that these behaviours were not a reflection of her mothering.

But during the period before we got diagnosed, just before, I was...he was horrible. He was self-injuring on a daily basis...he became physically aggressive and violent towards myself and towards others, which isn't him...um, meltdowns were ridiculous...his tantrums, like, to the point where I was stuck at my house. It was to the point where the two places I could go was either my home, or my parents' home and that was it, I couldn't take him anywhere...I was literally

trapped in my house with him because he would, like, throw himself down or he was running away and taking off and he didn't understand danger, and it was just...it was just ridiculously hard. And then once we got the diagnosis and switched the medication, he has been brilliant. (Sarah)

Kate had experienced an early tension or false start in the early diagnostic process of Adam's *severe* autism. The word *severe* hung in the space of the life she knew was coming compared to the life she thought she had. Kate prepared for the diagnosis, as she *knew* that *something* was coming because *something was different*. The hesitation she expressed came from the label that she feared her husband would be upset about; if it would help Adam, Kate was more than willing to accept the diagnosis, which came hand-in-hand with acceptance.

I don't know if they just don't want their child to be labeled, I mean, nobody really does, but if it's going to help them, you know, you don't want to wait and then five years later, you get the label and then, you know, you're that much further behind...I knew, I knew before my husband, like, I kind of had trying to tell him without, you know, getting him upset, you know, 'cause who wants anything wrong with their child, right? (Kate)

Adam's autism pushed Kate to seek more help and to get the contact numbers she needed. The autism diagnosis can be seen as a validation of autism and the beginning of the journey forward (Gill & Liamputtong, 2011; Mulligan et al., 2012). If there was something that Kate heard could potentially work, she was willing to try it. Like Sarah and Emily, Kate already had her heels in the starting blocks because she truly knew that her child's diagnosis would be confirmed when she met with the specialist.

Fixated on *fixing*. The process of knowing transitioned into a definitive *knowing* that something was different with their child, and because of the diagnosis, the mothers experienced a process of accepting that something was actually different. For most of these mothers, and their families, this process was not smooth or linear. The process of acceptance and the initial diagnosis of autism or Asperger’s syndrome was a starting block for most of these mothers to do what they could to get a head start on doing something to try and *fix* it. There is a perspective shift, exemplified by Emily, who is the mother of twenty-year-old Graham. Graham’s diagnosis solidified what Emily and her husband were feeling. For Emily and other mothers in this study, the child’s diagnosis was a progressive propulsion forward to something that the mother wished to be changed in the child, perhaps to what the child *can and will be*. Because the child was not, what the mother describes as *typical*, they were often back and forth between *yes, he has autism* and *no, he doesn’t...pffweef!*

...I knew something was wrong, but I didn’t know what, what it was. And when I...somebody said to me that it could be autism, I thought, ‘ok, we can fix this’ you know? (Emily)

And I said, ‘let’s get the ball rolling, it’s autism and, like, we’re going to fix him’...that was my thing... (Kate)

The idea that autism could be *fixed* was a concept that mirrored the enthusiasm to get out of the starting gates to a different life. *To fix*, a verb with Old French origins, means to “set one’s eyes or mind on something” (Harper, 2014, para 1). Once these mothers received the child’s diagnosis, “the something” was a determination to change the child; perhaps back to an idealized child or the child that he/she was before the

diagnosis. But had the child changed at the point of diagnosis? Was there a stark change in the child to *fix*? Being able to *fix* was a fixation, something that had been on the mother's mind since diagnosis, and something that she had set her mind to change, as if the diagnosis of autism had sprung these moms into action. The mothers in the study truly believed that the child could be *fixed*.

The metaphor of the starting blocks, as well as the concept of a false start is suggested as the mothers' reality of coming to know about something that she was not quite prepared for. Preparation is closely related to how women prepare for a new baby when they are pregnant. Coming closer to the baby's birth, the mother prepares the nursery, she gathers baby bottles and clothes, and she selects her doctor (Bergum, 1989). Chesler (1998) prepared for motherhood by talking to and asking several other mothers about their own motherhood. We can prepare for the birth of the baby, but how do we prepare for life after? Chesler's (1998) diary entries show a naïve and uncertain transformation of woman to mother. In questioning about motherhood, Chesler (1998) presents her expectations of what motherhood *could* and *should* be like. But what happens when we do everything right? What happens when we prepare, or as Shaw-MacKinnon (2001) describes as not prepared enough? There is a definitive notion that even if the child was not what she expected, she could change or *fix* that expectation into reality. In the process of coming to realize that the child could not be changed, these mothers saw that this was not the life they were expecting. How can you expect the unpredictable?

This Is Not My Life

More than anything else, these mothers were uncertain how their life would change after the diagnosis. The feeling that *something was different* was reflected in the feeling of uncertainty. Something is different, but what is that difference? How will this difference reflect in the changes to the child's life and the family's life? Although having a diagnosis confirmed that there was a developmental disorder, these mothers still experienced uncertainty, even though they felt that having the label of *autism* was almost a confirmation of what *could be*.

At the summit of diagnosis, these mothers experienced a cross-section between expectation and reality, where there was a junction between a lack of control and a longing for something that they did not know or could not ever experience. For Victoria, the mother of Nathan who has Asperger's syndrome, although she knew that *something was different*, it was not obvious to her until she received the diagnosis.

I mean, once you know, it's pretty obvious. (Victoria)

Victoria's awareness of Nathan's Asperger's syndrome from the confirmation of the diagnosis put her on what she explains as a *learning curve*, in which she was preparing herself for a wave of change as best that she could.

Um, for me, it was just...now...now we're on a learning curve. Now we know, we have a diagnosis and now it's like, "what can we do? How do we make this workable?" We can't change anything about him; he is who he is, but how do we help him cope in school, which was obviously difficult for him, but I mean, you know brilliant kid just...has some issues...

Other mothers also experienced a shift in thinking about the present and *what can we do now that we know?* Knowing was a central process in how their perception of the diagnosis had changed. Many of the mothers had difficulty describing, or even predicting, how their life was going to change. At this point, these mothers were highly focused on the present and what could be done *now*. The future was an uncertain concept of time, something that was always uncertain. Knowing that the child has autism is certain because of the diagnosis. Knowing how the autism will affect the child and the family is a dark hole of uncertainty.

Because autism presents uniquely, anticipating the future is often hard for these mothers. The loss they experienced was coming from a place that was uncertain and unknown because they had lost something that they could never experience and never even know to experience. For Erica, her experience of change and loss manifests as a very tiring and *exhausting* life/lifestyle. The changes that Erica has experienced in her life, although often small, have weight that she often cannot bear because of the *exhaustion* she faces in dealing with Matt's everyday challenges. Matt, like Helena's daughter Lily, also has particular food preferences. Matt prefers to eat chicken, rice, and vegetables for the texture, but refuses to eat *any of the traditional children's foods*. Exhausted and frustrated, Erica has tried several times to get Matt to eat the foods she sees that a normally developing child would eat, but he is not interested.

It adds to the exhaustion...because you can't have a lazy and just open a can of Zoodles because...no...he wont do it...and we will try periodically and, 'you want to try this again and see how you're feeling about it?' ...He gags, 'I don't like the

taste, mum.' So...and I mean, I shouldn't complain because he's eating chicken and vegetables, but...you know? (Erica)

In between her struggles, Erica is in tension between her challenges with Matt and her comparison of Matt to others, such as the children in Matt's classes at school. Initially, Erica's feelings of change were in comparison to a family friend who *got worse*.

Shocked, like, scared. Because I...you don't know how it's going to affect your child...so I knew what it was but I didn't know the severity, um, I didn't know if he would get worse...get better, you know? My friend's brother got worse, you know? He went from being a mobile child to being immobile and then had to learn how to walk again. So I was afraid things, um, it was...I was scared. (Erica)

Here, the perception of Matt's autism was compared to *knowing* something about someone else's autism. Because Erica's life with Matt has been fully intertwined within Matt's world of autism, especially after the diagnosis, she started to compare her own life to others around her and it appears that this constant comparison begins to define her as a mother. Erica questions, why is it so hard on me? Why am I struggling with one child? Even though she understands that autism is challenging and it *could get worse* demonstrated by the story she describes about her family friend's condition becoming *worse*, she still perceives herself to be different than other mothers, especially because of the severity of Matt's autism. Even though Erica understands that other parents may have similar struggles as her, there is a sense of curiosity in the tension she has around this wondering, as if she is longing for someone to tell her that it is okay for her to feel burdened, exhausted, and burnt out, just as much as it is okay to feel hope.

I don't have other children...and because I never wanted to be a mom before, I don't...I don't really know. Like, I don't see myself...everyone always says, 'it must be hard for you to always live this way.' But how do I know a normal child, raising a normal child isn't as hard? So I...I don't know...Like, I don't know. I don't...I try not to think of myself as worse off or a martyr, or...you know, because that's not what it is, you know? A normal parents, a parents of a normal child could have similar struggles, you know what I mean? (Erica)

Within Erica's dialogue, her exhaustion and frustration, and constant challenges with Matt's autism, is exposed. Erica questions *is this what I'm supposed to be feeling?* She asks me several times for reaffirmation if *this* is what other mothers are experiencing? Erica displayed a sense of vulnerability and doubt in both her mothering and her relationship with Matt. There was a sense of doubt that left a feeling of reservation. Is this what everyone else is experiencing?

I met another child that has Matt's same diagnosis and he's so [emphasis] different from Matt, like I would never put them in the same class. And I know it's on a spectrum now instead of individual diagnoses, but I wouldn't even think the other child had autism in comparison to Matt. (Erica)

For Victoria, the perception of herself is a reflection of how she has changed since accepting Nathan and the behaviours that make him unique. Reflecting back to coming to know about Nathan's diagnosis, Victoria described the *learning curve* that she was on as something that made her retreat from who she was, especially comparing her involvement in Nathan's school life to her daughter's school life.

...I don't feel like I have been as involved as I would have liked to have been...it was just like, 'you know what, I need to put my focus into other things...other places'...and so I just did that. (Victoria)

Overall, these mothers experienced a feeling of uncertainty and hesitation that *it can't be autism*. Defined by an unwavering longing and hope for *something different*, these mothers did not want to accept the diagnosis, even though they had an instinct that *it could be autism*. The period of time leading up to diagnosis was marked by flux, going back and forth between *yes, she/he has it* and *no, she/he does not have it*. Several mothers saw the diagnosis as a reflection of internal or external, often negative, behaviours, such as smoking or drinking alcohol, rather than an accident of biology. Whereas one mother questioned her son's Asperger's syndrome as a reflection of her mothering.

The diagnosis was perceived to be a starting point, a starting block, and a moment that appeared to be *frozen in time*. In the moments after the child's diagnosis, these moms hung in the balance as the fog started to settle. Sprinting out of the start gates, the *false start* of the child's behaviour was now confirmed by the diagnosis. Coming out of the starting blocks, these moms were ready to *fix* their child and expressed that they would do what it takes to help the child change, as if they were broken.

Many of the mothers were fixated on fixing the child because they perceived that they could change the child's behaviours and diagnosis. There was a significant feeling that this was not the life that the mother expected, especially after the confirmation of the diagnosis. Exploding through the starting gates at the time of diagnosis, these mothers experienced a tension between uncertainty and propulsion to fix the child.

The Womb is Extended: Transformation as a Process of Forever Change

Loss

What is loss? Can we interpret and perceive loss to be something that is not negative? Does loss always have to be without gain? The loss of *something* reflects a need to accept *something else*. Does this mean that we need to lose something to gain something else? In Kingsley's (1987) poem, *Welcome to Holland*, there is a build-up, an expression of excitement, and a longing for a beloved trip of a lifetime to Italy. With her bags packed and on the plane, Italy is classic and has stood the test of time, but when there is an unpredicted stop in Holland, there is no going back. Italy is just a dream, Kingsley (1987) explains. In Kingsley's poem, there is a distinction between *the loss of something that could have been* and *the loss of something that was*. Being two distinctly different places, preparing for Italy is not like preparing for Holland. The focus in Kingsley's essay is not the destination, but accepting the difference in the journey.

Through the process of coming to know about the child's diagnosis, many of the mothers in this study experienced acceptance as a process of change, where change is most notably defined by what the child does, rather than an expression of what mothering means. Change can be described in terms of what is lost compared to what has become different. The distinction between loss and change as a difference was often related to the mother's perspective and early acceptance of what the change from the diagnosis meant.

Loss of something that could have been. The loss that these mothers experienced was child-centered, and very much preoccupied on the process of obtaining the child's diagnosis. The label of the diagnosis was a central shift in the perception of the child's autism, changing the focus from what was different with the child, to a shift in

what was different within the mother's life. For Kate, within the process of diagnosis, loss was experienced as a perception of a loss of something that was unknown. The idea of loss is attached to something that *could have been*. The idealized football player that Kate mourns for reflects a tension between a *loss of something that could have been* compared to *a loss of something that was*.

How can you say that and how can you know that he won't ever improve? You know, it's just kind of, "he can do this and do this...but you know, you're not going to have, you know...that football player [laughs]...I don't know...but who knows? (Kate)

Other mothers experience loss as something that *could have been* because they have no other child or children; these mothers have no reference point of what they *could* be experiencing. Mothers experienced loss for something that they do not know and cannot ever know, but they experience a longing to be able to experience certainty. There is dissonance in the way that Sarah reflects who Toby *could potentially be*, especially in the early stages of coming to the final diagnosis.

Like, with AD--, my thought was, with ADHD, whatever...you can get over it...like, you can succeed in life. "Autism," like just that word, you're like, "Oh God, what is going to happen to him for the rest of his life? Is he going to function? Is he going to be able to be the person who I thought he was going to be...?"(Sarah)

Thinking about the future is also a concern of potential loss for many mothers. The possibility that Adam will never drive is something Kate has come to terms with, and he, as her only son, will never have his own children. Kate describes the loss that she

feels in realization that she will never be a grandmother; an unexpected feeling because she had never previously considered being a grandmother. Now, she must accept that this will never happen, even if she wished, and that being a *mom is good enough*.

...I think I'm a great mom, but I know a lot of great moms, like whether they have a special needs child or not so, yeah. The funniest thing is as much as I wanted to be a mother, I never thought of myself as being a grandmother...never...I don't know why and, um, and I'm hoping that I'm not ever a grandmother because I worry then about his kids, right? (Kate)

One mother's analogy of signing up for *one thing and dealing with something else* instinctively mirrors Kingsley's (1987) poem, *Welcome to Holland*. For many of these mothers, they signed up for Italy, prepared for Italy, and Helena, Kate, and Victoria have even experienced Italy before with older typically developing children. But now, these mothers are in Holland, questioning, *how did I get from Italy to Holland?* Even more so, they question and wonder if this is, indeed, *Holland?* These mothers search for meaning and understanding in how *Italy* and *Holland* could be so similar, but yet, so different.

Loss of something that was. For Helena, there was a difference in the change she experienced between the *loss of something that could have been* compared to the *loss of something that was*. In the moments that Lily and Amelia are potentially able to share, Helena describes a longing for a normalcy that her daughters, as sisters, are able to share together.

There's not a lot of milestones that she might be able to do that's the same as her sister and I wanted this for her. And if she could do it, we were going to try even if it took, like, a couple of years or whatever... (Helena)

For Helena, the *loss of something that was* is an awareness of *something that could be* when compared with her older daughter. Helena was one of three mothers in this study who had another child who was typically developing. These mothers experienced the differences between mothering a child with autism and mothering a typically developing child and often there was a distinct dissonance when these mothers described and compared their children. It is, perhaps, the mothers' comparisons between her children and the lack of the child with autism meeting his or her milestones that weigh heavy on these mothers with other typically developing children.

I asked Emily about the comparison between Graham and her two older sons. Emily denied a change in the perception of herself as a mother. Although she has two older typically developing children, she does not see herself any differently as a mother with a child that is not typically developing.

Wow. Man, it's all a blur. They're so close. I had three in three years. I barely remember now. No, I don't think so. I...I just. No. Nope. He's...he's your kid and you do whatever. So your perception...nope...it hasn't changed. I don't think so. No... (Emily)

Further, Emily describes a community-oriented focus of care that her two older sons take on with caring for Graham. Emily describes discrepancies between the older, typically developing sons and Graham's behaviours as *mistakes*, where these *mistakes* perhaps represent the changes or losses that can potentially be fixed by the people in her community of support.

The two boys, the other two boys are great. They are fantastic brothers...they help with everything. People can't believe how good they are. They can shave him.

They can brush his teeth. They can wash him... give him his medication. They can...if he makes an accident, they can change him. Not too many twenty-one year boys can change their twenty-year old brother's mistakes...but again, you know, he does need constant care. That's what it is. (Emily)

Although Emily does not elaborate on the *mistakes* that Graham makes or what she means by this term, the language that she uses appears to be a reflection of the comparison between what is normal and what is a *mistake*, a difference between *something that could have been* and something that it is not. The loss is a *mistake*; the loss of who the child *could* represent and the mothering that accompanies this representation.

In the Shadows of Unfairness

Through Erica's dialogue, it is apparent that her life has significantly changed since having Matt, revealing an unfairness for something that she feels that she does not know she did not have. Life is different and difficult; unfair. This unfairness is even more acute because Erica never wanted to have children and never saw herself as a mother, let alone a mother with a child with autism. She is in a push-and-pull tension and struggles to understand her role as a mother; it is as if she does not want to admit that her life is difficult and different and this tension that she identifies is her unfairness.

Yeah, I just...I know that my routine at home. My life is probably a little harder than other mothers at the school have said, like, when I make comments about doing homework, they said, "oh really? We don't do any homework with our kids" and it's like, "well, your kids are "A" students and reading on their own. My kid is a "D" student and can't read at all..." (Erica)

Erica reveals a tension that it is not fair that Matt struggles with school. Although Matt may be in the same class and/or socialize with other typically developing children, the constant comparison exposes the unfair difference between Matt and the other children. Not only is mothering Matt different than a typically developing child, it is also difficult.

...learning how to parent and learning how to parent him requires different...different parenting than a normal child, right? (Erica)

Sarah explains a similar story of longing for something that she does not have with Toby, where she is in a similar tension with a larger socialized public. Sarah's early life with Toby was difficult because Sarah felt isolated and alone, not knowing how to deal with Toby's unpredictable behaviors out in public. The difficulties and challenges of mothering a child with autism exposes the mother to criticism and misunderstanding by others that is unfair and unforgiving and further exposes what she cannot have as a mother. Sarah tells a story about swimming with Toby at Disney that sheds light on this unfairness and difference as a mother with a child with autism.

...at Disney, we were there in September and he was not coming out of the pool and he was having a little bit of a meltdown. So I had to go up to these complete strangers lying around the pool and be like, "Hi, my son has autism. I'm about to go get him out of the pool...he's going to have a massive meltdown. I'm not kidnapping him. I'm not hurting him [laughs] ...I'm not doing anything wrong. I am simply going to be picking him up forcefully out of the pool and carrying him back to our hotel and he is going to be screaming like a mad man [laughs]." And those are the things that we have to do as parents that most other people don't.

Anticipating that Toby was going to have *a little bit of a meltdown*, above, Sarah felt like she had to go to the people around the pool and explain that she was not kidnapping Toby, as he will probably kick and scream *like a madman* because he will not want to get out of the pool. Further, she describes her mothering role as something that others, perhaps other mothers without children with a developmental disability or autism, probably do not have to do.

Uphill and unfair. The unfairness that Kate experienced is because she can only long for, rather than experience, normalcy. Adam's differences challenge Kate to redefine her life when she is with other mothers with typically developing children. Kate tells me the story of her experience tobogganing with Adam and her friends over the winter break, explaining that she is the only mom who has to go up the hill with her child. She explains that, even the mothers with younger children do not have to climb the hill with their child, but Kate has to do this task with Adam.

My best friend, we're both the same age, her daughter is twelve and the kids are going to go tobogganing at Christmas when we all get together and I'm going to be going up the hill with mine. I'm the only one...so even, there's only one boy that's younger and he can go up the hill by himself, and there's another girlfriend who is a little younger than us, she doesn't have to go up and I'm thinking, I'm going to be the only one who has to go up the hill...I'm exhausted. (Kate)

Kate explicitly describes this difference between herself as a mother with a child with autism compared to the mothers with typically developing children. Simply, Kate exclaims *but they're not tobogganing...just their kids are, but I'm the only parent going up the hill*. Although Kate wants to be present, and perhaps experiences a longing to be

like her mom friends with typically developing children, there is an unfairness that she experiences being the mother with a child who has different, less-than typical challenges.

In contrast to the literature, the mothers in this study did not appear to change what they did previously because of the child's autism and this was seen in Kate who schlepped her son's toboggan uphill so *he* could toboggan with the other children. For Adam, tobogganing with the other children is *normal*, but for Kate who has to climb the hill with Adam, there is a difference in how she is experiencing being Adam's mother. In the process of trying to level the gaps between normalcy, Kate is experiencing mothering differently. For parents in Gill and Liamputtong's (2011) phenomenology exploring stigma, mothers often avoided situations completely to reduce the stigma and embarrassment felt when they were in public. Although Kate describes unfairness in having to toboggan Adam uphill, it does not appear that her unfairness stems from the stigma of autism, such as that perceived in Gill and Liamputtong (2009). Rather, Kate experiences these as subtle differences in mothering, not autism; she becomes autism.

Hiding. Dealing with others in public, Sarah very simply explains the tension between herself as a mother with a child with autism and how she perceives others through her interactions in dealing with Toby in public. In public, Sarah has a hard time dealing with both Toby and the public, where she describes this in terms of hiding. Hiding refers to the mother's inability to hide the child's autism, and rather than avoiding public situations completely, as the mothers did in Gill and Liamputtong (2009), Sarah is more acutely aware that she cannot hide who Toby is.

It's not like Downs where you can look at that kid and go "Ohhh."...They don't, people don't know, it's really...I don't know. I find I have to deal with a lot more

than other parents do...just dealing, like, with other people I guess. You know, I mean, every kid has temper tantrums, but they don't have the tantrums that my kid does, you know? (Sarah)

Sarah explains that she has a much harder time dealing with Toby and his behaviours in public than she does at home. Emily also describes a similar feeling while dealing with Graham's behaviours in public.

When he's younger, you can sort of hide those behaviours and people think it's just a kid having a temper tantrum. And now that he's 20, and he's throwing himself on the ground and hitting himself, you can't hide that anymore. (Emily)

In these moments, Emily explains that this is who Graham is and her family has accepted this reality. With Toby, Sarah recognizes that autism is what makes Toby who he is and autism is what makes her the mother that she is to Toby.

That's who he is. And I don't...this is who he is. I can't see him as anyone else but him and who he is today. I mean he is freakin' hilarious, like, I am in stitches almost every day because of him...he's just, like, an amazing kid and I just love him to bits and I can't see him being typically developed because then he wouldn't be him. (Sarah)

Different than the avoidance described in Gill and Liamputtong (2011), it seems that the mothers in this study have accepted the behaviour of the child, such as Emily has with Graham's *temper tantrums*. In public, the child as self and the challenges of both mother and child are more fully exposed. This experience renders autism as both visible and invisible. Referencing others in public, Sarah compares Toby's behaviours to the

invisibility of autism. Would it be easier to be a mother facing the public if the child was visibility *different*? *Should it be different or easier?*

They don't understand...they look at it as bad parenting and...or our fault, you know? Or...and not having control and they don't understand...and because autism doesn't have a certain look to them, right? (Sarah)

Not being able to hide Toby's autism has had a significant influence in Sarah's redefinition of herself as a mother and how she perceives herself as a mother with a child with autism. Having an autism diagnosis has helped in how she parents and mothers Toby and has made her reactions to his behaviours easier.

I know how to...deal with it, I know how to, like, be proactive about it and so dealing with him is ten times much easier than it was before having the diagnosis. Yeah, he has always been a great kid, and I always had super fun with him and I have always loved being his mom, but definitely since I've had the diagnosis, and his behaviours are explained, we can...I've been able to approach it with a more calm and patience that 'ok, it's not just you being a jerk [laughs]there's a reason behind this'. (Sarah)

Hiding the child's autism behaviours places the mother in a tension between dealing with the child and dealing with the social world. As Emily explains, Graham's temper tantrum behaviours can only be *hidden* for so long until the autism catches up with him in terms of how his behaviours are perceived by others. Gill and Liamputtong (2011) suggest that some mothers learned to deal with the child's behaviours over time where they did not care about the perception of themselves with their child in public. For

both Emily and Sarah, as a result of their child's autism behaviours, they are forced to accept a different reality as the child grows older.

Forced to accept a different reality. Both Emily and Sarah have been forced to accept the reality of what autism is and what autism means to their family life. Sarah has no choice but to accept that this is what her life is like *now*.

Some people can bring their kids to the parade...I can't. There's a lot of...some people have the freedoms to bring their children certain places...I don't have that freedom. I have to be well aware and conscious of what's going to set him off, what's not going to set him off, those kinds of things. (Sarah)

Emily's acceptance has come over time and reflection, where she sees herself much more as a mentor for other mothers now and *paving the way* for newer mothers. Emily tells a story of grocery shopping with her husband and Graham in the front seat of the shopping cart, where Graham started to eat a half of a watermelon in the cart and dripping the remnants trailing throughout the grocery store. Reflecting back on the story, Emily recalls this experience matter-of-factly.

Yeah, we don't care what people think [laughs], um, we don't care. We take him places. If he acts out, he acts out. That's Graham...we don't care. You know, we just take him places. Yep, sometimes it can be embarrassing, but um, it's funny now that we see other people, and kids acting out, and we say, "oh yeah, that kid looks like he has autism." We would never look, we would never state. My boys don't look...it's because we have been there, done that. People have stared at us so we tune it out. We tune it out. (Emily)

Perhaps because of Graham's age, Emily is more comfortable talking about Graham's behaviours of acting out, and it is now being able to anticipate and quell these behaviours swiftly and without much thought. Although Emily does anticipate many of Graham's behaviours, she is aware that there is predictable unpredictability, meaning that she can often predict many of Graham's self-harming behaviours because of the sounds that he makes. Anticipation is something that, for Sarah, is much more of an acceptance of who she is as a parent and a hope that *others* would change, rather than wishing that Toby would change.

And I think being a parent of a child with autism has just made me grown more as a parent. Yeah, I would never change him. No...no...[laughs]. I wish other people would change [laughs], but I would never change him, no...not at all. (Sarah)

For Kate, acceptance comes through the others. She believes that it is important to accept that Adam is different than the other children, thereby making her different than other mothers that she socializes with by association.

This is My Life *Now*

Bergum (1997) writes, "a woman does not make herself into a mother—she becomes one through coexistence with the child. The presence of the child transforms" (p. 34). This means that there is a distinct transformation from woman to mother while the woman is pregnant, and upon giving birth, the woman transforms into mother. For mothers with children with autism, the diagnosis was seen as an imminent point in another kind of transformation. Now that these mothers have raced out of the starting blocks after the child's diagnosis, it appears that a second change or transformation in the mother has occurred.

The experiences of the loss of *something that was* and the loss of *something that could have been* are a change in the locus of the mothering relation to the child. Some women *know* that they are pregnant because of the subtle changes in their body even before the confirmation by their doctor (Bergum 1989, 1997). Much like knowing about the baby when a woman suspects pregnancy, the child with suspected autism begins to change the mothering relation, as if the mother is pregnant with a child with autism and birthed at diagnosis. Life for these mothers has been transformed. But like the transformation from woman to mother, when does this shift, change, or transformation occur? Similarly, Bergum (1997) questions this transformation from woman to mother, “wherein does this transformation reside? Where does it begin? Is there a beginning? What does transformation mean for women who mother?” (p. 17). For mothers in this study, the question of transformation is not about the transformation from woman to mother, but the transformation from mother to mother with a child with autism. The process of what life is like *now* that these mothers have transitioned into being a mother with a child with autism is described here as a process of change and transformation.

A different mother life. Mothers experienced a different kind of mothering after the diagnosis. One mother described her life after the diagnosis as a *roller coaster ride*; the mother has been given her ticket to ride the roller coaster of autism and she has no choice but to transform her identity into a *rider*. The metaphor of the roller coaster is a vivid image of a rickety ride on a wooden roller coaster. The clickety clacks of the wheels on the ride become transformed over time; slowly changing and wearing down with the increasing challenges of autism. In this different, changed mother life, she does not get replaced as a shiny new roller coaster when she becomes fatigued or exhausted. Rather,

the mother takes on a changed, but not new identity in this different mother life; one that has no end.

For Helena, the experience of becoming a mother with a child with autism is much busier than mothering Amelia, Lily's older sister. Mothers in this study talked about their life now, hinting that their life within autism *is what it is* and there is a hesitation of her expectation out of her life now. Some of the mothers in this study explain to me that there is an expectation and a perception that they need to, and that she *should* be a *super mom* or *Wonder Woman*. The possibility of this, however, is not fathomable. Emily and Helena experience the need for a super mom persona, partially because of what they perceive from others and of their own expectation of mother. Emily describes that mothering Graham in a way that it *is what it is*, where Graham has become part of her routine and who she is as a person and as a mother.

...like, as much as it is expected for you to be "super mom," it's not possible, you know? (Helena)

It...it's hard. I'm not going to lie, it's hard. I have workers that come in and say, "I don't know how you do this." I have, you know, teachers and EAs [Educational Assistants] that get frustrated and say you have help there...you have four or five of you there and there's people that help you and I'm home alone some days...and just...you just do it. I guess I can handle him a lot better. I'm used to him. He's my child. (Emily)

...yeah, it's funny. People think I'm Wonder Woman [laughs]. I'm not [laughs]. The man across the street calls me Little Robin and he sees me running around the property all over the place chasing my son, you know? (Emily)

The relationship between the mother and the child is heightened by the child's autism. Not only did Kate suspect Adam's autism much earlier than her husband, she relates this *knowing* to the relationship that she has as Adam's mother. Perhaps it is the changes through the woman's pregnancy and transformation from woman to mother where she realizes, as Bergum (1997) suggests that there is "...the feeling of a connection to a reality larger than herself" (p. 16). The relationship between the mother and the child has changed and has become heightened through the intensity of the very tight space that Kate shares with Adam, and as Kate suggests, this relationship is far greater than the relationship with the father.

'Cause the mom understands her child, understands her child better than my husband understands him...even now! (Kate)

Much like in pregnancy, the woman feels the visceral presence of the baby where the father cannot (Bergum, 1989; Duden, 1993). The womb of pregnancy becomes extended through the knowledge and space shared *with* the child (Bergum, 1989). How does the womb change through the transformation from mother to mother with a child with autism? The womb as extended is a metaphor of the significant responsibility of the mother in and after the transformation as a mother with a child with autism. What does it mean when the womb never ends? Physiologically, when a baby stays too long in the womb, post-term syndrome may develop, as it appears that the (retained) placenta loses efficiency in nourishing the baby after full term (40 weeks) (Pillitteri, 2010). These babies born post-term are a special kind of baby; appearing perhaps smaller because of the inefficiency of the placenta (Pillitteri, 2010), where these babies may cause increased challenges after birth for both mother and baby.

When we think of the womb as extended, the womb as forever, we think perhaps of a placenta, a fetus, and a mother long past its prime. The retained placenta is a metaphor of the inability to grow beyond the walls of the womb, perhaps beyond the growth of the mother and the child where development is stunted by a lack of nourishment from the placenta. The placenta represents the ability of the mother to nourish the child with enough life and nutrients to sustain outside the womb, but what happens when the placenta is no longer able to sustain the life of a growing child, not fully birthed, yet cannot sustain life independently outside the womb? Here, the lines of pregnancy and birth, and those of mother and child, are blurred.

In this study, it was indeed the mothering perspective that gravitated toward a centralized shift around the child. The umbilical cord is surely long for most of the mothers in this study who describe how their life has changed and has become centralized around the child and the child's behaviours and the umbilical cord is an extension of the additional care required for the child.

For Emily, the community around her is supportive with these added challenges; they are very much aware of Graham and that he has autism and in a way, Emily's experience of a supportive community contradicts the experience of others in public experienced by other mothers in this study. Describing an incident where, because Graham is obsessed with drinking water, Graham went into the neighbour's house and took water from their fridge, Emily explains how there is reciprocity in her neighbours' understanding Graham's behaviours *because it's a community thing... people know him*. There is an extension of the support because of this understanding of who Graham is and his impulsive behaviours. Would this community of support be there if Graham did not

have autism? Would the womb be as extended? Perhaps because Graham is much older than the other children in Emily's life, she describes how she is much more of a mentor for younger moms who are still trying to navigate their early journey with a child with autism. Since navigating her own journey with Graham, and now, nearly twenty years later, Emily reflects this journey as a continuum over time.

I think in the beginning, I was so...gung-ho and just...I had to know what to do. I had to get him...I wanted to know how to help him. How do I help this child? Now, I'm still, sort of, paving the way for younger mothers. I still am, you know? He's an adult now. So what happens after school next year? This is his last year. He goes until he's twenty-one, but I've become, you know, you learn to accept it and deal with it. I'm more laid back now. I help other mothers. I see a few other mothers get very excited and hyper, because they want something quick. They want a quick fix. What do I need to do now? And it's not that easy. There is wait lists and the thing is...I tell these mothers that at least they have a wait list. Fifteen years ago, there was no wait list...we had no wait list to be on...to bring him to. (Emily)

Over time, the role of mother and the role of mother with a child with autism have changed for the mothers in this study; this is who these mothers are *now*. For Emily, perhaps this is because Graham is the oldest child with autism in this study, and too, because of the severity of Graham's autism, but perhaps also because of Emily's acceptance that being the mother with a child with autism is her life. Even though Graham is *a lot of work*, the work that Emily puts in is not just her as a mother, but it is

also work as a family. Having two other, older children, Emily receives a significant amount of help from her family; this is their family life now.

You just, you just love them to death and that's all. You do the best you can to guide them and help them and you can't do any more than that...he's your kid and you do whatever. (Emily)

Summary

Mothers in this study experienced a change since *coming to know* that the child had autism. Loss was expressed in a way that compared the *loss of something that was* to *the loss of something that could have been*. For some mothers, such as Emily, Helena, and Victoria, who had a reference point of other typically developing children, there was a constant comparison to their own children. For Erica, who is the mother of Matt, and who never really wanted to have her own children, there was a loss experienced through the perception of the unfairness of others. These mothers faced unique experiences of loss, but these are universally marked by change and unfairness in the process of becoming a *mother with a child with autism*.

The transformation of mother to a mother with a child with autism was a significant experience for mothers in this study. This transformation mirrors the transformation of woman to mother with the presence and birth of a child (Bergum, 1989, 1997). Mothers moved from suspicion to acceptance that they were mothers with children whose needs define them as a special kind of mother, and potentially, one whose wombs are forever. We begin to question what this experience is like and how it is different from that of mothers with typically developing children?

The Locus of Other

The relationships that these moms had with others, such as friends and family are intimately related to the space they share within the social world with another. Through the fogginess of the diagnosis, and living within the mist of what autism means, the meanings of the relationships created with others changed significantly through the trajectory of time. The presence of others was overwhelmingly related to a feeling of similarity or difference that the mothers in this study felt.

Sameness

Sameness is a feeling that was shared by several mothers in this study. Sameness and similarity were often experienced through a network, especially through similar autism organizations, groups, or functions. To these moms, there appeared to be a solace in a shared space between other mothers who have children with autism. Sarah's experience of her very first organized autism group was an emotional and life-changing experience, where she finally felt normalcy within the context of others.

I ended up crying after because it was like the first time I felt comfortable in public...bringing my son and knowing, like, if he had a meltdown, like, he started to have some behaviours, and not a single person blinked. In fact, I had people going like, "do you need any help?" ...Which was like the most amazing thing ever. And I started bawling my eyes out and people were going "what's wrong?" ... "It's the first time I feel comfortable in public..." (Sarah)

Sarah struggled early with Toby, having difficulty dealing with Toby's behaviours, and attributing these to his other diagnoses. As she describes the *autism moms* group that she belongs to, Sarah brightens.

Oh yeah, oh my gosh, yeah. We call our kids, yeah we're the "autism moms"...it's the "autism moms group." All we'll all Facebook, and say "hanging out with our autism moms today!" You know? [laughs] And we do all sorts of play dates and we get our kids to play together too because then that avoid issues, right, because a lot of kids...typically developing kids don't like to play with children with autism because they are seen as "weird" so they don't have a lot of friendships. Whereas these kids can really get together and they really understand each other and they are similar to each other. So, someone's all flapping, you know, or screaming or having a little bit of a meltdown, the other kids aren't phased by it because they do the same thing [laughs]...(Sarah)

The ease of being with others that are similar is, therefore, not only a benefit or a solace for the mothers, but they also perceive a positive sense of solace within the children as they play *together*. This is similar to what the mothers with children with autism in Markoulakis et al.'s (2012) study also described. Within this study, this network and its benefits were described as an "autism community" (p. 50). Social benefits, such as increased friendships and participation in new and different social activities, were heightened because of her membership to this *autism community* as a mother caring for a child with autism. Comfort in this experience of sameness was directly related to the behaviours of the child and being with other mothers (primary care givers) who were experiencing autism.

Increased similar and social networks can be socially and positively beneficial for both the mother and child with autism, strengthening previously existing friendships and social networks (Markoulakis et al., 2012). In this research study, Sarah describes a

notion that the children can also feel the same sense of similarity that the mothers do. Perhaps it is within this space of similarity that the fog of the diagnosis not only settles, but also relinquishes. The fog does not need to hang in the air because it, too, can take a break in the solace of similarity and sameness.

Getting it. The majority of mothers in this study relish in the warmth of sameness and similarity of being in a group of other mothers with children with autism. Comfort has played a significant role in redefining these mothers' lives, and especially for Sarah, where, compared to her friends with typically developing children, there is a dissonance that Sarah feels when talking to them about mothering Toby. With the *autism moms* that these mothers described to me, there is an intimacy felt when talking about the space that is created when they are with these other similar mothers; there are no physical boundaries, these mothers share more than physical space, such as the space created through social media, such as Facebook. The space experienced by these mothers is created, defined, and redefined through different autism encounters. Through the membership that these mothers have with other *autism moms*, they feel supported, as if the membership with these mothers is exclusive in terms of the ability of other similar mothers to understand what it is like to be a mother with a child with autism.

...it's a big community...I don't think when you have a child who is typically developing, you have your friends, but as with parents who have kids with autism, we have this really unique tight community where we all have, like, the same issues, like, we all get it and I think that brings us closer. And it enables us to have, like, much more, like...it's just a better friendship, I think. I think that community is really there for support. Everyone is very supportive. (Sarah)

The comparison of herself as a mother with a child with autism to mothers who have a typically developing child/ren is a central part of the difference between the *autism moms* and the perception of Others. Toby's autism has pushed Sarah to be a different kind of mother based on this perception of others in public as well as the feeling of sameness experienced as an *autism mom*. Although she takes on multiple identities, Sarah does not get to live in the comfort of her *autism moms* all of the time, rather, comfort is experienced within the small moments of similarity.

...I think it's a lot different than, say, my friends who have regular kids, like, I know that sounds horrible, but...yeah, I get more support from these people and they get it. So when I'm, like, having a bad day and he's like having meltdown and my friends are calling, and I'm like, "sorry, I can't talk" and they don't get it. And then I've got one of my autism moms is calling, and I'm like "oh, we are having a day"... "okay...gotcha!" [laughs]. (Sarah)

Emily and Sarah used the phrase *getting it* to refer to the sameness and similarity that their *autism moms* understand what their life within autism is like and this phrase was salient across the experience of other mothers in this study. The shared feeling of acceptance by these mothers is not only acceptance because of the similarity, but because of a shared feeling of something that cannot be described. The way that Sarah describes how the *autism moms* "get it" is a feeling like a secret that can only be known through membership as an *autism mom*. The majority of mothers in this study share a similar feeling, describing the relatedness that they feel when talking to other mothers with a child *who has the same* kind of developmental disorder. It is within these moments of similarity that comfort is experienced.

...as much as your friends with typical kids try to understand...they are good listeners but they can't understand. But they will say, "I can't even imagine" ...you know, that sort of thing. But when you're talking to a mom who has the same...going through the same thing, you can relate...you can relate better. (Kate)

Multiple mothers in this study also use the term *autism moms* to describe the space shared with other mothers with children with autism, describing a similar notion of uniqueness, defining these mothers as a group, but this uniqueness was difficult for these mothers to fully pin down or explain. Emily describes how mothers with children with autism almost exclusively relate to each other because there is no fear of judgment, nor worry that they will not understand what it is like to be the mother with a child with autism.

I have a lot of autism moms that I have become friends with. We have a support group. Our children all go to a recreation group that night and we go to the mothers group in the same building. We have become the closest friends. We don't have to explain to other moms. Nobody judges, we all get it. We're all living the same thing. They [the children] may be different, but if somebody brings up some thing that their child has done, nobody thinks differently, or...judges them, it's just a part of life. (Emily)

My parents...my friends that I usually hang out with, couples and stuff, they don't always get it. You can tell them until you're blue in the face, and they don't understand what you're going through. They might understand, but they have no idea. (Emily)

What does it mean to understand for these mothers? What does it mean to actually *get it*? It seems that, for these moms, *getting autism*, is something that is created and is a shared experience, even when the child has a uniquely different diagnosis under the spectrum of autism. There is something in the space between these mothers that changes the dynamics of what it means to mother within autism. The space that is created is something special even though the only clear defining feature is that the child must have a diagnosis, or maybe even a very strong suspicion, under the autism spectrum. Emily eloquently states that, for her, being with and within the company of these moms, it is a *break*, a pause from the everyday fast-paced, busy lifestyle of autism. The mothers in this study describe this as a break from having to explain to Others what autism is, why her child with autism does what he/she does, and what she is not as a mother. Because autism has defined who these mothers are and who they have become, autism has become their life in every sense of what it means to live through the diagnosis of autism.

In Emily's explanation describing the *autism moms* group as a *break*, there is a reservation or a hesitancy about the perception of autism from the inside, such as people within their social world, to the outside, such as those perceived to be outside of this social group. *Breaking* from the everyday life of the social world, these mothers can breathe or relax, similar to how Sarah has previously described the solace she felt the first time she met other mothers with children with autism in a group at an autism barbeque. Perhaps, it is the perception that the world around and outside of these moms that is different, rather than the mother with a child who is different. *Breaking* or taking a *break* implies that there is a beginning and an end, even if this end is mostly uncertain; it also implies that you are breaking *from something*, as if these mothers can take a time out

from life. There is solace in the ability to be able to be and *break* with other mothers dealing with the same issues who *get it*.

...I've met a lot of, like, great families, like, a saving grace for me is the moms support group that I belong to...and this circle of moms...there are some that come and go depending on when they're able to join us, but there's this core group that have been together for quite a while...and it's not like we celebrate holidays together and stuff, it's just Thursday nights...and it's during when our kids are in programming for an hour and a half, that's when we meet...(Helena)

This feeling of comfort and the way in which these mothers experience social Others who are similar to them has been described in a very positive way for Helena, Emily, Kate, and Sarah, who found serenity in sameness. Still, for Erica, there was an opposing feeling of anxiety and competition when meeting with other mothers who have children with autism.

...because I find some of them whine, like "oh poor me" or "my child is so special because..." and you know...well Matt is special but I find that you still have to follow society's rules...like I got to teach you how to learn in this box, live in this box...and they don't want to do that or you know or they're not prepared to do the work. So I don't know. I'm not...involved because it's just...they get me full of anxiety and stuff, you know? (Erica)

Erica's experience of how she perceives others is much different than the other perspectives of the mothers presented earlier. The special bond that Erica describes with Matt makes it difficult for others to understand what Erica's life is like. Erica explains that Matt is more receptive to her and because of this unique bond, it appears that others

do not really matter because they do not *get it*; the father and even other mothers with children with autism become Others.

Pregnancy is a human experience that only women can experience and it is within this unique experience that mothers develop a bond with the child that can only be experienced between the mother and baby (Bergum, 1997), impossible for fathers or others to feel this embodiment. This relationship, termed quickening (Duden, 1993), is the very basis of how the mother knows the child in a different, visceral way more so than anyone else. There is a sudden bodily connection between the mother and the child that attaches the mother to the child in a way that connects the mind and the body (Bergum, 1989, 1997; Engel, 2003). For Erica, the pregnancy, birth, and the transformation from mother to mother with a child with autism are an attachment or connection that cannot be undone.

Chesler (1998) describes the relationship shared between her and her son in her *Diary of Motherhood* where she expresses the birth of her son as the point of her death; the death of the close embodiment with the child. Women experience pregnancy and childbirth differently, and for others such as fathers, the presence of the child is also experienced differently; women experience the child viscerally, as a corporeal reflection of knowing in a way that the father cannot (Sandelowski, 1994). Despite the partnered and shared responsibility of successful conception, Sandelowski (1994) suggests that Others must seek permission from the woman to know the fetus, such as through touch and ultrasound technology, thus creating a dissonant space between the father and the fetus, a disembodiment of fatherhood, rather than the embodied relation of motherhood.

Through talking with Erica, it is apparent that she has become very independent and autonomous in being a single mother with a child who has multiple, exhausting challenges. It appears that others, not only the father or others in pregnancy as Sandelowski (1994) suggests, must seek permission to enter Erica and Matt's world. Therefore, Erica begins to take on the role, not only of mother, but also that of teacher, supporter, and friend with the deep level of connection she feels to Matt. This deep level of connection perhaps has developed over time, nurtured since the womb of Erica's motherhood, for this life and this world of mother is all that Erica (and Matt) know.

Rather than placing the locus on herself as a mother, Erica shifts her perspective on Matt, believing that Matt will learn the skills he needs in time and therefore, does not feel the same need for a support group if he does not learn a skill on time. This feeling is evidenced in Erica's disappointment in the lack of services during the time that she needed them, and thereby felt she had to take matters in her own hands to help Matt learn the skills that he needs, rather than utilizing others for support or for services. The locus of support, therefore, is placed internally rather than externally.

Yeah, so...waiting for services was exhausting because you...like, what do you do for you kid...he is covered in bruises, people are looking at you funny, he's acting out in public...people are making comments. I was offered in-services and workshops and I attended as many as I could, but I didn't have the support, like for baby—like for watching Matt and stuff like that to attend as many as I would have wanted to and just, I learned on my own how to cope...how to manage him, and um, what to do and life has never been the same. (Erica)

Erica has potty trained Matt, has taught him how to ride a bike, and she is optimistic that one day soon Matt will be able to tie his shoes without Velcro. Erica believes that these are skills that she *should* be able to teach her son, regardless of Matt's autism diagnosis. Here, it is evident that Erica does not see herself as similar to the other mothers because she sees these tasks as part of her responsibility as both a mother and a mother with a child with autism. Beyond having children with similar diagnoses, Erica does not see her membership to the *autism moms* as something that reflects her outlook or perspective on how she mothers Matt.

Overall, the experience of sameness and similarity was a significant finding of this study, related to the locus and corporality of Other. The shared space between other mothers with children with autism was found to be an important place of serenity. Feeling comfort with others who are experiencing the same thing was critical for several of the mothers in experiencing acceptance and normalcy, both for the mother and perceivably, for the child. Although all mothers did not share this experience, perhaps there is a special need for the physical and interpersonal space of similarity.

The Womb is Now and is Forever

“I’m Living in the Moment. That’s What We Do”

Always There

Time is not measured in seconds, minutes, hours, or days; time is a constant shadow, neither moving too fast, nor too slow. Although there seems to be a perpetual and inevitable movement forward, time is a shadow of moments; a collection of finished calendars marked with busy days. Time is always there for these mothers, but it is never there to take, to touch, or to grasp hold of. The days of the week always seem out of

reach, something that is difficult to pin down because these mothers are so immersed and busy with the child's schedule.

Go, go, go. It's Monday and then it's Friday. Oh my God, and then it's the weekend, like, and it's constant, right? (Kate)

There is an apprehension that, because time is always there, it is always constant. It never seems to end and the mother's efforts never seem to be enough. Time is insurmountable. There is a feeling that, not only is there not enough time in the day, but there is not enough time in general to do what these mothers feel like they need to do to just be able to live. These mothers are exhausted, tired, and fatigued. For older mothers, there is also exhaustion and *fatigue* in meeting the needs of the child, such as Engel (2003) describes, because of the immense emotional and physical challenges she faces. But what does living in time with immense emotional and physical challenges mean for mothers with children with autism? Time is living in the moment and it is an expectation that this is her life.

Taking on autism as part of her mothering identity, Kate has described autism as her *full-time job* and this expectation that she has of herself is to live within limits, both in space and time, of autism. When we look at early discussions of pregnancy and mothering, there is a notion that it was much of the mother's responsibility to be "devoted," where the devotion of the mother is her constant care; the mother is always there for the child and the child is always there for the mother (Winnicott, 1987, p. 4). Time, for Chesler (1998) during pregnancy and after her son's birth was a fine balance between the busy, traveling, married woman with a doctorate she was before her pregnancy with the life of mother after her son was born. In this study, time is a

significant aspect of the mother's identity as a mother with a child with autism and worrying about her child is a telling sign of the coming time. If this is what it is like now, what will the future be like?

These mothers' expectation of herself go beyond the influence of time. Emily's expectation is that, because she is the mother, she is the one that is expected to deal with the *challenges* that Graham's autism presents, they are her responsibility (Bergum, 1997). The mother's time is scheduled around the child's autism; autism, as the ticking clock, which perpetually moves her forward. The identity that these mothers take on is not a choice. Autism is always there; aware that the child's needs are very much dependant on her, these mothers worry that they are going to have to live forever to help the child.

Morality was also a fear experienced by older mothers, who wondered and worried when their child will be "*old enough*" (Engel, 2003, p. 166). For older mothers and the mothers with children with autism in this study, there is a desire to demand more of the body (Frank, 2013); more time taxiing to activities, more energy caring for a child who may not communicate. There is also uncertainty if the supply of time and energy input by these mothers is greater than the demand, greater than the need. Will the body be enough to mother (Engel, 2003; Frank, 2013)? There is a fear that no age will ever be *old enough*.

I always say, "oh, God, just please let me live until at least 87" 'cause I had him when I was 37 and then he will be 50, you know? And then I think, "oh, God, he could live until eighty, and then be thirty years without me." So I'm like, "well, maybe 100" [laughs] ...but I want my brain working; I still want to be functioning right? (Kate)

Although mothers may see autism as a separate construct in their life, such as the description of autism as a *full-time job*, it is hard to distinguish the difference between being a mother and being a mother with a child with autism. *Autism as a job* nods to the ability to be able to leave and go home, but these mothers cannot leave their job as a mother with a child with autism, because autism is always there. As Kate describes her busy schedule taking Adam to school, programs, and activities, it seems there is a loss of who Kate was before the diagnosis, and taking on a new job, one with a new title. How does the mother see her identity in the future when she is still trying to reconstruct who she is, now as a mother with a child with autism?

Autism is Kate's life and, within that, Kate has become very close to Adam. Kate's husband works throughout the week, making the weekend time as a family very important to Kate. Thinking that Adam was a typically developing child from early childhood, Kate thought that she would have been able to go back to work, but expresses that she has not been able to do so for nine years because of the demands of Adam's autism. Kate's life is equated with everything that autism means to her and her family.

We do family things on the weekend, but during the week, like, I take my son, I mean I take him in everything. (Kate)

Mothers described being physically exhausted, Kate even stating that she knew she only would have one child after having early challenges with Adam, even though she wanted to have two children. Physical exhaustion also had an effect on older mothers, who limited the number of children because of the demands of the first (Engel, 2003). For Emily, taking care of twenty-year-old Graham is a time-consuming and physically demanding task. Emily describes Graham's care as *challenging*, needing *24/7 care*.

You need to watch him always, can't take your eyes off him. (Emily)

I knew I didn't want another one...that's funny, 'cause I wanted two, but he was a lot of work and I had a terrible pregnancy, I had a terrible labour. He had colic for two weeks. So I'm like, I said to my husband after a while before we knew of his diagnosis, I said, "yeah, I don't think I can do another one." You're usually...your second is opposite but I didn't want to take a chance. (Kate)

There is constancy with the needs of the child and the contingency of the severity of the child's autism. The uncertainty of the future is difficult for these mothers to see because of the immediate focus that places the child's current needs above all. The presence of autism has interrupted a typical development trajectory (Frank, 2013) and the spectrum of time is lost, interrupted, and changed. Focusing your eyes on the future is especially difficult when you seem to only be able to look at the child's current and present needs. When Emily talks of the needs Graham has on a daily basis, she is referring to his immediate, physical needs such as *bathing, brushing his teeth, [getting] dressed, safety*. There is an immediate preoccupation on these care needs, as these needs are constant. Graham's needs are within the fogginess of the diagnosis, and they have been this way 24 hours a day, seven days a week for twenty years.

“He's always on your mind”. Time is a reflection of the space shared between the mother and the child and for these mothers, the time and space that they share with the child go beyond physicality. Emily explains the constant worry she has for Graham, even when he is not with her, and especially when he is with other people, without her. Not only are the *challenges* something that she experiences, but they are also something that she does not want someone else to experience. Each weekend that Graham is in

respite care are a *break from autism*, even though they are not physically together, *he's always on your mind*, never too far away from Emily's consciousness.

...Even though he's not with you during the day, he's always on your mind, you're always thinking, "what is he doing? I hope he's not causing anybody any grief." You feel bad for people. I know that that's their job, but as a mother, you feel guilty that you're dropping him off somewhere and he's giving somebody a hard time. You know, you don't want him to. Same when he goes to respite every seventh weekend, I just hope and pray that he doesn't give them too much of a challenge because he is challenging. (Emily)

Strung throughout the mothering literature there has been a common theme: The child is always on the mother's mind (Bergum, 1989, 1997; Chesler, 1998). Other literature on mothering dance around this idea by using terms such as *quickenings* (Duden, 1993; Rabuzzi, 1994). How does the child leave the mother's mind when they were, not long ago, attached in a visceral way, when she could not forget the feeling of the baby kick in her belly? The life connection between mother and child is still thriving. Erica shares Emily's experiences of worry because of the strong connection she feels with Matt. Erica becomes emotional discussing how her life has become a constant worry about Matt and his behaviours, especially his behaviours at school. Erica's description of her relationship with Matt was unique, describing how she is the *only* one that understands Matt and the burden this places on her as a mother.

...He is never far from my mind. Everyone always says I need a break, but how can you take a break when you're the only one that they will do what they need to do?...He's very close to me, I'm always worried about him...(Erica)

Mothers in this study described not being able to take a break from autism and, because the mother is the one that the child wants and needs, these mothers are always submersed in a life that is only autism. Like Emily, there is a progressive nature that Erica is always walking Matt through life and he is never far from her thoughts when she is physically away from him expressing no distance from Matt's Asperger's syndrome. The struggles that mothers face with autism have become something that they had to accept because there is never a time that autism is going to go away. Many mothers relished in the moments that she does get to experience similarity and success.

When I'm at work, especially if Matt's had a bad morning, you always think...you obsess...your kid does nothing but obsess about things, and you, in turn, obsess about them constantly. So yeah, no, he is never not on my mind, you know?

(Erica)

As much as there is difficulty, there is these high times too, you know. You kind of ride through the difficulty and you enjoy those times that, you know, that you're given. So, because there's always going to be something coming... (Helena)

For Emily, Erica, and Helena, the child was something that was always a constant presence in their life. Bergum (1997) proposes that mothering is a notion and a relation of the mind and body. One cannot be without the other. Emily has difficulty putting Graham's extreme behaviours away from her mind. *Having a child on one's mind* is a mothering experience that was described across a mothering space for biological mothers, teen mothers, and mothers who have placed their child for adoption, in which Bergum (1997) describes. This notion that the *child is on one's mind* is a significant experience across many types of mothering experiences; however, there is a difference in the

experience of mothers with children with autism because the child is sometimes never fully birthed and the special challenges that mothers with children with autism face are a testament to this difference. The womb is now and the womb is forever.

The Future is Uncertain

Living in the moment is living for the immediateness of the present. The cloudiness and the fogginess of autism can never lift, as there is, at this point in time, no known cause or cure. Some mothers described a feeling that the fog is starting to settle, and there are easier troughs in the *roller coaster*, even if the *roller coaster* has no foreseeable end. For Helena there are ups and downs along her journey, which she metaphorically describes a *roller coaster ride*. This metaphor is a recurring story line that Helena describes about their family's life in coming to know, and eventually learning to live with a child who is *different*. The roller coaster she describes is having a ticket for a ride, but not knowing what to expect or even how to expect what is going to happen. Unlike a roller coaster ride, life does not have a designated end point, there is no ability to get off the *ride*; there is no point in which you can give up your ticket. The roller coaster does not have only one car. For older mothers, the description of a *roller coaster* was also used to describe the presence of the child in the mother's life (Engel, 2003). It is as if autism has been dropped into the mother's life; she is on a roller coaster ride, and has no place else to go but to ride the ride, even if she hates roller coasters.

Is the *roller coaster ride* different? Trying to keep pace for these mothers is often an insurmountable task, one that they frequently had difficulty explaining. Helena takes nothing for granted and is always prepared for the next *thing* to come along. Helena explains the tension between her uncertainty with Lily in a way that nothing is really

certain for either mother or child. Currently, Helena describes the uncertainty she feels in not knowing when she will need to discuss with Lily about puberty. Helena understands that Lily will experience puberty soon, but the timing is completely out of her control. Unknowing, in these moments, such as the abstractness of puberty, and the lack of predictability and control is something that makes the present, and especially the future, so difficult and uncertain.

I mean, how do you explain such an abstract thing to her. Like, I don't know when everything's going to happen, you know, so like, that's when everything's going to be hard. So you just, like, as far as how our life has changed too, you just don't take anything for granted in that, that you know there's no entitlement. You have to... you have to work for everything. You try, um, just like, try to always stay five steps ahead. You have no choice really to kind of sit back and relax, you know? You think that you might be doing it, but you're not. Your mind's always going, you know? (Helena)

For Emily, there are other and new variations in the roller coaster as Graham reaches a different stage; Graham is nearly done school and Emily is starting to question and to worry, *what will the future be like? What will we do and what can we do next?* Describing the challenges with Graham's future, Emily is present-oriented. Emily experiences the *now-ness* of the challenges with Graham and how they appear to consume her life. For Emily's family, centered on Graham, what will the future be like? What will the future be like for Graham? What will the future hold within the present challenges that she describes? Emily does not know...but is anything ever certain?

Ok, so that's our challenge right now. He's twenty; he will be twenty-one in April. This is his last year of high school. We have no idea. We know it is a ten to fifteen year wait list for housing program. I don't know if I'm ready yet to put him in residential, but we are going to look into day programs... (Emily)

How does Erica begin to see a future for Matt when she is so focused on Matt's immediate behaviours? When Matt has difficulty processing the future, how does Erica begin to move forward beyond the immediateness of his needs? How does Erica separate herself from Matt's Asperger's syndrome? All that Erica knows is the vessel of life containing her world with Matt, but does she have an identity of her own as woman or as mother? Is this her present and future identity as woman or as mother? As a woman becomes mother, Bergum (1989) questions, "how does a woman come to live as mother—for her child—and yet for herself?" (p. 85). When women are mothers, there is a duality of her mother life, such as Chesler (1998) explains that whenever she goes out, there must be someone there to take her place, and when she is with the child, there is never a sense of solitary wholeness. The future of her identity is placed on the needs of the child. For Chesler (1998), the mother and the child are never apart, "*Ariel: Wherever I am, you're there too, hovering around my shoulders. I'm never alone. Not even when I'm lonely and quite alone; in my study, or in another city*" (p. 190). How does the mother begin to separate herself from the child to be able to move forward when the child is located in the immediate present?

Although the future for these mothers is uncertain, it is important to remember that the future is an abstract, and often vague and uncertain concept for other mothers, not just mothers with children with autism. The weight of this uncertainty is expanded, blown

out because of the immense dependence that the child has on the mother. With these mothers, we question if there will ever be a future-locus. Although the mother may worry about the child's future, such as with housing, finances, among other things, is this the same as preparing for the future? Are these preparations part of the practice of mother, rather than the relation of the mothering experience (van Manen, 1990)? *Being with* the child is different than *doing for* the child (Bergum, 1997). The relationality of the mother *being with* the child and having a *child on one's mind* (Bergum, 1997) reflects how the child is always connected to the mother in past, present, and future; whereas, *doing for* the child reflects a passive and task-oriented focus. How do mothers with children with autism begin to separate these concepts of *being with* and *doing for* (Bergum, 1997) when they are still in transformation, or even, when the future is so uncertain that they cannot prepare for what the future and the transformation will bring?

Summary

The future is just as uncertain for these mothers as it is, perhaps, for other mothers with typically developing children. The child is a constant source of worry and these mothers expressed that the child is never far from her mind. Remnants of exhaustion and fatigue, these mothers live in the moment and they live for each moment. Time is not only a collection of moments for these mothers, but it is the vessel that contains their life; it is neither attainable nor palpable, yet never too far off in the distance.

The findings from this study attempt to bridge the experience of being a mother with a child with autism with an open dialogue with the literature. The mothers in this study have described what it has been like to come to know about her child's autism and the profound implications this diagnosis has had on her and her family's life. Despite

early premonitions leading up to the diagnosis, mothers reluctantly toyed back and forth with the idea that it *could be* autism. A shift in the mother's perspective and locus of mothering has changed where the mother has transformed into the mother with a child with autism, especially after she received validation with the diagnosis. This second transformation reflects the transformation that Bergum (1989, 1997) suggests from woman to mother. The mother relation has been reflected in both how the mother sees herself corporeally contrasted with other, and how she sees herself temporally contrasted with time. The findings of this study reflect a deep orientation to the mothering experience constantly asking "*what is it like?*" (van Manen, 1990, p. 46), and probing further for the mother's experience, remaining true to the methodology in searching for what autism is like as a mother, a mother with a child with autism.

Chapter 5: Discussion

Through an evocative narrative, the voices of six mothers with children with autism have been shared. The stories told by these mothers reflect an orientation to the research question, *what is the experience of mothering a child with autism?* Mother, as previously defined, is a woman who has “given birth” (para 1) to a child “to bring up with care and affection” (Stevenson, 2010, para 4). Asking questions regarding the child with autism places the focus on the child, rather than the mother and the space shared between the child and the mother. The purpose of this study was to explore the experience of what it is like to be the mother with a child with autism. The guiding questions reflected the orientation to *mothering*, as defined by the mother. I began to ask these mothers *how did you know?* How did the mother know about her child’s autism and what was that experience like? To *know* means *to recognize or distinguish* (Oxford English Dictionary Online, 2014). Coming to question what it was like for these mothers to *know* about their child’s autism was a spiraling process, a back and forth hesitation. It was important here to maintain the locus of the initial questions and follow-up questions on the mother as the intent was in questioning *mothering* in relation to autism. This chapter will present a discussion of one interpretation of the narratives of these mothers.

The Womb is Forever

“Beyond mountains there are mountains”—Haitian proverb (Kidder, 2009, p. 36)

The Transformation of Mother

The transformation from woman to mother is a process of acceptance and change. Bergum (1997) describes that, although pregnancy is not always a choice, *mothering* is a choice. There is a distinct choice of a woman who is pregnant with a baby. There is the

choice to continue with the pregnancy or to terminate the pregnancy. The women included in this study are mothers who made the decision to continue with their pregnancy, whether they wanted a child or not. Bergum (1997) writes, “a woman does not make herself into a mother—she becomes one through coexistence with the child. The presence of the child transforms” (p. 34). After birth there was an unforeseen change or shift for these mothers that was often centralized around realizing that *something was different* with the child. In this study, I begin to question what is the experience of mothering a child with autism? How do we know that mothering a child with autism is different than mothering a typically developing child? Although the lines appear to blur between the distinction between *mother* and *mother with a child with autism*, there is an experience beyond corporality in the identity of being a mother that these women (mothers with children with autism) take on. Corporality refers to the bodily presence of ourselves in the world (van Manen, 1990); women with children are mothers corporeally (Bergum, 1997), but the existence of the child with autism transforms these mothers into a special kind of mother. The most significant finding of this study is what I describe as a second transformation from *mother* to *mother with a child with autism*.

Conversations with mothers in this study began by asking mothers about their first experiences with coming to know that they wanted to be a mother. For Emily, she knew that she wanted to have children *shortly after* marriage. Emily described that she *just knew* that she wanted to have children. As an active woman, Emily wanted children while she was *young enough* so that she could *enjoy them and put them in sports and music and stuff like that*. Erica, mother of Matt, expressed that she *never did want to be a mother* until her relationship with Matt’s father. Sarah, mother of Toby, describes a longing that

she *has always wanted to be a mom*. Sarah describes a feeling of always having a *maternal instinct*, even since she was very young.

The perception that these mothers had about knowing when they wanted to be a mother was idyllic. The mothers' idyllic perception of their children was a tension between the mothers that they wanted to be and the mothers that they actually are. They were in between transformations, still waiting for the child that they wanted, pregnant with autism. One of the first questions I asked mothers during our conversation was "when did you know that you wanted to be a mother?" Perhaps because of the openness of this question, mothers were hesitant and uncertain how to answer, looking to me for guidance and reassurance. In this first question, mothers told me stories of what kind of mother they wanted to be, or what they wanted to do with their child, and one mother told me stories about her son with autism. Victoria told me about Nathan's love of dinosaurs and the trip she and her family took to Drumheller, Alberta to see the dinosaur museum. Although I had specifically asked Victoria about mothering here, she told me about Nathan, perhaps suggesting that the life of mother and child are so entangled that the womb is possibly extended.

Within the third theme of the findings, "The Womb Extended: Transformation as a Process of Forever Change" I described how the mother's life had changed in the description of "this is my life *now*." Bergum (1997) describes that a woman changes into a mother when she has a child. The mothers in this study offer the possibility of a second transformation that occurs in the process of becoming the mother with a child with autism. The point that a mother becomes a mother with a child with autism is unclear. With the mothers in this study, I became distinctly aware that the lines between *mother*

and *mother with a child with autism* started to blur, especially around the child's diagnosis. I question, at what point did these mothers *become* the mother with a child with autism? At what point is the *mother with a child with autism* conceived? Is there a definitive switch, a moment in time that unquestionably, undeniably distinguishes these mothers between *mother* and *mother with a child with autism*?

Through the dialogues with the mothers in this study, it becomes apparent that there has always been a point of *knowing*, as suggested by the constant hesitation and back and forth notion that *it can't be autism* that most mothers in this study experienced. Hesitantly, mothers doubted if the difference they were experiencing was, indeed, autism. During the time before these mothers received confirmation of the diagnosis, I question if these mothers are mothers with a child with autism? What is the mothering difference between being a mother and being a mother with a child with autism for these mothers? In the recruitment phase of this study, it was identified that mothers did not need a diagnosis of an autism spectrum disorder to be included in the study. All children in this study, however, did have a confirmed diagnosis of an autism spectrum disorder, either autism or Asperger's syndrome, from a specialist or a pediatrician.

Is it the diagnosis that classifies these mothers as a *mother with a child with autism*? Although the diagnosis was a significant moment for these mothers, there appears to be something more than the diagnosis, something that is not as concrete. Perhaps the diagnosis plays a role in the definition of the mother's identity and part of the transformation of the mother as a *mother with a child with autism*, the weight of the role, and perhaps the acceptance of the diagnosis over time, varied by mother. I suggest that, from the group of mothers I talked with, there were different kinds of mothers,

distinguished by their perception, relationships, and also age of the mother. I suggest that there was a type of mother membership, exclusive to these mothers, with the diagnosis perhaps as the membership card. There appears to be a culture of autism mothering, perhaps like the motherhood culture that pregnancy evokes (Nelson, 2007). The act of sharing birth stories, such as Nelson (2007) describes, is important in the transformation to mother, “it is not merely hearing other women’s stories, but also sharing one’s own and having it responded to in affirming ways that can offer validation and reassurance to a new mother” (p. 95). These mothers appear to differ in their perspective, perhaps because of how soon the transformation occurred and was accepted. Bergum (1989) describes the mother who quits smoking because of a new pregnancy, but for other mothers, this transformation takes time to realize that there is “‘someone else’ to think about” (p. 86). The presence of autism is different from the acceptance of autism, and perhaps it is along this acceptance transformation that makes these mothers different.

Most mothers in this study described a feeling of solace in sameness and similarity. Several mothers identified with a group of other mothers who had children with autism, even so far as calling themselves *autism moms*. Being with other mothers who shared the same experience suggests a defining feature that appears important to the membership of being a *mother with a child with autism*, but what is this defining feature?

Transformation is temporal. The influence of time, or temporality, is a significant finding of this study. Time has a notable impact on the transformation that these mothers experienced in coming to know about their child’s autism, and this transformation appears to continue throughout the child’s life. For mothers such as Emily, who has lived with Graham for twenty years, she knows and understands

Graham's challenges in a way that is different from mothers who have encountered these challenges more recently with a younger child. Does the influence of time mean that Emily's mothering challenges are *easier* than the other mothers in this study? Although Emily sees herself as a mentor, *paving the way* for other, younger mothers, Emily still faces challenges, but these challenges are different than the other mothers in this study who seem to be navigating the early process of the *second transformation*.

In suspecting that the child had autism, time influenced the transformation of *woman* to *mother* and from *mother* to *mother with a child with autism*. Time appears integral to the mother's acceptance of autism. Rarely do these mothers have the ability to take a *break* in caring for their child. Some mothers described autism as a full-time job, suggesting that they take autism on as part of their identity. For example, much like a full-time registered nurse who takes on the identity as *nurse*, Kate took on the role and identity of *mother with a child with autism*. The time she spent with Adam and caring for Adam as part of her job was an extension of the influence of time on how she perceived herself as a mother. Kate described her busy schedule and the exhausting amount of time she spends with Adam, defining the fourth and final theme of this study, "The Womb is Now and Is Forever," where Kate expresses, *I'm living in the moment. That's what we do*. Kate's expression of *we* takes on an attachment between her and Adam (Bergum, 1989), perhaps, too, between her and autism.

Living in the moment was something that these mothers could not escape. Calendars filled with activities, moments filled with exhaustion, and sleepless nights filled with fatigue. How is this different than mothering children outside of autism? Here we make the distinction that time in mothering children with autism is not sped up, nor is

it slowed down. Time, for these mothers is living in the in-between. As the dust from the explosion at the starting blocks begins to settle, time begins to be something that is only measured by missed milestones or learning to ride a bike seven years too late, or even, by a child still wearing Velcro shoes at twelve years old. Time hangs in the air, it is the dust that settles but it is not tangible. Time cannot be pinned down for these mothers, it is not theirs to touch or take, nor is it theirs to slow down or speed up. Like autism, time is not defined by boundaries.

There is a Haitian proverb, “beyond mountains there are mountains,” which roughly translates into meaning that beyond one challenge lies another (Kidder, 2009, p. 36). For these mothers, their lives are mountains of challenges and changes and these mountains never end; although they may change in shape or size, difficulty or severity, beyond one mountain, there is another. Time reaches a never-ending cycle of mountains to climb, and over time, these mountains become uncertain. Uncertainty for these mothers was related to the inability to see the future, unable to see the forest through the trees, these mothers cannot see well past the unfair shadow of a uniquely steep mountain; always climbing uphill, always unfair, always there.

Transformation is corporeal. With Graham, Emily’s son, his needs are overwhelming. Not only does she provide 24/7 care for Graham, it appears that it is nearly impossible for Emily to separate herself from Graham’s needs; *Graham as a child with special needs, Graham as a child with autism*. Helena describes the *exhaustion* she experiences trying to potty train Lily. Whereas, Kate experiences a similar physical *exhaustion* related to Adam’s sleep cycle. Kate explains that Adam does not sleep well and his sleep cycle has had an impact on her own. In a way, Kate is forced to synchronize

to Adam's schedule because Adam depends on Kate, but the relationship is not reciprocal. Kate must change who she is as a woman to adapt to the changes she sees in Adam. Perhaps this experience is not unique solely to mothers with children with autism, but there is a deep presence of physical and emotional exhaustion when these mothers describe how they care for their child, as Emily states, 24/7. Kate, aware that Adam's needs are very much dependant on her, worries *I'm going to have to live forever to help him*; lingering on forever, Kate laughs.

For Kate, there is a junction between time and body. Will her body be enough for Adam? Is mother enough? Through Adam's dependence on Kate, and Matt's dependence on Erica, these mothers are physically attached to the child. The womb of pregnancy is not only extended, but for Kate, the womb is now and forever. Questioning their own mortality, mothers in the literature also experienced a feeling that they may not live long enough to care for an aging child, such as older mothers (Engel, 2003). For mothers who experience pregnancy loss, there is also a feeling that the loss becomes part of who they are as women and as mothers (Patey, McIntyre, & McDonald, 2007). Pregnant with autism, an expression that represents the hesitancy and the fullness of the autism diagnosis as an attached yet, separate entity of the mother, represents a child that has not been fully birthed. The umbilical cord, although once cut, is still attached, and it cannot be hidden. The attachment is visceral and tangible, the blood of life bounding through the attachment between the mother and the child.

Disability scholars caution the discussion of the ethic of care between caregivers and the person with a disability. In this study, we do not wish to subordinate either mother or child especially because of the role differential between the non-disabled

caregiver and the person with the disability (Griffiths et al., 2006; Wendell, 1996). In describing *the womb as extended*, we speak of the relationship between the mother and child; the visceral connection during pregnancy when the woman felt and experienced the child. Mothers in all facets, not necessarily mothers with children with autism and/or other disabilities, may experience an extension of the relationship and the closeness they feel with the child, one that never relents as was described by Chesler (1998).

Conjuring images of a forever womb may subordinate the child as one that needs constant care and a child that is so dependant on the mother as primary caregiver, that he or she may never reach independence. Further, because of few policies in place, the child may never have the opportunities for greater independence, such as with residential or group home care. Many persons with disabilities often struggle with their rights, as dependently independent. Griffiths et al. (2006) described the restrictions of persons with disabilities within independent community living homes, where many persons felt their needs were unmet in regards to the limitations they felt or perceived (both persons with disabilities and caregivers). Therefore, the warning by Wendell (2006) is that we need to be careful that the person with disabilities is not subordinated. As we saw with the mothers in this study, the child's future is uncertain and the possibility of change is unknown. The extension of uncertainty for both mother and child is intertwined in the *possibility* of the future because of the extension of the child or adult with autism as a dependant on the mother.

Despite these precautions presented in the literature regarding care and persons with disabilities, it was, indeed, the mothers with children with autism in this study that related their experience to being potentially *forever*. These mothers described their

relationship with the child as one that is different, as was seen very early in the coming to know process and the difference between the mother and Others around her. Corporality between the mother and child with autism was experienced by these mothers, which manifested in their constant exhaustion and fatigue, rendering it difficult to deny the implications of a heavy womb, no longer filled with a delicate growing fetus, but replaced by the bustling life of a child or adult with autism. The weight of autism is heavily placed on the mother.

The attachment between the mother and the child is perhaps what so signifies mothering a child with autism, as we have seen the significant attachment for mothers of all kinds (Bergum, 1989, 2007; Engel, 2003; Patey et al., 2007). For Erica, she feels a very special and unique attachment to Matt, who is only receptive towards her. With Matt, Erica feels like there is a magical bond that only they share, as mother and child; mother and son. The umbilical cord is visible only to them; invisible to the outside social world. With Matt's unique and challenging behaviours within Asperger's syndrome, Erica is challenged daily with trying to communicate with Matt within the social world, but in the moments between, Matt is Erica's everything and Erica is Matt's everything.

Transformation as Other. Kate explains that the mother knows and understands her child more so than her husband, and possibly, as an extension of this, she knows her child more than others as well. There is a significant relationship described where the relation between the mother and the child is also *something different*. Others can be described as family, friends, and people within the social world. For the mothers in this study, there was a pronounced space between the mother and Others and the relationships created between these mothers and the social world.

Through *coming to know* about the child's autism and the label of the diagnosis, there suggests a kind of membership within the social role of *mother with a child with autism*. Most mothers within this study expressed a solace in being with other mothers who have children who are similar. Sameness and similarity were expressed not only as a shared intimacy that only these mothers could really *get it*, but the membership as an *autism mom* appears to have a bond or connection because these mothers need something from each other, although it is unclear what this *something* is. The relationships created between these *autism moms* helped to cultivate an identity shift, one that perhaps was already present, but added weight to it as if a confirmation that what they are feeling is shared by others. For individual mothers, there was an identity shift of the mother as not only a mother, but also a special kind of mother.

Mothers were often challenged by an external other, such as a family doctor or a pediatrician, to accept the child's diagnosis. Mothers were seen as in a tension and comparison between their child and a typically developing child, either their own older child or someone else's. The constant comparison between the child with autism and a typically developing child was a central part of the comfort that mothers felt when sharing moments with mothers who are experiencing the same thing. For these mothers, sameness and similarity was not experienced all day, every day. Rather, moments of similarity were relished as a break, taking serenity that the other moms *get it* if the child had a meltdown. Therefore, not only was the similarity perceived for the mother, there was also a similarity experienced when the children played together in sameness.

Implications

The voices presented in this research represent a small number of mothers who experience a challenging, unique, and very contemporaneous phenomenon. What do the findings of this study mean for nursing practice, research, education, and policy? What does a second transformation mean for practice? What kind of care do we need to provide as nurses, friends, and others when a mother is *pregnant with autism*? How do we take what we have heard and learned from these mothers into the world of other?

Mothering and Nursing Practice

When mothers come to us, as partners, friends, or health care professionals, there is a tendency to reject the notion that *something is different* as we saw with the mothers in this study early in the *coming to know process*. Frank (2013) suggests that our narratives are interrupted with the onset of illness or disease. But when these mothers question autism, are their narratives interrupted? We need to be cautious when mothers present us with the vulnerability of their questions, *is this autism? Is this normal?* When presented with such questions, it is important that we address, not only the needs of the child, but also the needs of the mother, especially within the mothering role.

As mothers with children with autism grow older, their children, too, become bigger, older, but their questions do not quell. The questions of older mothers with children with autism become different, slightly more focused on the future as worry and fear reach a junction. How do we navigate a future that is foggy? Anticipatory guidance is something we can offer other mothers. The transformation in mothering was a constant notice that the child was not meeting his or her milestones. The developmental stages of childhood and adolescence in children with autism are exploded, magnified, and drawn

out much longer than a typically developing child. What takes months for a typically developing child may take years for a child with autism. How do we offer reassurance for mothers when we, as nurses, physicians, others, do not know how the child will proceed (or not proceed) through the stages of development? There may always be an ongoing struggle between uncertainty and reservation that the child's dependence on the mother is going to be forever. Not only is the womb extended, but the womb is perhaps, forever.

Mothers in this study were recruited using recruitment posters through an autism program on a Canadian university's campus. The majority of the mothers in this study had been involved with this autism program at one time and may represent a 'best case scenario' because they have access to local and subsidized autism support. Because of this support, the experience of these mothers may or may not be true for other mothers with children with autism. Some of these mothers were themselves students and scheduled conversations between classes, adding to the inference that these mothers represent a 'best case scenario' for their children. If these mothers largely represent mothers with children with autism who are supported, subsidized, and educated, what about those mothers who do not receive support or funding?

The mothers in this study described significant difficulties in gaining access to and navigating a world in which something is different with their children. For other mothers, with fewer supports, the experience of mothering a child with autism compounds what may already be a socially and financially constrained family system.

These mothers can also be described as mentors for younger mothers with children with autism by helping them navigate the intricacies of growing older within autism. We can learn from these mothers and the relationships they find important. The

solace that these mothers felt in the presence of other mothers experiencing mothering a child with autism was important. Maintaining and increasing these connections would be important to continue the strength that these mothers expressed in the relationships with other mothers. Maintaining support groups and services for mothers is important to help foster the mothering role, just as it is important to maintain funding for the child's developmental needs as the mother is in a place of developmental flux as well.

Mothering and Nursing Education

What can we learn from mothers who are experiencing autism as a transformation? Educating nurses and nursing students, we look to the support we can give mothers during childhood development. As childhood development is exploded out and expanded over time, we need to recognize that the child may not meet his or her milestones at the same pace as a typically developing child. Therefore, we must support these mothers through the transitions of mothering and childhood, not only focusing on the child's developmental needs, but also the developmental needs of a different kind of mothering process.

Here, we need to recognize that the needs of the mother are separate from the needs of the child. The experience of loss needs to be something that is recognized in how mothers are dealing with the process of transformation. In helping mothers through this process of acceptance, we must also recognize that this process of acceptance is not linear. Some mothers, especially within the recognition of loss, expressed grief where either the mother did not have time or space to grieve or the mother expressed that she needed to set aside time to cry. How do we educate nurses and nursing students in

transitioning these mothers into a process of grief and/or acceptance? What is it that we can do to perhaps ease this transition and decrease uncertainty?

Often when women find out that they are pregnant, they are compelled to excitedly tell others, ask other mothers for advice, and relish in the mother culture (Bergum, 1989; Nelson, 2007; Redmond, 2001). But do we ever hear of the mother excitedly asking other mothers about a *different child*? Redmond's (2001) essay on the experience of having an abortion exposes a different kind of dialogue; one that is hushed when these women find out they are pregnant and wish to have an abortion. The pregnancy becomes quieted, hidden, something unknown to others (Redmond, 2001). I am curious how we, as women, friends, nurses, others, and too, mothers and other mothers with children with autism open this dialogue. For the mothers in this study, there was solace in experiencing sameness within a community of other mothers with children with autism, perhaps creating awareness of others that they can reach out to for support.

Many mothers used the transition phrase "you know?" when discussing their narratives and Erica specifically asked me about the themes I had been finding with other mothers. She asked if other mothers were married, if they too had a special bond with their child. The reaffirming nature of the questions and phrasing of the narratives suggests that mothers need to feel like their efforts are correct, that what they are doing is appropriate within what other mothers are doing, not only other mothers within autism.

Mothering and Nursing Research

Looking to future research, there was a significant distinction between Erica and the other mothers of this study. Erica is a single mother of Matt and she shared her experience with reservation, asking for reaffirmation multiple times throughout our

conversation. Is Erica's experience somewhat of an outside experience? How is Erica's experience different? Why is Erica's experience different? Is there something that Erica has taken on, as both mother and father to Matt, in which the mothering relation is different as a single mother with a child with a disability?

Because the findings and discussion from this hermeneutic phenomenological study are only one interpretation (van Manen, 1990), this study can lend to future studies on mothering and autism. Although there are similarities in mothering as a phenomenon, we offer the possibility that other mothers with children with autism may not experience what the mothers in this study did. With this study, we begin to open dialogue about the experience of being a mother with a child with autism, where previous studies have primarily focused on the child with autism, rather than the mother. Future research calls for a scrutinous orientation to the mother to develop knowledge of what it means to be a mother with a child with autism.

Using hermeneutic phenomenology within van Manen's (1990) orientation, we bridge notions of mothering as being both particular and universal, meaning that there is something that holds the experience of mothering a child with autism apart, and yet something too that keeps it situated together with other kinds of mothering. Exploring these similarities and differences, we can look to other experiences of mothering within the phenomenon. For example, is mothering a child with autism similar to mothering a child with Down's syndrome or with ADHD? What makes this mothering relation similar or different? Bergum (1997) described the way of the mother and the mothering relation of women becoming mothers, adoptive mothers, teen mothers, and within this study we have described similarities and differences looking at the experience of older mothers

(Engel, 2003), mothers who have had an abortion (Redmond, 2001), and mothers who have lost a child during pregnancy (Suddes, 2013).

What is qualitatively similar or different to this experience? Although we do not wish to unearth exactly what mothering is, we wish to “open up possibilities of what mothering is and what it could be for women” (Bergum, 1997, p. 6). Through opening up the dialogue between other kinds of mothering, we can better understand mothering within these experiences and too, what mothering is beneath the experiences of these special kinds of mothers.

The findings of this research also suggest mothering differences within autism. Half of the mothers in this study had older typically developing children and these older children were described as a “reference point” for the mother. Not necessarily comparing these mothers, loss was described as *a loss of something that was* because they had the experience of mothering a typically developing child, where the mothers with only one child, the child with autism, did not. There were similarities and differences described by these mothers that leave us questioning if mothering has changed. As childhood development becomes blown out, so too does mothering, especially with time and change. Is navigating autism different for these mothers because they have this reference point as something to compare the change to, something to compare the loss to?

The life transitions of these mothers to mothers with children with autism must also take into consideration the influence of time. When mothers are older, their challenges are also different (Engel, 2003). Although we see similarities between these experiences, we must also look to anticipate what the future will bring. Little is known about the experience of mothers with older adult children with autism and other

developmental disabilities, and with a loss of services and funding when these children reach 18 (Government of Ontario, 1990), the future becomes particularly uncertain. The mother of the older child in this study was different than the other mothers in this study because of this unique experience and the different challenges she faces. Not only do we need to look at this experience of mothering children with autism, but also how mothering is different within autism, such as mothers with older typically developing children, mothers with older adult children with autism, as well as mothers with children with different developmental disabilities other than autism.

Mothering and Policy

Looking to broader implications, this research lends itself to supporting the need for policy development, especially in regards to program funding and support for both mothers and children. When mothers in this study looked to an uncertain future, their communal voices reflected a collective need for future support. Mothers' questions about an uncertain future reflect their immediate needs and preparation for the coming times. Respite care and group home facilities become a necessity when the mothering body is not enough for an aging child. The implications of an older mother caring for a grown child whose challenges have changed and grown over time require policies to change; mothers in this study described the lack of support early in the stages of receiving a diagnosis. Does this lack of support change over time as the child ages?

Having an older child with autism meant longer waiting lists and uncertainty in what will happen to the child when he is too old for the public school system; too old to be cared for during the day. What happens to the child (or adult) with autism when the mother becomes older? What happens next? How can we influence the decisions to

continue support for these mothers in the larger social system? Mothers in this study described the necessity for respite care and the potential need for group home services. These needs often place the locus on the child, but what happens when the mother is too old to care for the child and is in need of her own care?

Concerns are raised about an aging child and advocacy for a child who is dependant on an aging mother. We must be cautious in talking about a dependant child, one whose needs are potentially forever. We must remember that the child's growth and development may be stunted but the child is still attached; the needs of the child may never be detached from the mother. The implication is that locus of mothers' needs in this study was very much around the needs of the child. In describing the mother's womb as potentially forever, we raise the concern that the child is perhaps unable to care for himself or herself like a typically developing child. We raise the question as to whether the rights of this child are tied to the rights of the mother because of the dependency on the mothers that we saw with many of the children in this study, because of the intrinsic features of the autism diagnosis. For these mothers in this study, there was an enduring concern for safety and the well being of the child.

He doesn't know that a car could kill him if he ran on the street, but he does know not to run out and I trust him up to a point, but I would never, like, let him just go outside and wait inside here and wait for his bus.

The implication of the mothering experience is that these mothers recognize the forever quality of caring, despite greater social recognition of the need to encourage independence of these children as adults. How does the mother help the child become

independent when these concerns will not diminish with the aging of the mother or with the adulthood of the child?

Anticipating that the growing and aging needs of both mother and child (or adult) with autism will not waver, the voices of these mothers leads to the necessity to continue and potentially increase support for mothers who navigating a large social system and for mothers, who may themselves require care as they age. With lengthy waiting lists, mothers are uncertain if group homes are the *best* or *right* choice for her child, but what happens when they become the *only* choice?

The future may be uncertain for these mothers where living in the moment is her only option. Policies need to be in place to help support these mothers through a difficult system of funding and services to decrease her uncertainty of what may happen to the child in the future, when she is no longer able to be the primary caregiver.

Reflection

As I sit drinking my first cup of coffee for the day, the literature, the books, and the novels that I have been collecting over the past eighteen months or so surround me. Each piece sought for the uniqueness it would lend this project. In this process, I have come to be engulfed in the knowledge of mothers, encased and bound by cardboard paper and glue. These writings have become a significant part of my life, deeply filling every inch of the cells of my body in some way to help me orient to the phenomenon (van Manen, 1990). As I carefully pile the books, the authors have inadvertently become close friends, and ones I reach out to for help. I place one on top of the other. All spines face me; the smallest and daintiest one on top and the thickest and heaviest book placed strategically on the bottom supporting each one above. I began to nestle these books into

my life, carefully placing them around me for support. Like a mother bird collecting sticks and twigs to resource for her own mother project (Engel, 2003), I began to build something much larger than I had expected.

One meeting close to the end of this project, I jokingly told my supervisor that in this process of collecting mothering books and creating the multiple large stacks of mothering literature, I began to nest. But it was true. I was becoming entangled in the mothering literature so deeply and so closely that I began to sit with the phenomenon in a nearly visceral way. The tensions I once had about not being a mother nor a mother with a child with autism at the outset of the study began to become much less important. Although these presuppositions cannot leave as long as I am not a mother or a mother with a child with autism, these tensions began to resolve as I found meaning in the experience of the mothers in this study.

Preparing this thesis has been a labour of coming to grips with my own internal tensions and struggles that I came with into the research process. I questioned how would I ever be able to understand the experience of mothers when I am not a mother? How could I ever discuss what it is like to be a mother and too, a mother with a child with autism, when I have never had this experience? Beyond what it means to be a mother, an experience that has been discussed at length within this study, I wonder if there is something underlying the curiosity that I had in coming to research mothering. Is it, perhaps, the voice of a vulnerable other that I wish to share? Is it the relationship of the mother and child I wish to explore?

In the research process, I have become so close with the voices of these mothers; *my* mothers. I have carried large pieces of paper around campus, clutching the themes

close to my body as I walked to my supervisor's office. Through mind mapping with coloured pens during late nights in my bedroom on my bed, I have embodied this experience caring for the transcripts, listening to the voices of the recordings of the mothers in this study. I have become situated so close to the voices, I can hear Kate laugh and cry when I read and re-read her emotional, reflective, and thoughtful transcript.

A few months after our initial interview, I see one of the mothers that I interviewed while out in public. Recognizing each other, we awkwardly smile, asking how the other is doing. I am hesitant to ask more. She asks me how the research process is going and how the write-up of this thesis is coming along. I offer answers to her questions. She asks me, once again like she did during our conversation, if I am seeing the same themes from the other mothers that I talked with. We talked very briefly, but there was a sense that our short conversation held meaning for this mother. In telling me about her story, I entered her world; one that rarely is seen by the eyes of another.

I am reminded of one of the reasons why I started this research. Looking to vulnerability, I am torn between engaging in a conversation with this mother while in public, two of my closest friends in earshot of our conversation, potentially revealing her identity. Yet, still wanting to listen to her story, wanting to engage in her offerings of plausible potential implications for this research and how she sees it helping. We talk about how she sees these conversations as a starting point for potential funding, especially in Ontario, as well as potentially creating awareness for other mothers who are in a similar situation; something that has been previously offered in the discussion section; an offering that, perhaps, this project has already started to create internal awareness, of myself as a researcher, as well as for these mothers.

But yet, I am still not a mother and I am still not a mother with a child with autism. Through this experience, I have become compelled to share Kate and Erica's voices, and each other mother's voice in this study, because I cannot ignore their vulnerability. How do I begin to create a space where these mothers will feel comfortable sharing their very deep and personal stories of a phenomenon so deeply seated in their lives? How do I, without children, begin to relate to what it feels like to be a mother? Especially when I have discussed the role of how fathers and others experience the mothers as disembodied (Sandelowski, 1994) because they are at a distance to the mother, how do I meaningfully relate to mothers? Me, as a researcher, further disembodied from the phenomenon.

Further, how do I resolve these tensions? During the research process I needed to come to terms with why I came to this research and this research question. I am curious about the vulnerability that mothers experience when they are uncertain about a change in their role and in their relation to the child. Through long, deep and self-reflective discussions with my supervisor, advisory committee, and the mothers in this study, I have become very close to the voices of these mothers and the voice of the phenomenon. I began to accept that my identity as a woman researching mothering is *enough*. Earlier, a discussion of the use of the pronoun "we" suggested a partnered collaboration between the mothers in this study and myself as I do not have their experience, I cannot speak *for* these mothers. Speaking *through* their voices, the offering of *we* is both in what I offer as a woman, nurse researcher, daughter, sister, and friend in coming to the question, but also in the very presence of the voices of these mothers. Our partnership is what Spiegelberg (1975) suggests as *we-partners*, and because of this partnership, I have come to know and

become excited about mothering in a way that I never thought possible. I have, finally, let these tensions go and embraced the tension and uncertainty and accepted my role as a narrator of the stories of other women; mothers.

References

- American Psychiatric Association. (2013). *DSM-5 Autism Spectrum Disorder fact sheet*. Retrieved from www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf
- Barnett, K. (2013). *The spark: A mother's story of nurturing genius*. Toronto, ON: Random House Canada.
- Bergum, V. (1989). *Woman to mother: A transformation*. Granby, MA: Bergin & Garvey Publishers, Inc.
- Bergum, V. (1997). *A child on her mind: The experience of becoming a mother*. Westport, CT: Bergin & Garvey.
- Bergum, V. (2007). Way of the mother. In V. Bergum & J. Van der Zalm (Eds.), *Motherlife: Studies of mothering experiences* (pp. 2-21). Edmonton, AB: McCallum Printing Group.
- Brock University. (2010). *ORS forms*. Retrieved from <http://brocku.ca/research/policies-andforms/research-forms>
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2010). *Tri Council policy statement: Ethical conduct for research involving humans*, December 2010. Retrieved from http://www.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf
- Carr, D. (1977). *Husserl's problematic concept of the lifeworld*. In F. Elliston & P. McCormick Eds.), *Husserl Expositions and Appraisals* (pp. 202-212). University of Notre Dame Press: Indiana.

- Chesler, P. (1998). *With child: A diary of motherhood*. New York, NY: Four Walls Eight Windows.
- Cotterill, P. (1992). Interviewing women: Issues of friendship, vulnerability, and power. *Women's Studies International Forum*, 15, 593-606.
- Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*, 26, 623-630.
- Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: SAGE Publications Inc.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Thousand Oaks, CA: Sage Publications.
- Dahlberg, K. (2006). The essence of essences—the search for meaning structures in phenomenological analysis of lifeworld phenomenon. *International Journal of Qualitative Studies on Health and Well-being*, 1, 11-19. doi: 10.1080/17482620500478405
- Duden, B. (1993). *Disembodying women: Perspectives on pregnancy and the unborn*. Cambridge, MA: Harvard University Press.
- Dukes, S. (1984). Phenomenological methodology in the human sciences. *Journal of Religion and Health*, 23, 197-203.
- Eide, P., & Kahn, D. (2008). Ethical issues in the qualitative researcher—participant relationship. *Nursing Ethics*, 15, 199-207.
- Engel, J. K. (2003). *The thinking heart: The lived experience of older first time mothers* (Unpublished doctoral dissertation). University of Alberta, Edmonton.

- Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatization of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, 31, 1011-1027. doi: 10.1111/j.1467-9566.2009.01174.x
- Feinstein, A. (2010). *A history of autism: Conversations with the pioneers*. West Sussex, UK: Wiley-Blackwell.
- Finlay, L. (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2, 209-230.
- Finlay, L. (2009). Ambiguous encounters: A relational approach to phenomenological research. *The Indo Pacific Journal of Phenomenology*, 9, 1-17. Retrieved from www.ipjp.org
- Fletcher, P. C., Markoulakis, R., & Bryden, P. J. (2012). The costs of caring for a child with an autism spectrum disorder. *Issues in Comprehensive Pediatric Nursing*, 35, 45-69. doi: 10.3109/01460862.2012.645407
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, 33, 365-382.
- Frank, A. W. (2013). *The wounded storyteller: Body, illness, & ethics*. Chicago, IL: The University of Chicago Press.
- Gadamer, H. (1975). *Truth and method*. (G. Barden & J. Cumming, Trans.). New York, NY: Seabury Press. (Original work published 1960).
- Genova, L. (2012). *Love Anthony*. New York, NY: Gallery Books.
- Gill, J., & Liamputtong, P. (2009). 'Walk a mile in my shoes': Researching the lived experience of mothers of children with autism. *Journal of Family Studies*, 15,

309-319.

- Gill, J., & Liamputtong, P. (2011). Being the mother of a child with Asperger's Syndrome: Women's experiences of stigma. *Health Care for Women International, 32*, 708-722. doi:10.1080/07399332.2011.555830
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Prentice Hall Inc.
- Government of Ontario. (1990). *Child and Family Services Act*. Retrieved from http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90c11_e.htm#BK46
- Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness, 15*, 102-120.
- Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness, 24*, 734-749.
- Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine, 56*, 631-642.
- Green, J. (2013, March 13). Toronto Star nominated for nine national newspaper awards. *The Toronto Star*. Retrieved from http://www.thestar.com/news/canada/2013/03/13/toronto_star_nominated_for_nine_national_newspaper_awards.html
- Green, S. E. (2003). They are beautiful and they are ours: Swapping tales of mothering children with disabilities through interactive interviews. *Journal of Loss and Trauma: International Perspective on Stress and Coping, 8*, 1-13.
doi:10.1080/15325020390168672

- Griffiths, D. M., Owen, F., Gosse, L., Stoner, K., Tardif, C. Y., Watson, S., Sales, C., & Vyrostko, B. (2006). Human rights and persons with intellectual disabilities: An action research approach for community based organizational self-evaluation. *Journal of Developmental Disabilities, 12*, 165-181.
- Hard, R. (2004). *The Routledge handbook of Greek mythology*. [Taylor & Francis e-book]. Retrieved from <<http://www.myilibrary.com.proxy.library.brocku.ca?ID=2482>>
- Harper, D. (2014). Fix. *Online etymology dictionary*. Retrieved from http://www.etymonline.com/index.php?allowed_in_frame=0&search=fix&search_mode=none
- Higginbottom, G. M. (2004). Sampling issues in qualitative research. *Nurse Researcher, 12* (1), 7-18.
- Hoad, T. (1996). Mother. *The concise Oxford dictionary of English etymology*. Oxford University Press, USA. Retrieved from <http://www.oxfordreference.com/view/10.1093/acref/9780192830982.001.0001/acref-9780192830982-e-9824>.
- Jackson, D., & Mannix, J. (2004). Giving voice to the burden of blame: A feminist study of mothers' experiences of mother blaming. *International Journal of Nursing Practice, 10*, 150-158.
- Kidder, T. (2009). *Mountains Beyond Mountains*. New York, NY: Random House.
- Kimura, M., Yamazaki, Y., Mochizuki, M., & Omiya, T. (2010). Can I have a second child? Dilemmas of mothers of children with pervasive developmental disorder: A qualitative study. *BMC Pregnancy and Childbirth, 10*, 1-12.

- King, G., Baxter, D., Rosenbaum, P., Zwaigenbaum, L., & Bates, A. (2009). Belief systems of families of children with autism spectrum disorders or Down syndrome. *Focus on Autism and Other Developmental Disabilities, 24*, 50-64. doi: 10.1177/1088357608329173.
- Kingsley, E. P. (1987). *Welcome to Holland*. Retrieved from <http://www.health.qld.gov.au/mhcarer/docs/articleholland.pdf>.
- Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative research interviewing* (2nd Ed.). Thousand Oaks, CA: SAGE Publications Inc.
- Landsman, G. H. (1992). Reconstructing motherhood in the age of “perfect” babies: Mothers of infants and toddlers with disabilities. *Journal of Women in Culture and Society, 24*, 69-99.
- Landsman, G. H. (2009). *Reconstructing motherhood and disability in the age of “perfect” babies*. New York, NY: Routledge.
- Leiter, V., Wyngaarden Karuss, M., Anderson, B., & Wells, N. (2004). The consequences of caring: Effects of mothering a child with special needs. *Journal of Family Issues, 25*, 379-400. doi: 10.1177/0192513X03257415
- Liamputtong, P. (2009). *Qualitative research methods* (3rd Ed.). New York, NY: Oxford University Press.
- Lord, C., Kim, S. H., & Dimartino, A. (2011). Autism spectrum disorders: General overview. In P. A. Howlin, T. Charman, & M. Ghaziuddin (Eds.), *The SAGE handbook of developmental disorders* (pp. 287-305). Thousand Oaks, CA: SAGE Publications.

- Markoulakis, R., Fletcher, P., & Bryden, P. (2012). Seeing the glass half full: Benefits to the lived experiences of female primary caregivers of children with autism. *Clinical Nurse Specialist, 26*, 48-56.
- Mayes, S. D., & Calhoun, S. L. (2011). Impact of IQ, age, SES, gender, and race on autistic symptoms. *Research in Autism Spectrum Disorders, 5*, 749-757. doi: 10.1016/j.rasd.2010.09.002
- McConnell-Henry, T., Chapman, Y., & Francis, K. (2009). Husserl and Heidegger: Exploring the disparity. *International Journal of Nursing Practice, 15*, 7-15. doi: 10.1111/j.1440-172X.2008.01724.x
- McNamara, M. S. (2005). Knowing and doing phenomenology: The implications of the critique of 'nursing phenomenology' for a phenomenological inquiry: A discussion paper. *International Journal of Nursing Studies, 42*, 695-704. doi:10.1016/j.ijnurstu.2005.02.002
- McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*, 368-383. doi: 10.1016/j.jaac.2012.01.007
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: SAGE Publications.
- Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope, and empowerment: A model for partnering with parents of a child with an autism spectrum disorder at diagnosis and beyond. *Social Work in Mental Health, 10*, 311-330. doi: 10.1080/15332985.2012.664487

- National Epidemiologic Database for the Study of Autism in Canada [NEDSAC]. (2012). *Findings from the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC): Changes in the prevalence of Autism Spectrum Disorders in Newfoundland and Labrador, Prince Edward Island, and Southeastern Ontario*. Retrieved from http://www.autismsocietycanada.ca/DocsAndMedia/KeyReports/NEDSAC_Report_Mah2012.pdf
- Nelson, F. (2007). Motherhood as culture: Rituals and rites of passage. In V. Bergum & J. Van der Zalm (Eds.), *Motherlife: Studies of mothering experiences* (pp. 86-100). Edmonton, AB: McCallum Printing Group.
- Oberle, K., & Raffin, S. B. (2009). *Ethics in Canadian nursing practice: Navigating the journey*. Toronto, ON: Pearson Education Canada.
- Ouellette-Kuntz, H., Coo, H., Yu, C. T., Lewis, M. E., Dewey, D., Hennessey, P. E., ... Holden, J. J. (2012). Status report: National Epidemiologic Database for the Study of Autism in Canada (NEDSAC). *Chronic Diseases and Injuries in Canada*, 32, 84-89.
- Oxford English Dictionary Online. (2014). know. Oxford University Press. Retrieved from <http://www.oed.com>.
- Patey, J., McIntyre, M., & McDonald, C. (2007). Mothers transformed through pregnancy loss. In V. Bergum & J. Van der Zalm (Eds.), *Motherlife: Studies of mothering experiences* (pp. 244-256). Edmonton, AB: McCallum Printing Group.
- Pillitteri, A. (2010). Nursing care of a family when a child has a cognitive or mental health disorder. In A. Pillitteri (Ed.), *Maternal & child health nursing: Care of the childbearing & childrearing family* (pp. 1615-1635). Philadelphia, PA: Lippincott

Williams & Wilkins.

- Posavad, J. (2009). *Acknowledging mother's lived experience of raising a child with Autism: A phenomenological inquiry*. (Unpublished master's thesis). Brock University, St. Catharines, Ontario, Canada.
- Rabuzzi, K. A. (1994). *Mother with child: Transformations through childbirth*. Bloomington and Indianapolis, IN: Indiana University Press.
- Redmond, L. (2001). Mrs. Jones. In C. Shields & M. Anderson (Eds.), *Dropped threads: What we aren't told* (pp. 157-166). Toronto, ON: Random House of Canada Limited.
- Robb, M. (n.d.). *Deciding to have a child: A woman's perspective*. Retrieved from <http://www.phenomenologyonline.com/sources/textorium/robb-marnie-deciding-to-have-a-childa-womans-perspective/>
- Roulston, K. (2010). *Reflective interviewing: A guide to theory & practice*. Thousand Oaks, CA: Sage Publications Inc.
- Ryan, S. (2010). 'Meltdowns', surveillance and managing emotions; going out with children with autism. *Health & Place*, 16, 868-875.
- Ryan, S., & Runswick-Cole, K. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22, 43-53.
- Sandelowski, M. (1994). The epistemology of expectant parenthood. *Western Journal of Nursing Research*, 16, 601-622.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, 18, 179-183.

- Shaw-MacKinnon, M. (2001). Birth, death, and the Eleusinian mysteries. In C. Shields & M. Anderson (Eds.), *Dropped threads: What we aren't told* (pp. 221-229). Toronto, ON: Random House of Canada Limited.
- Spiegelberg, H. (1975). *Doing phenomenology: Essays on and in phenomenology*. Netherlands: Martinus Nijhoff, The Hague.
- Stevenson, A. (2010). Mother. *Oxford dictionary of English* (3 ed.). Oxford University Press, USA: Retrieved from http://www.oxfordreference.com/view/10.1093/acref/9780199571123.001.0001/m_en_gb0536100.
- Suddes, K. (2013, November 11). Nice Baby Boy [Web log post]. Retrieved from <http://joannagoddard.blogspot.ca/2013/11/motherhood-mondays-i-had-stillborn-baby.html>
- Swedo, S. E., Baird, G., Cook, E. H., Jr., Happé, F. G, Harris, J. C., Kaufmann, W. E.,... Wright, H. H. (2012). Commentary from the DSM-5 workgroup on neurodevelopmental disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51, 347-349. doi: 10.1016/j.jaac.2012.02.2013
- Tidmarsh, L., & Volkmar, F. R. (2003). Diagnosis and epidemiology of autism spectrum disorders. *Canadian Journal of Psychiatry*, 48, 517-525.
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16, 837-851. doi: 10.1177/1077800410383121.
- Tracy, S. J. (2013). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. West Sussex, UK: Wiley-Blackwell.

- Van der Zalm, J. E., & Bergum, V. (2000). Hermeneutic-phenomenology: Providing living knowledge for nursing practice. *Journal of Advanced Nursing, 131*, 211-218.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.
- van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Walnut Creek, CA: Left Coast Press Inc.
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York, NY: Routledge.
- Winnicott, D. W. (1987). *Babies and their mothers*. Reading, MA: Addison-Wesley Publishing Company, Inc.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075-1083. doi: 10.1177/1049732308320112
- Yantzi, N. M., Rosenberg, M. W., & McKeever, P. (2007). Getting out of the house: The challenges mothers face when their children have long-term care needs. *Health and Social Care in the Community, 15*, 45-55. doi: 10.1111/j.1365-2524.2006.00663

Appendix A

Recruitment Poster

ARE YOU A MOTHER WITH A CHILD WITH AUTISM?
IF SO, YOU ARE INVITED TO PARTICIPATE IN A STUDY
THAT INVOLVES RESEARCH.

I Invite You to Participate in a Research Study with the Purpose of Understanding What It Is Like to Be the Mother with a Child with Autism.

If you choose to take part in the study, I will ask you to meet with me for **1-2 CONVERSATIONS** that will take about **90 MINUTES** of your time.

It is anticipated that this research will benefit other mothers with children with autism. Possible benefits of taking part in the research for you include being able to discuss the experiences in your life in a private and safe space. One possible benefit of sharing your experience is that it may help other mothers who are in a similar situation.

IF YOU ARE INTERESTED IN BEING A PART OF THIS STUDY, AND/OR IF YOU HAVE ANY **QUESTIONS**, PLEASE FEEL FREE TO CONTACT ME

Samantha Micsinszki
MA Applied Health Science
(Community Health) (c)
Brock University
sm08yd@brocku.ca

Thank you for your interest in the study.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board [**File # 13-027-ENGEL**].

Appendix B

[Brock logo]

Letter of Invitation

Title of Study: Exploring the Lived Experience of Mothering a Child with Autism

(Student) Principal Investigator: Samantha Micsinszki, RN, MA (c)
Applied Health Sciences, Brock University

Faculty Supervisor: Dr. Joyce Engel, Associate Professor
Department of Nursing Brock University

I invite you to participate in a project that involves research. The purpose of this study is to gain insight into what it is like to be the mother of a child with autism. Through conversational sharing of the mothering experience with a child with autism, this study aims to shed light on the nature of this experience.

It is anticipated that this research will benefit other mothers with children with autism. Possible benefits of participation for you include being able to discuss your experience in a private and safe space. One potential benefit of sharing your experience is that it may help other mothers who are in a similar situation. A further benefit is that it may assist nurses and other care providers to more fully understand your needs.

Your participation in this study is completely voluntary. If you choose to take part in the study, I will ask you to meet with me for one or two research conversations that will take about 90 minutes of your time (45 to 60 minutes apiece). The conversations will be at a time and place that is comfortable for you. I will ask questions such as “how did you come to know or think that your child had or may have autism?” “what is it like to be a mother with a child with autism?” and “what is your relationship like between you and your child?” Our conversation will be recorded and transcribed. All conversations are confidential unless mandatory reporting laws (for example, those related to child abuse), require reporting. Your name will not appear in any thesis or report resulting from this study; if I quote you, I will use a pseudonym. There are no companies or agencies sponsoring the research.

If you are interested in being a part of this study, and/or if you have any questions, please feel free to contact me (see below for contact information).

Thank you for your interest in the study.

Samantha Micsinszki
MA Applied Health Sciences
(Community Health) (c)
sm08yd@brocku.ca

Dr. Joyce Engel, Associate Professor
Faculty Supervisor
Brock University
905-688-5550 x3168;
jengel@brocku.ca

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca). This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board [File # 13-027-ENGEL].

[Brock logo]

Appendix C

Informed Consent

Title of Study: Exploring the Lived Experience of Mothering a Child with Autism: A Hermeneutic Phenomenological Understanding

(Student) Principal Investigator: Samantha Micsinszki, RN, MA (community health)(c) Applied Health Sciences, Brock University
905-688-5550; sm08yd@brocku.ca

Faculty Supervisor: Dr. Joyce Engel, Associate Professor
Department of Nursing Brock University

(905) 688-5550 Ext. 3168; jengel@brocku.ca

INVITATION

You are invited to be part of a project that involves research. The purpose of this study is to gain insight into what it is like to be the mother of a child with autism. Through conversations about of the mothering experience, this study aims to shed light on the nature of this experience.

WHAT'S INVOLVED

As a participant, I will ask you to meet with me for one or two research conversations that will take about 90 minutes of your time. The conversations will be at a time and place that is comfortable for you. I will ask questions, such as “how did you come to know or think that your child had or may have autism?” “what is it like to be a mother with a child with autism?” and “what is your relationship like between you and your child?” These questions will guide our conversation and are not to set limits on what you wish to share. You may choose to answer these questions as broadly as you wish. Our conversations will be recorded and then transcribed.

Once the conversation has been transcribed, you will be given a copy of your transcript to review. You may add, clarify, or change what you have said during the interview so that you can give approval for the use of what you have said. If you feel that you need support when reviewing the transcribed conversation, I will be available to meet with you in person.

POTENTIAL BENEFITS AND RISKS

It is anticipated that this research will benefit other mothers with children with autism. Possible benefits of taking part in the research for you include being able to discuss the experiences in your life in a private and safe space. One possible benefit of sharing your experience is that it may help other mothers who are in a similar situation.

CONFIDENTIALITY

Our conversation will be recorded and transcribed and will be kept private between the researcher and the mother. Only in rare cases, will it not be possible to ensure privacy of

information (confidentiality) because of mandatory reporting laws (e.g. suspected child abuse). Recordings will be destroyed once they have been transcribed. Access to any data or information will be restricted to Samantha Micsinszki and Dr. Joyce Engel.

Your transcribed conversation will be stored on the student principal investigator's pass-code protected personal computer. Data will be kept for one year. After this, the recorded and transcribed conversations will be removed from the student principal investigator's personal computer. Any paper copies of transcribed conversations will be shredded.

Your name will not appear in any thesis or report resulting from this study. If I quote you, I will use a pseudonym.

VOLUNTARY PARTICIPATION

Participation in this study is completely voluntary. If you wish, you may decline to answer any questions or take part in any part of the study without consequence. You may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. If specific information that you have shared is published in the study, your name will be changed to protect your privacy.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact Samantha Micsinszki or Dr. Joyce Engel using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [**File # 13-027-ENGEL**]. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____

Date: _____

Appendix D: Ethics Clearance Approval



Research Ethics Office
Tel: 905-688-5550 ext. 3035
Email: reb@brocku.ca

Social Science Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE: 9/11/2013

PRINCIPAL INVESTIGATOR: ENGEL, Joyce
Nursing

FILE: 13-027 - ENGEL

TYPE: Masters Thesis/Project STUDENT: Samantha Micsinszki
SUPERVISOR: Joyce Engel

TITLE: Exploring the Lived Experience of Mothering a Child with Autism: A Hermeneutic Phenomenological Understanding

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW Expiry Date: 9/30/2014

The Brock University Social Sciences Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 9/11/2013 to 9/30/2014.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 9/30/2014. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.