Protecting Myself and My Child: A Grounded Theory of Parents' Journey through Diagnostic Feedback for Autism

by

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Abstract

The diagnostic feedback meeting represents the first time that parents hear the news that their child has autism. Given the essentially unanimous agreement around the significance of this event, surprisingly little of substance has been said about it in the clinical and empirical literature. In this project, I developed a social-psychological conceptualization of parents' journey through this pivotal period. My work was guided by the methodology of grounded theory and the onto-epistemological lens of critical realism. I generated data from in-depth interviews with 27 parents of children (ages 1-10) who were recently diagnosed with autism at a clinic in Ontario, Canada. The central process, labelled *protecting myself and my child,* indicated that parents rapidly make meaning of, feel, think, and respond to the delivery of the diagnosis as signalling a hazard from which they must protect their family. Primary categories of action-interaction consisted of an *undercurrent of anticipating* in the lead-up to the feedback meeting, *sounding the alarm* when hearing the official pronouncement, followed by *swelling distress and uncertainty*. Depending on a complex interplay of conditions, parents dealt with their situation in three ways: *protective maneuvering, instrumental responding,* and/or *processing-oriented advancing,* which, in turn, affected their swell of distress and uncertainty. These findings can help clinicians and service providers to think deeply about their role and how they can best use their expertise to facilitate parents' journey through what is, primarily, an emotional process.

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Chapter 1
Introduction

In this first chapter, I introduce the research problem and articulate what led me to select this topic for my dissertation. Next, I review the literature on diagnosis, disability, and autism to provide context and to position my work's contribution to the field. Lastly, I provide an overview of the current study of parents'[1] journey through diagnostic feedback for autism.

1.1 Problem Statement

Those who know families of children with autism will know stories of adaptation, happiness, and humour, but will also know stories of isolation, frustration, and exhaustion. In the words of a parent, raising a child with autism is, "my greatest joy and my greatest heartache" (Myers, Mackintosh & Goin-Kochel, 2009). In Ontario, Canada, the median age of diagnosis is four and a half (Ouellette-Kuntz et al., 2009) but, for many parents, the suspicion that something is different about their child begins well before (Braiden et al., 2010; Guinchat et al., 2012; Midence & O'Neill, 1999; Mulligan et al., 2012). This period is often characterized by dismissive and disparate messages from professionals, family members, and others; parents are often left feeling afraid, confused, and exasperated. (Braiden et al., 2010; Chamak et al., 2010; DePape & Lindsay, 2015; Mulligan et al., 2012; Sansosti et al., 2012). It is into this milieu that the label of autism is delivered. Hearing a clinician share the results of her assessment – including the pronouncement of autism – can be a highly emotional and overwhelming experience for parents (Abbot, Bernard, & Forge, 2012; Braiden, Bothwell, & Duffy, 2010; Mulligan et al., 2012).

Clinical practice guidelines on communicating an autism diagnosis, while few, are unanimous in the importance they place on this pivotal event (e.g., "the importance of conveying a diagnosis

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[1] The term parent is used throughout this paper to denote adults who identify as a child's caregiver, including biological/adoptive parents, step-parents, grandparents, or legal guardians.

sensitively to families cannot be overstated" [National Institute for Health and Clinical Excellence, 2011, p. 35]). And yet, we know relatively little about parents' experiences receiving the diagnosis. Research across North America and Europe demonstrates that parents are predominately dissatisfied with feedback (Chamak et al., 2010; Crane et al., 2016; Gaspar de Alba & Bodfish, 2011; Goin-Kochel et al., 2006; Keenan et al., 2010; Siklos & Kerns, 2007), but what does dis/satisfaction mean, and to whom? A Canadian parent advisory group put forward the following statement:

> "Clinicians and researchers sometimes forget they are dealing with real families who are going through difficult times [...] The process of assessment is not just about symptoms and questionnaires, but concerns [our] tears, fears, joy, relief, anguish, and hope" (Miriam Foundation, 2008, p. 63).

Receiving a diagnosis of autism is a pivotal event in parents' lives. However, parents' experiences of this event remain poorly understood and insufficiently attended to by clinicians and researchers.

1.2 Selecting the Substantive Area

I am completing my dissertation as part of my doctoral program in clinical psychology, and diagnosing autism is one of my areas of clinical specialization. I have six years of involvement in autism assessment and I have helped facilitate workshops to train other psychologists and psychology trainees how to identify autism in children and adolescents. Under supervision, I have communicated diagnostic feedback for autism as well as other mental and behavioural disorders. These clinical experiences led me to reflect critically on what constitutes good care in these interactions. If the only goal of the feedback meeting was to state the diagnosis, the clinician could write it on a post-it note, hand it to the parent, and walk out of the room. Thankfully, that is not what happens. Instead, we spend 1-2 hours sharing information with parents – but what do we share, why do share it, and is what we share helpful? How do we support parents in absorbing, making sense of, and adjusting to the news? These questions are not easy to answer, and my curiosity spurred me to choose this substantive area for my dissertation.

Another driving force behind my decision was my desire to generate knowledge that could have the potential to impact clinical care. Both basic and applied research hold value, but I knew myself well enough to know that I needed to see direct and immediate applications of my work to stay motivated throughout the long and arduous process of my doctorate. Studying diagnostic feedback allowed me to dedicate my time to better understanding a significant aspect of my future career. I trusted that learning about parents' experiences would help me do my job better – and, if all goes well, that it would have the potential to help other clinicians too.

1.3 Literature Review on Diagnosis, Disability, and Autism

In this section, I provide context for my research by reviewing the research and clinical literature relevant to the diagnostic feedback meeting for autism. I begin with a broad lens, exploring the act of diagnosis before turning to diagnosis in developmental disability. Subsequently, I provide an overview of autism, the lead-up and delivery of the diagnosis of autism, and parents' experiences receiving a diagnosis of autism. I draw on the literature to develop the rationale for this study, illustrating the importance of this topic and the gaps in our current understanding.

1.3.1 The Act of Diagnosis

Diagnosis is the act of interpreting a disorder from its symptoms. The modern practice of diagnosing mental and behavioural disorders emerged in the mid-twentieth century, stimulated by the development of standard classification schemes by the American Psychiatric Association (APA) and the World Health Organization (Kawa & Giordano, 2012; McGann & Hutson, 2011). These classification schemes define various aspects of human experience as symptoms, and various groups of symptoms as disorders located in the individual. They have helped conceive, establish, and reify what is to be discerned in the act of diagnosis, carefully constructing cut-points between normal variation and pathology (Hyman, 2010). The authority to assign a diagnosis is generally restricted to health care professionals such as psychologists and physicians, who are granted the power and responsibility to 'medicalize' human experience by investigating, interpreting, and communicating a diagnosis (Conrad, 2005; Maynard & Turowetz, 2017). Annemarie Jutel, a forerunner in the sociology of diagnosis, describes the act of diagnosis as such:

> "It provides structure to a narrative of dysfunction, or a picture of disarray, and imposes official order, sorting out the real from the imagined, the valid from the feigned, and the significant from the insignificant. On the other, diagnosis is an important site of contest and compromise because it is a relational process with different parties confronting illness with different explanations, understandings, values, and beliefs." (Jutel, 2009, p. 5)

Clinicians, researchers, and society at-large place much emphasis on the importance of diagnosing mental and behavioural disorders. Many have articulated the potential benefits that can come from the labelling process (see Hyman, 2010 and McWilliams, 2011 for a critical overview). For people receiving a diagnosis, it can help clarify their experience and legitimize their struggles. For others (e.g., family, friends, educators, co-workers, health care professionals), the label can be a bridge to understanding and acceptance of the affected person. Holding a diagnosis can grant access to societal supports and services, such as intervention, tax credits, or unemployment certification. Diagnostic labels also help to guide and organize research, allowing clinicians to generalize results to inform treatment planning and prognosis.

The shared language offered by diagnosis has substantial usefulness, but it can also have problematic consequences. Diagnosis helps to construct and reify some parts of human experience as disordered, deviant, or abnormal – for people receiving a diagnosis, this can feel alienating and suggest that their "problem" can or should be cured (Hyman, 2010). Diagnostic labels frequently become a source of cultural stigma (McGann & Hutson, 2011), and they locate the problem within the individual rather than society (Leiter, 2007; McLaughlin, 2005). In contrast to the current diagnostic paradigm, the social model of disability encourages us to consider that "disability is not about an individual condition;

rather it is about how society supports a diverse humanity to have equal access to all that society has to offer” (Harnett, 2007, p. 22).

Diagnostic practices have evolved significantly since the mid-twentieth century, with its image of an omniscient, omnipotent doctor deciding what was in the patient’s best interests (Fischer, 2012). The humanistic movement of the 1950’s and 1960’s, the civil rights and antipsychiatry movements of the 1960’s and 1970’s, the rise of advocacy groups in the 1980’s, and the internet’s increasing democratization of knowledge have all influenced the action-interaction of diagnosis (Brown, 1995; Jutel, 2009; McGann & Hutson, 2011; Poston & Hanson, 2011). More and more, clients are recognized as agentic participants in their own diagnostic process, and there is an expectation of respect and information sharing between clinician and client (e.g., the obligation to share assessment results with clients was codified into standards of ethical practice in Canada and the United States in the 1990’s [American Psychological Association, 2002; Canadian Psychological Association, 2000]). Delivering a diagnosis in a sensitive manner has become an ethical imperative (Brinchmann, Forde, & Nortvedt, 2002; Fischer, 2012).

By the 1990’s, clinicians and researchers began to consider the potential therapeutic value of diagnostic feedback for mental and behavioural disorders (Finn & Tonsager, 1997, 2002; Riddle, Byers, & Grimesey, 2002), and this shift in attitude included diagnostic feedback provided to parents of affected children (Tharinger et al., 2008). It was theorized that the manner in which the assessment and feedback was conducted would impact how clients absorbed and responded to the news. A series of case studies have demonstrated proof-of-concept that a collaborative, highly-involved diagnostic process can lead to positive outcomes for clients (Hamilton et al., 2009; Tharinger et al., 2009; Smith, Wolf, Handler, & Nash, 2009). Hanson and Poston have published and republished (with new analyses) the only known meta-analysis of psychological assessment as a therapeutic intervention (Hanson & Poston, 2011; Poston & Hanson, 2010). They included seventeen studies that compared groups who received personalized, collaborative feedback with groups who received more traditional feedback.

Dependent variables spanned a range of domains, such as self-understanding, hope, and symptomatology. In both versions of their analyses, the groups who received personalized, collaborative feedback outperformed groups who received traditional feedback (Hanson & Poston, 2011; Poston & Hanson, 2010).

Research on the act of diagnosis is still in its early stages. There is a relatively small and disparate body of literature, dispersed across a variety of disciplines (e.g., sociology, clinical psychology, medicine, psychiatry, counselling, and disability) which often do not cite or integrate each other's work (Hanson & Poston, 2011). In the applied fields especially, conceptualization around how clients receive diagnostic news and how clinicians deliver (or should deliver) diagnostic news has been neglected. Sweeny and Shepperd (2007) provide an appraisal of medical research into giving bad news well, highlighting the lack of consensus over what 'well' means. They collate the disparate goals chosen by researchers as follows: providing sufficient information to recipients; promoting recipients' satisfaction with the transmission; improving news-recipients' memory for and understanding of the news; reducing recipients' distress in response to the news; promoting hope; and decreasing news-givers' discomfort. Sweeny and Shepperd (2007) argue for the integration of these goals under a superseding objective: guiding news-recipients to a desired response that maximizes quality of life. This is a well-founded goal, but it has not been picked up in subsequent literature. Further, clinicians undergo little formal training in how to conduct feedback meetings, and many report being reluctant or anxious to share so-called bad news (Barnett, Fisher, Cooke, James, & Dale, 2007; Braaten, 2007; Fallowfield & Jenkins, 2004; Merker, Hanson, & Poston, 2010).

1.3.2 Diagnosis in Developmental Disability

Developmental disability is an umbrella term for disorders that begin early in childhood, persist across a person's life, and affect how a person learns, speaks, and/or behaves (Centre for Disease Control, 2018). As autism falls into the category of developmental disability, in this next section I narrow my scope from the act of diagnosis to diagnosis in developmental disability. I explore the assumptions related to communicating a diagnosis of this nature to parents as well as the conceptual models that have been applied to explain parents' reactions to the news. The literature on diagnosis in developmental disability has historically focused on children with genetic conditions, congenital malformation, and birth trauma (Harnett, 2007). There are key differences between these disabilities and autism, such as diagnostic timing (e.g., antenatal or neonatal identification in many conditions compared to preschool or school-aged identification of ASD) and the level of certainty in determination and etiology (e.g., definitive identification and etiology for Down Syndrome compared to best estimate identification and ambiguous etiology of ASD). Despite these differences, the broader literature on developmental disabilities may still provide a useful analogue for autism.

Much of the early work on the diagnosis of developmental disability was guided by clinical expert opinion above and beyond empirical data (Harnett, 2007). In the 1980's and 1990's, it became widely acknowledged that receiving the news of a child's developmental disability is difficult for families and is an event they never forget; parents are often unhappy with the disclosure process but their dissatisfaction is not inevitable; how the clinician delivers the news influences how it is received; and parents who receive support during this crucial time fare better than those who do not (Cottrell & Summers, 1989; Cunningham, Newton, Appleton, Hosking, & McKinlay, 2002; Cunningham, Morgan, & McGucken, 1984; Halpern, 1984; Lewis, 2003; Sloper & Turner, 1993). Empirical studies across several decades have demonstrated that parents receiving a diagnosis of a developmental disability want the news to be delivered with empathy and honesty, in a private space, with ample time to ask questions, opportunities to express their emotions, and timely follow-up contact with a key worker (Graungaard & Skov, 2006; Hatton et al., 2003; Quine & Pahl, 1987; Sharp, Strauss, & Lorch, 1992). Clinicians can be uncomfortable openly discussing the nature of developmental disabilities with parents – it is likely painful to tell and respond to parents. In sociolinguistic analyses of interactions from real feedback meetings, clinicians are seen to be hedging around the diagnosis, its implications, and prognosis (Abrams and Goodman, 1998; Bartolo, 2002; Gill & Maynard, 1995).

The literature cited above is predominately atheoretical. There has been limited application of theory to understanding parents' experiences receiving a diagnosis of developmental disability for their child, leaving it hard to hypothesize when and why parents respond as they do. Next, I will review the few conceptual models that have been applied to this context. One of the first conceptual models researchers applied was that of Kubler-Ross' (1969) model of dealing with loss. The process of adjusting to their child's new diagnosis was likened to that of bereavement – the loss was that of the wished-for healthy child (Cunningham & Davis 1985; Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975; Emde & Brown, 1978; Kennedy, 1970). Parents were understood to be cycling through phases of denial, anger, bargaining, depression, and acceptance (as per Kubler-Ross, 1969).

Quine and Rutter (1994) considered the merits of two competing models of doctor-patient communication to explain parental satisfaction with diagnostic feedback for severe intellectual disability. The first was Ley's (1977) cognitive model, which states that dissatisfaction with doctor-patient communication occurs when parents do not understand or remember the information that was presented. The second was Korsch's (1968) affective model, which states that dissatisfaction with doctor-patient communication occurs when parents perceive the doctor's affective behaviours negatively (i.e., businesslike, not understanding, and/or communicating poorly). Between these two models, Quine and Rutter (1994) found that Korsch's affective model accounted for more of the variance in parental ratings of satisfaction of diagnostic feedback.

Finally, Lalor, Begley, and Galavan (2008) offer an inductive qualitative study of parents' reactions following antenatal diagnosis of fetal abnormality. The authors conceptualized two main categories of responses, which they titled "Getting my head around it" and "I'll cross that bridge when I come to it". Lalor et al. (2008) connected their findings with Miller's (1980) theory of coping styles in response to perceived threat. Miller (1980) described the first style as monitors, who are highly attuned to the sense of threat. Lalor et al. (2008) found that mothers in their sample who were identified as monitors had high information needs and became distressed when information was not readily available. The authors interpreted their information-seeking behaviour, in part, as an attempt to establish a sense of control. Miller (1980) described the second style as blunters, who minimize the sense of threat. Lalor et al. (2008) found that mothers in their sample who were identified as blunters displayed information avoidance behaviours and became distressed when presented with too much information.

1.3.3 Overview of Autism Spectrum Disorder

The previous sections set the stage by outlining the social-cultural context of diagnosis as well as the literature on parents receiving a diagnosis of developmental disability. In the following sections, I transition to the research and clinical literature that is specific to autism. First, I provide an overview of autism and the associated implications of this diagnosis for children and parents.

Once considered rare, autism is now estimated to affect over 1% of children globally (Baio et al., 2018; Elsabbagh et al., 2012; Kim et al., 2011) and 1 in 66 children in Canada (Public Health Agency of Canada, 2018). To our best knowledge, autism is a lifelong condition that emerges early in development and persists across the lifespan (Billstedt, Gillberg, & Gillberg, 2007; Brian et al., 2016; Charman et al., 2005; Ozonoff et al., 2015). The scientific and clinical communities have come to define autism as a neurodevelopmental disorder – or group of neurodevelopmental disorders – characterized by pervasive social-communication deficits and the presence of repetitive behaviours, the symptoms of which cause significant impairment in daily functioning (APA, 2013). The fifth edition of the Diagnostic and Statistical Manual (DSM-5; APA, 2013) classifies the social-communication deficits of autism into three areas, all of which must be present to meet criteria for the diagnosis: social-emotional reciprocity (e.g., deficits in engaging in back-and-forth conversation), non-verbal communication (e.g., deficits using and integrating eye contact, facial expressions, and gestures in communication with others), and relationships (e.g., deficits in developing and maintaining friendships). The DSM-5 classifies repetitive behaviours in autism into four areas, two of which must be present to meet criteria for the diagnosis: stereotyped motor movements, use of objects, or speech (e.g., repeating idiosyncratic phrases), insistence on sameness (e.g., inflexible insistence on taking the same route to school everyday), highly restricted interests (e.g., obsessive fascination with trains), and abnormal sensory responsivity or sensory interests (e.g., side viewing of spinning objects in peripheral vision). Clinicians identify autism based on the interpretation of behavioural observations and developmental history.

People with autism have a wide range of abilities, talents, and skills. At the same time, the disorder is associated with significant and pervasive challenges at home, school, in the community, and the workplace. Children and adolescents with autism often have behaviours that are difficult to manage (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Matson & Nebel-Schwalm, 2007), and adults with autism have low rates of post-secondary employment and education (Shattuck et al., 2013). Autism is associated with a high financial cost to persons with autism, their families, and society, taking the form of therapeutic interventions, school support, medical expenditures, costs of caregiving (often including lost income for parents), and other needs (Lavelle et al., 2014). While not part of the diagnostic criteria, many people with autism also have difficulty regulating emotions and have higher than average rates of anxiety, mood problems, inattention, and hyperactivity, as well as medical issues such as seizures, gastrointestinal issues, and sleep dysfunction (Levy et al., 2010).

Parenting a child with autism brings with it a complex set of challenges and rewards. Parents of children with autism report high levels of stress – higher than parents of children with other disabilities such as Down syndrome (Dabrowska & Pisula, 2010; Hayes & Watson, 2013; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Pisula, 2007). In a web survey of 493 parents of children with autism, Myers, Mackintosh and Goin-Kochel (2009) found a combination of positive and negative themes related to caregiving. Positive themes highlighted how children with autism can enrich family life and teach tolerance, patience, and joy. Negative themes highlighted the high demands of care, impact on personal well-being (e.g., depression, guilt, blame), and strain on marital/family relationships (Myers, Mackintosh, Goin-Kochel, 2009). In a meta-synthesis of qualitative studies on caring for children with autism, DePape and Lindsay (2015) depict the pervasive impact of autism on all aspects of the family: daily life, finances and career, spousal relationships, siblings, going out in public, navigating school, planning for the future, and more. In an ethnographic study of the experiences of 85 Canadian mothers of children with autism, Nicholas et al. (2016) theorize a "reconfigured" sense of parenting: facing the challenges and appreciating the joys of parenting a child with autism may drive families to forge new identities and redefine their aspirations. Raising a child with autism can lead parents to change their values and priorities and, over time, derive new meaning from life (Gray, 2006; Green, 2007; King et al., 2006, 2012). However, the focus of this study begins much earlier, at diagnosis.

1.3.4 The Lead-up and Delivery of the Diagnosis of Autism

In this next section, I outline the lengthy and confusing journey parents traverse in the lead-up to receiving a diagnosis of autism as well as the parameters, challenges, and significance of the feedback meeting. Well before the diagnosis of autism, many parents are worried or unsure about their child's development. Oswald et al. (2017) found that there is a longer delay between first concerns and diagnosis of autism compared to other developmental disabilities. Early on, many parents suspect that something is different about their infant or child, such as motor concerns, language delay, or a passive temperament, and some parents wonder specifically about autism (Braiden et al., 2010; Guinchat et al., 2012; Midence & O'Neill, 1999; Mulligan et al., 2012). During this time, parents receive mixed messages from those around them that exacerbate feelings of uncertainty, worry, confusion, and frustration (DePape & Lindsay, 2015; Mulligan et al., 2012). In retrospective studies of the diagnostic process, many parents report having their concerns dismissed by professionals; they heard messages such as "nothing is wrong", "your child may grow out of it", or "boys just develop slower than girls" (Braiden et al., 2010; Chamak, Bonniau, Oudaya, Ehrenberg, 2010; Howlin & Moore, 1997; Hutton & Caron, 2005; Oswald et al., 2017; Sansosti, Lavik, & Sansosti, 2012). Goin-Kochel, Mackintosh, and Myers (2006) analyzed the responses of almost 300 parents in Canada, U.S., U.K., and Australia, and discovered that they visited an average of 4-5 clinicians in the process of finding out that their child has autism. Similarly, in a smaller Canadian sample, Siklos and Kern (2007) found that parents saw an average of 4.5 clinicians before receiving the diagnosis. The waiting period ends when a family finally arrives at a diagnostic assessment where a clinician with sufficient training and expertise identifies and subsequently communicates a diagnosis of autism.

The feedback meeting is a rare opportunity for parents to receive information and advice from an autism expert who knows their child's current profile. However, it is a very small window: a feedback meeting typically runs one or two hours maximum and, all too frequently, it represents the only opportunity for parents to speak with the professional who is diagnosing their child (Austin, Katz, & Reyes, 2012). There is a noticeable lack of empirical research on what 'good' care means in the context of feedback meetings for childhood disabilities, and even less research tackles autism specifically. Clinical guidelines attempt to fill the gap; however, much of the clinical literature focuses on the assessment and identification of autism and stops short of addressing how to communicate these findings to the family. The few publications that extend to the process of delivering the news come from a mix of government agencies, clinical societies, and research groups in the U.S. and U.K. (e.g., Autism Treatment Network, 2012; Missouri Autism Guidelines Initiative, 2010; National Institute for Health and Clinical Excellence, 2011; Psychological Society of Ireland, 2010; University of Connecticut, 2013).

Among the groups who extend their best practice guidelines to the act of diagnosis, there is unanimous agreement on the importance of delivering the news in a sensitive fashion as well as the need to clearly and directly state the diagnosis, describe the diagnostic evidence/criteria, explicate recommendations, and provide written materials for the parents. Several groups highlight the need to express hope, discuss the causes (and non-causes) or autism, discuss the implications for the child's future, and encourage parents to share the details of the results with others (e.g., educators, family

Table 1.

Comparing Five Clinical Guidelines on Delivering an Autism Diagnosis to Parents

	Recommendation	**Clinical guideline**				
		ATN[a]	Ireland[b]	Missouri[c]	NICE[d]	UConn[e]
Clinical manner	Sensitive delivery	X	X	X	X	X
	Attuned non-verbal communication	X				X
	Reflective and empathic listening	X	X			X
	Express hope	X	X			X
	End on positive note	X				
Logistics	Delivered soon after assessment	X	X		X	X
	Thought given to who attends	X	X			X
	Limit professionals in the room		X			
	Interpreter if needed					X
	Private, interruption-free space	X				X
	Have tissues available	X	X			
	Sufficient time for feedback	X	X	X		X
	Review assessment process	X				
	Opportunity for questions	X	X			X
	Provide written materials	X	X	X	X	X
	Timely follow-up appointment		X			X
Content	Assess parents' beliefs/expectations		X			X
	Content at parents' level of understanding (must assess)					X
	Use lay terms and parents' language	X	X			X
	Acknowledge strengths	X		X		X
	Clearly and directly state diagnosis	X	X	X	X	X
	Describe autism criteria and/or diagnostic evidence	X	X	X	X	X
	Discuss cause (e.g., not caused by parenting)	X				X
	Discuss future implications and prognosis; acknowledge uncertainty	X	X	X		X
	Acknowledge when you do not know	X	X			X
	Provide recommendations	X	X	X	X	X
	Encourage sharing information	X		X	X	X
	Counsel on recurrence risk				X	

Note. Results selected to include those directly related to the feedback meeting; categorization by current author.

[a]Autism Treatment Network (ATN), United States, 2012

[b]Psychological Society of Ireland, 2010

[c]Missouri Autism Guidelines Initiative, 2010

[d]National Institute for Health and Clinical Excellence (NICE), United Kingdom, 2011

[e]University of Connecticut (UConn), 2013

physician). Several groups also stated that feedback should be scheduled soon after the assessment and for enough time to allow ample opportunity for questions and discussion with parents. See Table 1 for a collated summary of guidelines on the clinical manner, logistics, and content of diagnosis delivery.

1.3.5 Parents' Experiences Receiving the Diagnosis of Autism

In this study, my primary interest is in understanding parents' journey through diagnostic feedback for autism. In the current state of the literature, investigations of parents' perspectives of this pivotal event most commonly takes the form of an analysis of their ratings of 'satisfaction' – an ill-defined and rather elusive concept. Despite a small number of studies reporting parent satisfaction in the diagnostic disclosure process (Brogan & Knussen, 2003; Hasnat & Graves, 2000; Mockett, Khan, & Theodosiou, 2011), a growing number have revealed high degrees of dissatisfaction (Chamak et al., 2010; Crane et al., 2016; Gaspar de Alba & Bodfish, 2011; Goin-Kochel, Mackintosh, & Myers, 2006; Keenan et al., 2010; Siklos & Kerns, 2007). Some of these studies have linked parental satisfaction with factors such as the age of the child at diagnosis (Goin-Kochel et al., 2006; Hasnat & Graves, 2000; Howlin & Moore, 1997; Siklos & Kerns, 2007) and the parent-professional relationship (Brogan & Knussen, 2003; Crane et al., 2016; Moh & Magiati, 2012; Osbourne & Reed, 2008). However, without a critical examination of what satisfaction means, and without a more in-depth examination of what constitutes a helpful parent-professional relationship, it is hard to know how to use these studies to inform conceptualizations of parents' experiences receiving diagnostic feedback for autism.

Several studies have explored parents' perspectives on the benefits of receiving a diagnosis of autism. Mansell and Morris (2004) took a deductive approach to this topic and asked parents to respond to a list of predicted outcomes. They found the highest rates of endorsement for the following: relief (90%); better understanding of child's behaviour (87%); accepting child's behaviour (83%); adapting family life to child's behaviour (74%); and getting practical help for child (71%). These results converge with those of two studies that took an inductive approach to exploring parent perspectives. In a thematic analysis of interviews with 17 families, Nissenbaum et al. (2002) highlighted the following benefits of feedback: relief, no longer to blame, able to explain child's behaviour to themselves and others, realize you have to do something, help obtaining information, and access to services. Through a series of focus groups, Osborne and Reed (2008) identified feelings of relief/confirmation and understanding/support as the most helpful outcomes of the diagnostic process. In a meta-synthesis of qualitative research on caring for children with autism, DePape and Lindsay (2015) elucidate a more complicated picture of the emotional aftermath of receiving the diagnosis: ambivalent feelings of relief and devastation, mixed with guilt and blame surrounding the cause of their child's autism. Others echo this ambivalence, finding a combination of feelings of relief, dismay, loss, and grief (Chamak et al., 2010; Mulligan et al., 2012; Potter, 2016). Receiving the diagnosis is an emotionally intense and stressful experience for many parents (Abbot et al., 2012; Braiden et al., 2010; Mulligan et al., 2012; Siklos & Kern, 2007).

The literature on the diagnosis of autism reveals that parents see many benefits to receiving a diagnosis, but they hold ambivalent feelings about the news and are generally dissatisfied with the way in which is it delivered. This research falls short of providing a rich and nuanced understanding of parent perspectives of this life-changing event. Two qualitative studies have recently made the first foray into exploring parents' experiences of receiving a diagnosis of ASD; the studies of Mulligan et al. (2012) and Abbott et al. (2012) are compared in Table 2. Analyzing interviews with 10 and 9 families, respectively, these authors reveal the importance of the clinician's style and structure of the meeting, as well as the impact of the intensity of parental reaction and their difficulty assimilating information during the feedback meeting.

Table 2.

Comparing Two Qualitative Studies of Parent Experiences of the Diagnostic Feedback Meeting

		Mulligan et al. (2012)	**Abbott et al. (2012)**
Methods	Methodology	Phenomenological	General inductive
	Data generation	Semi-structured interviews	Semi-structured interviews
	Diagnostic setting	Specialist clinic at a hospital	Community child mental health service
	Diagnostic disciplines	Developmental pediatrics and psychology	Psychiatry and psychology
	Time since feedback	*M* = 17 months (3-24 months)	*M* = 2 months (1-4 months)
Sample Characteristics	Parent demographics	8 mothers, 2 fathers Canadian, range of ethnicities Range of education levels	9 mothers, 4 fathers British, white Range of socio-economic backgrounds
	Child demographics	10 boys, 0 girls *M* = 4.8 years old Unknown functioning	8 boys, 1 girl *M* = 11.2 years old No intellectual disability
Selected Results[1]	Importance of clinicians' style	Importance of honest, yet hopeful messaging	Importance of supportive, positive, and open relationship with clinician Appreciated optimism and hearing positive things about child/parenting
	Intensity of parental reaction	Left physically exhausted, emotionally drained, and overloaded with information	Feelings of anxiety, vindication, relief, guilt Emotional impact impeded absorption of information during the meeting
	Difficulty assimilating information	Difficulty absorbing and assimilating information in the meeting Suggested follow-up meeting to help absorb information	Difficulty understanding technical information Confused and overwhelmed with how information was conveyed Written information was helpful
	Structure of meeting	Appreciated having meeting in small setting	Valued reviewing the assessment process Appreciated clinician keeping meeting focused

	Needed time to ask questions	Appreciated opportunity to ask questions, but hard to do so as uncertain/unsure of self

[1] Results selected to include those directly related to the feedback meeting; categorization by current author.

In a recent descriptive study of web-survey responses from fathers in the U.K., Potter (2016) called attention to the underrepresentation of men in research on this topic. For example, in two recent large-scale studies of the diagnostic process (Crane et al., 2016; Gaspar de Alba & Bodfish, 2011), only around seven percent of the participants were fathers. The results from Potter's web-survey indicated that many fathers experienced a strong emotional response and anxiety about their child's future when they heard their child had autism. However, they felt ignored by others, such as family members and health care professionals, who focused on their child's mother during the diagnostic period.

1.3.6 Conclusions from the Literature

The last half century has seen many changes in the diagnosis of mental and behavioural disorders, not least of which is a shift in the attitudes and values toward the act of diagnosis. Sharing results of an assessment with clients is now recognized as essential and, at its best, a therapeutic process that can guide clients toward desired responses that maximize their quality of life. In the case of autism, it is typically the parents who receive diagnostic feedback for their young child. The act of diagnosis authoritatively interprets their child's behaviour as a pervasive, lifelong, and costly disorder. Despite its life-altering implications, parents' experiences of this event remain poorly understood and insufficiently attended to by clinicians and researchers.

Overall, research on the act of diagnosis is sparse. We know that parents of children with autism are frequently dissatisfied with the way the news was delivered. We also know that parents' reactions to diagnostic feedback fluctuate from relief to devastation, and parents may struggle to absorb the information presented in the meeting with the clinician. Literature from the broader context of developmental disabilities have suggested a small handful of conceptual models to make sense of parents' experiences receiving their child's diagnosis. Millers' (1980) model of monitors and blunters suggests that information-seeking and information-avoiding are styles of coping with perceived threat. Kubler-Ross' (1969) model of bereavement suggests that parents are dealing with loss by cycling through phases of denial, anger, bargaining, depression, and acceptance. Neither model has been empirically applied to the case of autism – the research and clinical literature on the act of diagnosis in autism is predominately atheoretical. This makes it hard to generalize findings or generate hypotheses to explain why parents respond as they do and under what conditions they might respond differently.

1.4 Overview of the Current Study

In the current study, I take an emic approach to exploring parents' experiences of diagnostic feedback for autism. Building on the foundational work of Mulligan et al. (2012) and Abbott et al. (2012), I generate knowledge on how parents think, feel, and respond to diagnostic feedback. Further, I build a conceptualization of why and under what conditions parents respond as they do. As this study is one of theory development, not hypothesis testing, I apply a qualitative research approach to guide study design, implementation, and interpretation. My research approach will be explicated in the following chapter.

The current study focuses on parents of children with autism at all levels of functioning, ages 1-10, and recruits a larger sample than previous studies. Like Abbott et al. (2012), parents are interviewed as close as possible to the time of diagnostic feedback to encourage rich description of this event. I generate data with a diverse group of parents, who come from a range of sociocultural backgrounds, hold a range of expectations about their child's assessment, and experience a range of reactions to the news that their child had autism.

1.4.1 Research Objectives

My primary research objective was to develop a social-psychological conceptualization of parents' journey through diagnostic feedback for autism, grounded in data generated from parents' experiences. By gathering and analyzing the unique knowledge and perspectives of parents, I hope the results of this study will advance our understanding of how service providers can provide high-quality, compassionate care to families when communicating a diagnosis of autism.

Chapter 2
Research Approach

In this chapter, I lay the groundwork for my methods by detailing the research approach that underpinned my decisions around data generation and analysis. I begin by exploring the fundamental assumptions of my theoretical framework and methodology. Next, I make the case that these two parts of my research approach are compatible with each other. Finally, I offer my rationale for choosing this research approach for this study.

2.1 Theoretical Paradigm

A theoretical paradigm is a set of beliefs, values, and approaches that provide the philosophical premise for what we can we know and how can we know it – for how we can explain, generalize, and make inferences about the world. Articulating a theoretical paradigm increases the coherence and rigour of our scientific inquiry, as how we think about reality and knowledge necessarily shapes what we choose to study, how we approach our research, and how we make sense of our findings (Carter & Little, 2007; Denzin & Lincoln, 2011; Giacomini, 2010). I undertook this project from a critical realist lens. My primary sources were the writings of Berth Danermark and his application of critical realism to social science research and disability (Bhaskar & Danermark, 2006; Danermark, 2002; Danermark, Ekstrom, Jakobsen, & Karlsson, 2002). Making my theoretical paradigm explicit ensures that both I and my readers are aware of the implications of my onto-epistemological position.

2.1.1 Exploring the Philosophy of Critical Realism

Critical realism is a young but robust philosophy, first solidified in the seminal work of Roy Bhaskar (1975, 1989) and expanded on by Margaret Archer, Andrew Collier, and others (Archer, 1995; Archer, Bhaskar, Collier, Lawson, & Norrie, 1998; Collier, 1994). Bhaskar pointed to a widespread 'epistemic fallacy' where ontology is reduced to epistemology. He argued, instead, that while we can only ever know reality through our ideas of it (the transitive dimension), a reality still exists beyond our ideas (the intransitive dimension). Critical realism signifies a passionate rejection of positivism (i.e., the belief that we can know reality through objective observation and logically rigorous inference) and empiricism (i.e., the belief that knowledge can only come from sensory experience) as well as radical constructivism (i.e., the belief that we can only know the world through our ideas and subjective experiences, and thus any truth is one claim among multitudes).

The main tenets of critical realism are ontological realism, epistemological relativism, and judgmental rationality (Bhaskar, 1989; Archer et al., 1998). It asserts that reality is, to some degree – but never fully – knowable, and our knowledge of reality is always conceptually-mediated. Danermark et al. (2002) puts it thus: "Facts – the empirical observations, scientific data – are seldom objective or neutral in any definite sense. To be at all understandable they always comprise earlier, more or less hidden, everyday and/or scientific conceptualizations." The final tenet of critical realism, judgmental rationality, contends that while all knowledge is fallible and a partial truth, it is not *equally* fallible. We can tentatively and yet meaningfully evaluate some knowledge as better than others, such as knowledge that carries more explanatory power than its alternatives (Vandenberghe, 2014).

A primary feature of the ontological view of critical realism is that reality is stratified and emergent. One dimension of this stratification is between the empirical, actual, and real domains (see Danermark et al., 2002). The empirical domain consists of our observable experiences; the actual domain consists of events occurring whether we experience them or not; and the real domain consists of experiences, events, and the structures and mechanisms generating them. Thus, critical realism differentiates between what is immediately accessible to our senses and the deeper underlying structure of reality. Critical realism contends that reality is not transparent. For example, we cannot simply look around us and derive the properties of a neurotransmitter like serotonin, or the generative mechanisms of stereotyped behaviour, or the role of stigmatization in the lived experience of disability. We must actively investigate and conceptualize to build an understanding – more or less truthlike – of the real domain.

The second dimension of stratification is between the molecular, biological, psychological, and social levels of reality (see Danermark et al., 2002). Critical realism asserts that each stratum is formed by the powers and mechanisms below it *but also* provides a distinct contribution that cannot be reduced to the strata below. For example, the phenomenon of anxiety involves biological and chemical processes but cannot be explained only in reference to these processes – there is a unique contribution of thoughts and feelings at the psychological level that makes anxiety what it is. An implication of this belief is that scientists can study the emergent mechanisms of any level with meaningful results, without knowing the deep structure of the strata below. Further, scientists can attempt to isolate a stratum from those above it but not below it. The higher the stratum, the more complex the contextual environment and the harder it is to study events and processes by creating an artificially closed system. For example, we can isolate a chemical process from a biological process and manipulate it in a petri dish, but the social process of classism cannot be detached from a myriad of psychological processes or manipulated in well-controlled experimental designs without losing meaning.

Critical realism centers conceptualization and causal analysis as the goal of science – the role of the scientist is to explain why what happens tends to happen (see Danermark et al., 2002). Accordingly, critical realism articulates a clear and sophisticated view of causality. It uses the language of mechanisms or generative mechanisms to describe those things that have the power to produce events, and it differentiates the *power* to produce events from the *frequency* of producing events (e.g., a knife may have the power to cut bread whether it is ever used to do so). Properties inherent to the mechanism relate to its propensity to cause an event, but conditions in the contextual environment are part of the equation regarding whether the event occurs. With this perspective, critical realism elucidates causal tendencies rather than causal laws. Deterministic laws such as A-then-B do not hold unfailingly true in the natural or social sciences, and statistical co-variance tells us only how things cooccur rather than offering a causal explanation. Critical realism asserts that due to the nature of reality, the usefulness of science is in explanation not prediction. Proponents of this ontological view recognize that explanation does not necessarily lead to prediction, and that explanation can be useful in and of itself. Danermark et al. (2002) use the example of petroleum: geologists have developed an understanding of how petroleum is formed but still cannot predict where it is located due to the complex interplay of conditions in the contextual environment that are needed for its formation. As discussed earlier, critical realism contends that generative mechanisms belong to the real domain, and thus our knowledge of them (the transitive dimension) always approaches rather than mirrors reality (the intransitive dimension).

2.1.2 Applying Critical Realism to Research

A theoretical paradigm influences all stages of the research process. When applying a critical realist lens to study design, a researcher foregoes *ordering frameworks* (i.e., ordering relationships between empirical observations such as is often done in quantitative analyses) in favour of *conceptualizations* (i.e., abstracting properties, structures, and mechanisms of events as well as the relationships between events). While I conducted a qualitative project, the goal of conceptualization can be furthered through qualitative, quantitative, and mixed methods approaches (McEvoy & Richards, 2003). Due to the complex and contextual nature of reality at higher strata, social scientists subscribing to critical realism generate data about naturally occurring phenomena rather than trying to run experiments in an artificially closed system (Danermark et al., 2002). Critical realism lends itself well to epidemiology or the intensive study of a limited number of cases.

Regardless of the methodological approach, critical realists seek to go beyond the empirical domain – beyond immediate experience and the accounts of participants – to build a tentative understanding of the underlying processes in the real domain. A primary approach of critical realism is to use abductive and retroductive reasoning along with empirical data to draw realist generalizations

(Bhaskar, 1989; Archer et al., 1998; Danermark et al., 2002). Strict deduction and induction alone does not lead to new conceptualizations (e.g., deduction involves linking an existing premise with an individual observation, and induction involves extrapolating an observation to another population or context rather than drawing new conclusions about what is observed). In contrast, *abduction* involves taking observations of an event and relating them to a conceptualization, which leads to new ideas about the event being observed. This is the type of reasoning that a clinician uses when diagnosing a client or a social scientist uses when applying the concept of 'ritual' to better understand interactions at the hospital bedside. *Retroduction* involves advancing from observations to a conceptualization. This is the type of reasoning that Mary Ainsworth, for example, would have used when developing the concepts of secure and anxious attachment styles. Danermark et al. (2002) suggests supporting the abductive and retroductive reasoning process with counterfactual thinking, thought experiments, studying extreme cases, and comparisons of different cases.

Given the stance of critical realism whereby we cannot simply apprehend reality, the researcher becomes one of the main tools of analysis. Our life experiences, perspectives, and mental faculties all come to bear as we attempt to make sense of our data. Thus, reflexivity is essential to rigorous work (Archer, 2010). Reflection involves thinking deeply about our research, while reflexivity involves thinking deeply about how we are thinking about our research. The work of Bhaskar, Archer, Danermark, and others urges us to be cautious and critical of our knowledge generation processes, to avoid blindly reifying prevailing 'truths'. We must consider the influence of power and dominance in our current knowledge. Further, critical realism maintains that knowledge generation should be emancipatory and that new understandings of the world can and should change our beliefs and actions (Archer et al., 1998; Sayer, 2000). Investigations of social structure and human agency feature prominently in the social sciences – *structure* refers to patterned arrangements in society such as norms and institutions; *agency* refers to the capacity of an individual to act independently and exercise choice. Critical realism guides social scientists to take both structure and agency into account in our analysis and to examine them as distinct strata of reality with their own emergent mechanisms (Danermark et al., 2002; Vandenberghe, 2014).

2.2 Methodology

A methodology provides the structure and rationale for how research proceeds (Carter & Little, 2007; Lipscomb, 2008; Mayan, 2009). Articulating a methodological approach helps to guide clear decision-making around strategies for data collection and analysis (i.e., the methods). Common methodologies in the social sciences include experimentation, quantitative description, qualitative description, phenomenology, ethnography, participatory action research, and grounded theory. In this project, I utilize grounded theory. My application of grounded theory was informed by all of the authors cited in the forthcoming section, but my main guide was the structure put forth by Juliet Corbin in the fourth edition of her handbook with Anselm Strauss (Corbin & Strauss, 2015).

Grounded theory is a methodology that makes use of qualitative data generated from interviews, field observation, documents, or other sources. The debate between quantitative and qualitative research raged in the latter half of the twentieth century and 'methodolatry' persists in some disciplines, whereby methodologies such as the randomized control trial are idealized, and others devalued (Danziger, 1985). However, qualitative approaches are now well-respected in the social sciences and beyond (Patton, 2002). I appreciate the words of Agar and Kozel to this end, "Each data point is a person with a biography… who can show and tell what is in their life that the data point reflects" (1999, p. 1936). I also appreciate Corbin's revelation that she was drawn to qualitative research because it involves, "reaching out to people, listening to what they have to say, and then using that knowledge to make a difference in their lives" (2009, p. 36). I elaborate more on the suitability of a qualitative approach for this project in the context of my discussion of grounded theory.

2.2.1 Exploring the Methodology of Grounded Theory

Grounded theory was first proposed by Barney Glaser and Anselm Strauss (1967) as a practical alternative to 'armchair theorizing' when generating knowledge about social processes. There was a fulsome appetite for an accessible and systematic approach to knowledge generation in the social sciences, and grounded theory quickly became established as a popular and respected methodology (Charmaz, 2008). The work of Glaser and Strauss diverged after their initial collaboration. Glaser propagated a positivist version of grounded theory (1992), more or less in line with the original publication of grounded theory in 1967. Strauss, with his roots in symbolic interactionism, continued the evolution of a more pragmatist and flexibly idealist grounded theory, and he partnered with Juliet Corbin in his methodological endeavours (Strauss & Corbin, 1990). Strauss died in 1996 but Corbin continued to build on the legacy of their work, "[holding] on to what is good about the past while updating a method to bring it more in line with the present" (Corbin, 2009, p. 37). Two students of Strauss, Kathy Charmaz and Adele Clarke, have adapted grounded theory to the lens of constructivism (Charmaz, 2014) and post-modernism (Clarke, 2005), respectively. For all of the splintering, these methodologists generally maintain the same essential elements of grounded theory – although the products of their analyses vary due to their divergent theoretical paradigms (Charmaz, 2017; Morse et al., 2009).

The hallmark of grounded theory is in its name: it is an open-ended approach to developing new theory, grounded in data (Denzin & Lincoln, 2011). Theory development focuses on action and interaction in social processes, and "offers explanations for why events or happenings occur" (Corbin & Strauss, 2015, p.12). Rather than testing hypotheses, concepts underpinning the resultant theoretical statement are derived during the interplay of data generation and analysis (Charmaz, 2014; Corbin & Strauss, 2015; Glaser, 1992). Data generation and analysis are concurrent, iterative, and emergent (Dey, 2004). This is supported by strategies such as theoretical sampling, by which decisions around what data are sampled next are explicitly driven by the objective of fleshing out the developing theory (Gentles &

Vilches, 2017; Suddaby, 2006). Charmaz aptly summarizes: "Grounded theorists value theory construction over description, patterns in the data over individual stories, developing fresh concepts and theories over applying received theory, and theorizing processes over assuming stable structures" (2017, p. 2).

Building a *theoretical statement* with grounded theory entails an intensive time spent coding data. Coding is the process of cutting data into pieces and denoting concepts to stand for the analyst's interpretation of the meaning (Corbin & Strauss, 2015). The researcher starts coding close to the data (e.g., line-by-line coding of interview transcripts) and becomes more conceptual as she proceeds, relating and integrating concepts as they are fleshed out. Concepts are grouped together and subsumed under categories, which stand for the analyst's interpretation of the meaning of the cluster of codes. Corbin and Strauss (2015) use the terms open coding, axial coding, and selective coding to refer to the work of coding at different levels of abstraction and theory development. Open coding is conceptual labelling and categorizing; axial coding is classifying the relationships between categories; selective coding is integrating categories into a larger story. Other methodologists, such as Charmaz, discard these labels but speak to a similar process of moving back and forth between the work of line-by-line coding, clustering codes, and concentrating on the story the codes are telling (2014). Regardless of how they are described, the researcher frequently cycles up and down through these different levels of coding during analysis (Corbin & Strauss, 2015).

Perhaps one of the reasons grounded theory has flourished is that methodologists in this tradition have provided detailed guidance on how to conduct analysis. Most notably, Corbin and Strauss (2015) write at length and offer illustrations of techniques and procedures to facilitate coding, such as asking questions of the data (e.g., What is being said? Who is being spoken about? Who is not being spoken about? Why?), examining negative cases (cases that do not fit a pattern), and reflecting on language choices and expressions of emotion. They also offer a so-called conditional-consequential matrix to remind novice researchers of the various micro-to-macro conditions that could be at play.

None of these procedures are prescriptive; they are offered to help researchers build a flexible arsenal of strategies in the service of conceptualization (Corbin, 1998; Corbin, 2009). A fundamental feature of the abstraction process in grounded theory is the use of constant comparison. Constant comparison is the process of continually checking and re-checking your emerging understanding (i.e., of concepts, properties and dimensions of concepts, and the developing theory) with the raw data and the less abstracted versions of your analysis (Charmaz, 2008; Dey, 2004). Strauss expressed the view that “abstraction inevitably simplifies… yet to comprehend deeply, to order, some degree of abstraction is necessary” (1993, p. 12). Constant comparison is a key strategy in keeping the abstraction grounded in the data.

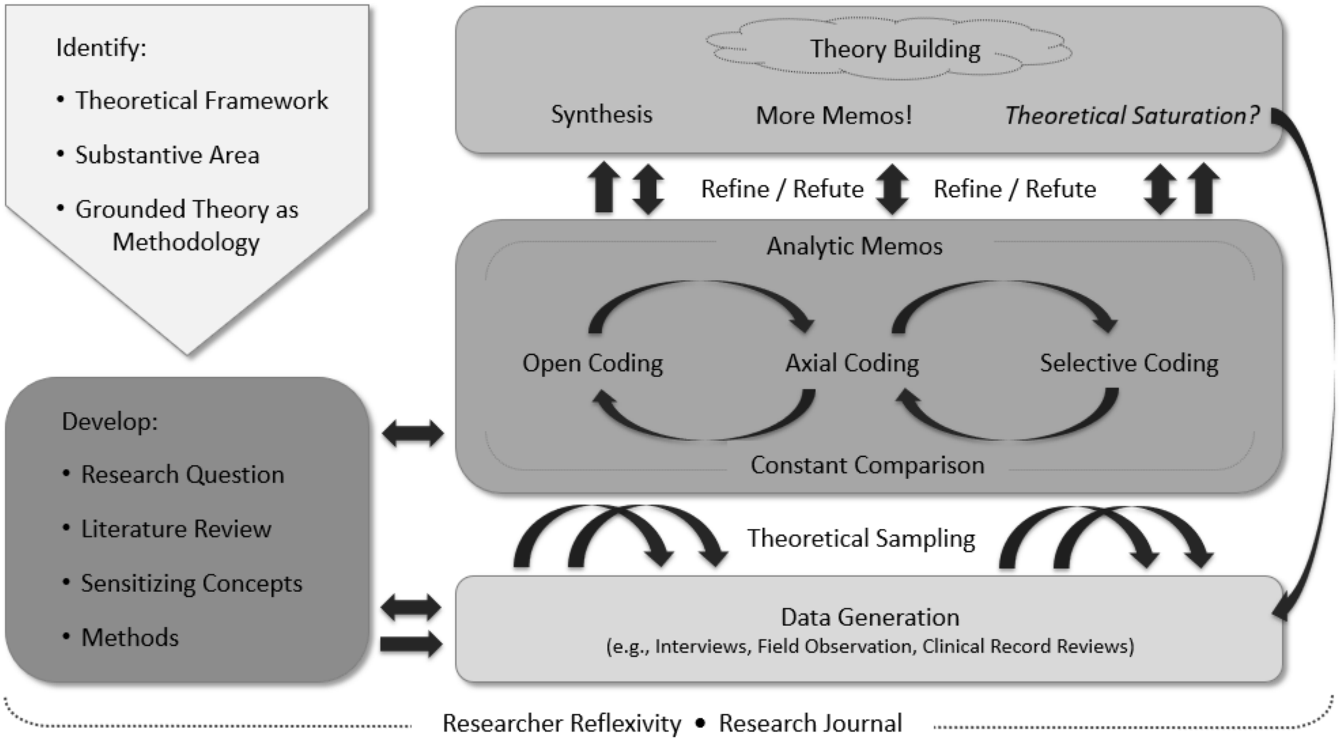

Figure 1. A depiction of the grounded theory research process.

Note: This diagram is based on my reflections on the work of Corbin and Strauss (2015).

Figure 1 attempts to illustrate the grounded theory research process. As can be seen by the abundance of bidirectional arrows, the research process is emergent and flexibly responds to the needs of theory development. While grounded theory does not test a priori hypotheses, Corbin and Strauss (2015) and Charmaz (2014) both embrace the notion that information beyond the data generated during a project (e.g., a researcher's previous experiences and knowledge of the literature) influences the results. Glaserian grounded theory is the exception, as Glaser claims that it is possible to conduct research without preconceptions (2013). One way that Charmaz (2014) harnesses the extant literature is by borrowing the term *sensitizing concepts*, which suggest "directions along which to look" in analysis (Blumer, 1954, p. 7).

Two more terms from Figure 1 require defining: memos and theoretical saturation. Given the iterative and intricate nature of grounded theory analysis, memo writing is a crucial part of the research process. Memos are a record of the researcher's thoughts and reflections about the events, interactions, codes, and relationships between codes – a record of the researcher's conversation with herself, written or drawn throughout the research process (Charmaz, 2014; Corbin & Strauss, 2015). These records can increase credibility in the research process and results by creating an audit trail. They also stimulate the analytic process itself by helping to distill and crystalize the researcher's thoughts (Corbin & Strauss, 2015).

Finally, theoretical saturation is a methodological strategy that originated from Glaser and Strauss (1967) and partners with theoretical sampling. Data generation is guided by the objective of fleshing out the developing theory and stops when the researcher decides that they have reached a point of theoretical saturation – that is, the themes and ensuing theory is well-developed enough to provide an answer to the research questions (Charmaz, 2014; Corbin & Strauss, 2015). As with other techniques of grounded theory, theoretical saturation has a history of being overextended and applied uncritically (Thorne & Darbyshire, 2005). Rather than declaring 'saturation' as a panacea, a rigorous approach necessitates that the researcher elaborate on what saturation means in their context and how they reached that interpretation. Dey (1999) contends that the term *theoretical sufficiency* would be a more apt description, and I agree.

2.3 Methodological & Theoretical Congruence

A research project's methods are driven and constrained by its methodological approach and its theoretical paradigm (Carter & Little, 2007). These two components are distinct, but they must be compatible at a fundamental level if the researcher is going to make coherent decisions for how to go about her research. Our philosophical and practical answers to the question *'how can we know reality?'* must be concordant. To my knowledge, the core methodologists of grounded theory have not addressed critical realism directly, and the philosophers behind critical realism have spent similarly little time exploring grounded theory. Perhaps one of the main reasons for this omission is that the intellectual home of grounded theory is in the United States and North America, while the intellectual home of critical realism is in the United Kingdom and Europe (Gorski, 2013). Despite the lack of "official" sanctioning, a handful of researchers have started articulating the compatibility of these two approaches (see Belfrage & Hauf, 2016; Fletcher, 2017; McNeill & Nicholas, 2017; Oliver, 2011). In this section, I make the case that grounded theory and critical realism are compatible.

The Introduction to Critical Realism in the Social Sciences (Danermark et al., 2002) contains one of the rare critiques of how grounded theory may or may not fit into the critical realist paradigm. Danermark et al. (2002) describe grounded theory as a popular methodology with much to offer social scientists who work from a critical realist lens. However, the authors also highlight the limitations of inductive theory generation as emphasized in (orthodox) grounded theory. As stated earlier, the purpose of grounded theory is to develop *theory* that is *grounded* in data. Corbin and Strauss clearly state: "only those conditions that can be found in data and pertain to the phenomena under investigation are to be brought into the analysis" (2015, p. 124). When taken to an extreme, grounded theory could be interpreted as disregarding knowledge that is external to the data and, thus, promulgating empiricism (the epistemological belief that knowledge can only come from sensory experience). This would be problematic for my project, as critical realism rejects empiricism. Given the stance of critical realism regarding the stratified nature of reality (i.e., the empirical, actual, and real domains), researchers subscribing to this paradigm are challenged to go *beyond* the empirical domain to best apprehend reality. Danermark et al. suggest that, "the research process is probably most productive when we manage to combine a fairly open attitude towards data with the use of established concepts as a resource" (2002, p. 136).

As outlined, Corbin and Strauss (2015) posit that only processes found in the data should be part of analysis while Danermark et al. (2002) posit that the significance of general theory should not be disregarded. I argue here that these statements are not incongruent. My aim in this project was to develop a conceptualization that was grounded in my interviews as well as other sources (e.g., my previous experiences, knowledge of the literature, and general theory). While this may be at odds with orthodox grounded theory as signalled by Glaser (1992; 2013) and the original collaborative work of Glaser & Strauss (1967), Corbin, Charmaz, Clarke, and others have led a substantial evolution of grounded theory (Annells, 1997; Hallberg, 2006; Hall, Griffiths, & McKenna, 2013; Morse et al., 2009), one that has resulted in a more flexible methodology that is cynical of naïve realism. As early as 1998, Corbin acknowledged a shift in thinking regarding the feasibility of researchers bracketing other influences to conduct a purely inductive, data-driven analysis – she states, "more and more qualitative researchers have come to realize the implausibility of detached and objective interpretation of data" (p. 123). In the fourth edition of her textbook, she fervently argues that describing grounded theory as primarily inductive is a misreading of her and her mentor's work (Corbin & Strauss, 2015). When considering Danermark et al.'s (2002) reservations, it is important to consider the chronology of their publications. The 2002 reference used here denotes the English version of this work; however, the original Swedish distribution date was 1997. Thus, the authors were reacting to the first editions of the explanatory texts by Corbin and Strauss (1990) and Glaser (1992). Danermark et al. (2002) offer an important critique of grounded theory; fortunately, the methodology has continued its evolution away from a staunchly empiricist or inductive approach (Morse et al., 2009).

Glaser represents the more orthodox, positivist extreme of grounded theory and Charmaz and Clarke represent the more idealist, constructivist end of the spectrum. Corbin, the methodologist I am following, sits in between, making her approach the most adaptable to a critical realist lens (Oliver, 2011). In Table 3, I have collated the fundamental features of Corbin's grounded theory methodology and its correspondence to the philosophy of critical realism.

Table 3.

Fit between Grounded Theory Methodology and the Philosophy of Critical Realism.

	Features of Corbin's Grounded Theory Methodology	**Correspondence to Critical Realist Philosophy**
Goal	- Develops a theoretical explanation of a phenomenon from a specific set of data (Corbin, 2017) - Attempts to get at the underlying social processes of a phenomenon, including conditions of when and why things happen (Corbin & Strauss, 2015)	- The role of the scientist is to explain why what happens tends to happen (Danermark et al., 2002) - Conceptual abstraction and causal analysis are core activities of social science (Danermark et al., 2002)
	- Aims to help and to change practice (Corbin & Strauss, 2015) - Research creates knowledge that can be the foundation for bringing about change (Corbin, 2009)	- Aims to emancipate (Sayer, 2000) - Theory can reform practice (Archer et al., 1998; Collier, 1994) - Social science should have practical applications (Danermark et al., 2002)
Scope	- Embraces complexity and considers conditions at both micro and macro levels, such as individual, family, institutional, community, and cultural levels (Corbin & Strauss, 2015)	- Reality is an open system that is too complex to be artificially closed at the psychological-social levels; reality is stratified with emergent mechanisms at the molecular, biological, psychological, and social levels (Danermark et al., 2002)
	- Takes both structure and agency into account and sees them as always inter-related (Corbin & Strauss, 2015)	- Takes both structure and agency into account and examines them as distinct strata of reality with their own emergent mechanisms (Vandenberghe, 2014)

	- Sees people as taking an active role in responding to the conditions and events in their lives (Corbin, 2017)	- Structures lay down conditions but only human beings act (Danermark et al., 2002)
	- Concepts rather than cases are the focus of analysis (Corbin, 2017)	- Seeks to go beyond immediate experience and the accounts of participants to build a tentative understanding of the underlying processes (Danermark et al., 2002)
Outcome	- Developing theory is an interpretive process and the final product is a construction of both the data and the researcher (Corbin, 2017) - Grounded theories should be 'living' and contribute to the ongoing knowledge creation process (Corbin & Strauss, 2015)	- Our knowledge of reality is always conceptually-mediated and thus our theories of reality are always fallible (Archer et al., 1998; Danermark et al., 2002)
	- The resulting theory identifies and explains the relationship between categories while the properties and dimensions of each category provide the detail and help make sense of variation in phenomena (Corbin, 2017) - Theory should be credible, useful sense of the data (Corbin & Strauss, 2015)	- Scientific concepts should endeavour to speak of the mechanisms that produce courses of events and go beyond more superficial and accidental circumstances (Danermark et al., 2002)
Design	- Research design evolves to respond to the needs of theory development rather than being specified beforehand (Corbin, 2017) - Data generation and analysis are inter-related through the processes of theoretical sampling and theoretical saturation (Corbin, 2017	- Research is most productive when it takes an open approach to knowledge production (Danermark et al., 2002) - Values knowledge that is plausible and holds explanatory power (Danermark et al., 2002)
	- Employs an interplay of inductive and deductive reasoning (Corbin & Strauss, 2015) - Analytic procedures include constant comparison, asking questions, and creating memos and diagrams (Corbin, 2017)	- Sees all modes of inference as essential to science; contends that abductive and retroductive reasoning are required for conceptualization (Danermark et al., 2002) - Recommends using counterfactual thinking, thought experiments, studying extreme cases, and comparisons of different cases (Danermark et al., 2002)
	- Reflexivity is a valuable tool in the research process (Corbin & Strauss, 2015)	- As all knowledge is conceptually-mediated, reflexivity is essential (Archer, 2010)

The tenets of grounded theory are versatile and have evolved to be compatible with a wide range of theoretical paradigms (Corbin & Strauss, 2015; Morse et al., 2009); so too is critical realism versatile and compatible with a diversity of methodological approaches (Outhwaite, 1987; Williams, 2003). Consistent with Belfrage and Hauf (2016) and Oliver (2011), I contend that table 3 demonstrates the compatibility of these approaches and their potential to be integrated with each other. The integration of these approaches requires flexibility, but at a fundamental level they are compatible in their implications for the goals, scope, design, and outcome of a research project.

2.4 Selecting the Research Approach

So far in this chapter, I have provided an overview of critical realism and grounded theory, and I have made the case that this theoretical paradigm is compatible with the chosen methodology. In this final section, I explain my reasoning behind applying this combination to my work.

2.4.1 Selecting Critical Realism

I selected critical realism as the theoretical paradigm of this project for two main reasons. First and foremost, it resonated deeply with how I see the world. I found myself making affirming exclamations whenever reading sources describing the position of critical realism. Its way of explaining causality and a stratified reality answered questions that had always lingered on the edges of my consciousness. As an illustration, critical realism offered me a nuanced approach to conceptualizing autism that could integrate and transcend the medical, functional, and social models of disability (Bhaskar & Danermark, 2006; Danermark, 2002). To me, it makes sense that there are mechanisms in the intransitive dimension that create the real phenomena that we group together (more or less accurately) and call autism. However, our knowledge of what we call autism is neither value-neutral nor infallible. We would be remiss to claim objectivity, as this would blind us to the role that the social-historical context and reification plays in our diagnostic classification systems (Hyman, 2010). We would also be mistaken to try to reduce autism to differences in molecular and biological mechanisms. Psychological mechanisms produce the experience of impairment and it is the domain of thoughts, feelings, and behaviours that relate to function or dysfunction in daily life. Social mechanisms such as stigma put constraints on the individual and disable them from having equal opportunity to participate in society. Critical realism has helped me to articulate my understanding of autism as well as the value of interdisciplinary research that embraces complexity over reductionism. I find the philosophical position of critical realism to be convincing, particularly in the context of the current work.

The second reason I selected critical realism as my theoretical paradigm is that it is well-established and well-suited to my topic of study. Critical realism has been effectively applied to a range of health research subjects such as cancer care (Angus, Miller, Pulfer, & McKeever, 2006), dementia care (Kontos, Miller, Mitchell, & Cott, 2011), and health decision-making (Harwood & Clark, 2011). It has been heralded as a powerful alternative to the more traditional and polarized options of positivism and constructivism (Angus & Clark, 2011; Bergin, Wells, & Owen, 2015; Clark, Lissel, & Davis, 2008; Houston, 2001; McEvoy & Richards, 2003; Schiller, 2016). A strength of critical realism is its focus on identifying and relating complex social and psychological mechanisms (Schiller, 2016), which is particularly relevant to my context of families receiving a diagnosis of autism. Given our currently limited understanding of parents' journey through the diagnostic feedback meeting, my project benefited from a theoretical paradigm that centers on elucidating more or less visible factors that have the power to impact this journey.

2.4.2 Selecting Grounded Theory

I came to the decision to use qualitative methods long before arriving at grounded theory. After choosing my substantive area and completing an initial literature review, I was surprised at how little knowledge had been generated about the process of delivering or receiving a diagnosis of autism. For example, I discovered I could not define a positive outcome of the diagnostic feedback meeting – there was a pocket of research on parent ratings of satisfaction, but researchers had not explored what satisfaction means to whom or why it matters. I first attempted to design a quantitative study following the hypothetico-deductive model that is so popular under the hegemony of positivism. This is the model of research that I have been trained and enculturated in throughout my education. However, the state of the literature meant that I had feeble grounds on which to choose variables or hypotheses to test. I desperately wanted to conduct a rigorous research study with the potential to inform clinical practice; I was aiming to produce good, useful knowledge. Qualitative research offered an alternative. Qualitative inquiry is well-suited to learning about a topic about which little is known, learning about the inner experiences of participants, and understanding the context and complexity of a problem or issue (Denzin & Lincoln, 2011; Mayan, 2009).

Once I decided on qualitative inquiry, I needed to select my methodological approach. As this would be my first foray into the qualitative world, I looked for an approach that would provide sufficient structure and guidance to support my journey. I was wary of underestimating how difficult and nebulous the research process would be for a previously positivist doctoral student in a positivist world (see Nagel, Burns, Tilley, & Aubin, 2015 to hear the journey of four similar doctoral students). Grounded theory drew my attention as it is both well-established and well-described (Denzin & Lincoln, 2011; Mayan, 2009). Further, I valued the emphasis on conceptualization and explanation at the social-psychological level. While the prospect of theory development felt intimidating, I knew that it would keep me intellectually stimulated and engaged. It was also the kind of work I would find meaningful. As I dug into the literature on delivering and receiving a diagnosis of autism, it appeared that a theoretical underpinning was a crucial piece that was missing from the field. With grounded theory, I could hope to contribute to this gap. Corbin suggests that "investigators should choose the approach to research that is most suitable to the problem and to their time, interest, and motivation" (2017, p. 301). On all accounts, grounded theory looked like the right fit.

Finally, the diverse and at times incompatible guidance of grounded theory methodologists led me to select one that I would follow over and above the others. These methodologists have differing assumptions about the nature of reality and knowledge, and it is chiefly these differences that have incited the divergence in their methodological approaches (Carter & Little, 2007). For example, Glaser argues that researchers must be objective and come to their work without preconceptions – consequently, he instructs researchers to avoid reviewing the literature. Strauss, Corbin, Charmaz, and Clarke all reject this methodological approach as they reject the premise that researchers *can* be objective or without preconceptions. I found myself to be most aligned with Juliet Corbin because she is the best fit with my onto-epistemological position. When discussing the epistemological underpinnings of her research, Corbin included the following quote: "One can reasonably hold that concepts and ideas are invented (rather than discovered) yet maintain that these inventions correspond to something in the real world" (Schwandt, 1998, p. 237). Positivism, constructivism, and post-modernism do not resonate with my worldview; Corbin and Strauss occupy territory in between. I recognize that the convention is to refer to Straussian grounded theory, and after his passing, Corbin dedicated much of her writing to articulating the grounded theory of Anselm Strauss. However, it was still *her* evolving and increasingly flexible articulation of grounded theory that captivated me. More recently, Corbin has acknowledged the role her own growth as a researcher has had on her interpretation of grounded theory (Corbin, 2009). I thoroughly appreciate the contribution of both Strauss and Corbin – both superlative methodologists – and I chose to employ the significantly revised fourth edition of their handbook (2015) as the primary analytic reference in this project.

Chapter 3
Methods

In this chapter, I detail the decisions I made and actions I took when undertaking the practical activities of generating and analyzing my data. I offer reflections on my positionality as the researcher as well as ethical issues from an everyday-ethics perspective. References to and direct excerpts from participant interviews are included in this chapter and in the following two chapters. I have taken several steps to ensure the privacy and confidentiality of my participants. When needed, I refer to participants by descriptors (e.g., a father of a preschooler) and pseudonyms (e.g., Farah, a fictitious first name). To best safeguard confidentiality, I refrain from linking quotes with any personal information that might be uncommon, I alter gender and sex in some references to parents and their children, and I use multiple pseudonyms for each participant. While pseudonyms were changed, I carefully chose quotes to ensure I was amplifying the voices of all my participants rather than a select few. Along with my participants, I took steps to ensure the privacy and confidentiality of the clinicians or any other individuals or organizations that were mentioned in the source material. As less than 10% of clinicians at the recruitment site were male, I altered all references to clinicians to use female pronouns and replaced their names and specific titles with 'clinician'. I also inserted generic placeholder names for any references to local organizations (e.g., [Centre for Autism Services]).

3.1 Study Context and Location

I recruited families who received their child's autism diagnosis through a large clinic in Ontario, Canada. This clinic offers a publicly-funded autism assessment service for children living within the city limits of Toronto. With a population of over 2.8 million, Toronto is the largest and most multiculturally diverse city in Canada, and families seen at this clinic reflected this diversity. The clinic has multiple locations across the city and accepted referrals from pediatricians and family physicians for children ages 0-18 with a query of autism. In a typical year at this clinic, they complete approximately 800 autism assessments, of which approximately half result in a diagnosis of autism. There were limited program evaluation activities examining this service at the time of this study.

The recruitment site for this study employed developmental pediatricians, child psychologists, and nurse practitioners in their autism assessment service. All had specialized training and experience in autism assessment. Due to their varied professional backgrounds, I refer to this group simply as clinicians throughout this paper. In the Ontario context, communicating a diagnosis is a controlled act under the Regulated Health Professions Act (RHPA, 1991). In the case of neurodevelopmental disorders such as autism, three professional groups are authorized to perform the controlled act of communicating a diagnosis: physicians, psychologists, and nurse practitioners. Any physician, psychologist, or nurse practitioner who holds the knowledge and skills to assess, formulate, and communicate a diagnosis of autism would have authority to do so. Thus, the clinicians at my recruitment site represented all three professional groups that diagnose autism in Ontario.

I recruited families for this project in 2017 and 2018, during which time the average wait time for this autism assessment service was about six months. The typical assessment process for families included 1-2 visits to the clinic to complete a developmental history and play-based assessment. Depending on the clinician and presenting issues of the child, some assessments included standardized testing of adaptive functioning (e.g., Vineland Adaptive Behaviour Scales) and/or cognitive abilities (e.g., Mullen Scales of Early Learning or a Wechsler intelligence scale). All assessments included the Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012), which is considered the gold standard for autism assessment. At the end of the assessment process, families were invited to a feedback meeting. Feedback meetings – the focus of my research – usually occurred on a separate day from assessment activities and lasted between 45 to 90 minutes. The final stage of the autism assessment service at this clinic was an appointment with a social worker, which typically occurred within 35 days of the feedback meeting. At this final appointment, the social worker shared information about resources and referred families back to community organizations to access services and supports.

I chose this recruitment site for a combination of practical and theoretical reasons. Practically, the clinic welcomed my recruitment strategies and provided a sufficiently large pool of participants from which to sample. Theoretically, I was interested in exploring feedback meetings that were conducted by clinicians with classically-defined 'expertise' and experience in autism, as this is (i) the typical pathway for autism diagnosis in Canada, and (ii) seemed likely to provide rich opportunity to consider parents' experiences when receiving more-or-less 'good' care in the feedback meeting.

3.2 Participant Recruitment

Given my critical realist-grounded theory approach, my method of sampling was purposive rather than random. Thus, I sought to reach parents with diverse experiences and perspectives of the feedback meeting. In this section, I outline my recruitment parameters and pathway.

3.2.1 Recruitment Parameters

I decided on a minimal list of inclusion criteria before beginning data generation. I have included the list below, with an explanation for each parameter. As throughout this paper, the term parent is used to denote adults who identify as a child's caregiver, including biological/adoptive parents, step-parents, grandparents, or legal guardians.

(i) *Parent of a child age 1-10 diagnosed with autism at the recruitment site:* The recruitment site accepted referrals for children up to age 18; however, the vast majority of their clients are 10 and under and the most frequently seen ages are 3- and 4-year-olds. As per a recently released report on autism diagnoses in Canada, the majority of children who receive a diagnosis of autism receive it by age six (Public Health Agency of Canada, 2018). I decided to increase the homogeneity of my sample by limiting my recruitment to the most common demographic: parents of young children, rather than parents of pre-teens or teenagers.

(ii) *Parent attended the feedback meeting:* As I was studying parents' journey through diagnostic feedback for autism, parents must have attended the feedback meeting to take part.

(iii) *Parent self-identified as being comfortable taking part in an interview in English:* Any level of conversational English was welcomed; however, I am only fluent in English and did not have means to provide translation services. As one of the first forays into this topic, I believe this study has much to offer without the added complexity of including non-English speakers. At the same time, there is a need for future research to listen to the voices of this marginalized group and explore any distinctive aspects of their journey through diagnostic feedback.

(iv) *Research interview was able to be completed within six months of the feedback meeting:* As I was focused on such a specific moment in time, I decided to recruit parents who had received their child's diagnosis within a maximum of six months of the research interview. I wanted to reach parents with rich information and stories to tell relating to this part of their parenting journey, while the experience was still vivid to them.

3.2.2 Recruitment Pathway

My research team and I shared the aims and inclusion criteria of this study with the clinic's social workers, clinicians, and staff through individual conversations and presentations at staff meetings. Recruitment occurred through the clinic's social workers. As described, these social workers usually met with parents within 35 days of the feedback meeting to connect them with community resources. During the recruitment period, four social workers informed parents about this research study and, if interested, they provided parents with a flyer for the study and asked permission to share their contact information with the research team.

I decided to recruit through the social work meeting rather than the feedback meeting for a few reasons. First, I had an idea that the feedback meeting would be a stressful and overwhelming event for parents. Approaching parents on a later date seemed like the more sensitive option; it also seemed less likely that the research study would get lost in the gravity of the diagnostic moment. In addition, I considered that due to understandable aspects of pride, shame, and human nature, it might be difficult for clinicians to refer parents who had a negative experience in their care – and I wanted to hear about the gamut of experiences. The social workers were positioned to have insight into parents' experiences without the personal investment of someone who had delivered the diagnosis themselves.

The social workers hand-delivered or faxed me the contact information of parents who were interested in hearing more about this project. I contacted parents by phone or e-mail to provide more information about the study, answer any questions, and complete a brief screen for inclusion criteria. All parents I contacted met the inclusion criteria, and all but one agreed to participate in the study (this parent shared that she would not have time to participate because her child had started an intensive intervention program). Parents who were participating in the study were invited to review the consent form and book a meeting with me at a location of their choosing. Having recruited for several studies in the past, I was surprised at the sweeping response rate for this study. I wonder if this was due, in part, to parents' desire to talk to someone about their experiences and/or the relatively low burden of participation.

3.3 Strategies for Data Generation

In this section, I describe how I generated data, which primarily entailed interviewing parents. I selected this method as my primary data source because I believed parents naturally had the most valuable perspectives on their experiences, and my research objective was to build a conceptual understanding of their journey through diagnostic feedback (interviewing clinicians, for example, would also have been a worthy endeavour, but one that would ultimately serve a different research objective). I augmented the data generated from parent interviews by gathering demographic information, reviewing children's clinical records, journaling, member checking, and peer debriefing, which I describe next. Following the description of my data sources, I report on my strategies for initial and theoretical sampling as well as data management. While I discuss the steps involved in my data analysis in the next section, they did not occur sequentially. In line with my critical realist-grounded theory approach, the generation and analysis of my data was an emergent, iterative, and concurrent process.

3.3.1 Parent Interviews

My primary method of data generation was interviewing parents who had recently received a diagnosis of autism for their young child. I scheduled a face-to-face meeting with each parent at a time and location of their choosing. I recommended that we meet somewhere that was convenient for them and suitable for private conversation, such as their home, a local library, or the clinic. To make the study accessible to families with limited time or resources, I was willing to meet participants anywhere in the city and I offered a flexible schedule including evening and weekend appointments. Additionally, I let parents know that their children were welcome to join the meeting if desired. The study covered any parking expenses parents incurred and provided a $20 gift card to a local chain of cafés as a token of our appreciation. After introductions and brief small-talk, each meeting began with an informed consent process before transitioning to the interview. Interviews were audio recorded and later transcribed by a transcription specialist to support in-depth analysis. I added paralinguistic cues and contextual information to the transcriptions where needed to clarify meaning.

As is common in grounded theory studies, I conducted semi-structured interviews. I chose a semi-structured format to establish the focus of the interview on the diagnostic feedback meeting while also allowing participants to take the interview where they thought it should go. The participants were the authorities on their experience, and I wanted to remain open to the unexpected and gather their emic viewpoint. The interviews loosely took the form of a conversation, one where my side of the conversation was focused on listening, clarifying, and exploring the others' experiences and perceptions in rich detail. The structure I brought to the interaction came from an evolving list of open-ended questions regarding parents' journey through the feedback process. My questions were intended to (i) help get the conversation flowing and provide contextual information (e.g., Tell me about your child; what is he like?), (ii) focus the conversation on the research topic (e.g., Can you walk me through what happened during the feedback meeting? What were you thinking and feeling during the meeting?), and (iii) engage in theoretical sampling around ideas I wanted to explore further, driven by the concurrent analytic process (e.g., How did the news and your reaction to the news impact on your relationship with your partner?). See Appendix A for an example of the list questions I carried with me approximately half-way through the study. While I asked questions like these in the interviews, I aimed to do more following than guiding. Parents were free to bring up any topics that were of importance to them.

3.3.2 Complementary Sources

In addition to interviews, I gathered demographic data to characterize the parents involved in the study and monitor the different socio-cultural groups I was reaching through my recruitment and sampling process. I asked each parent to complete a demographic questionnaire about themselves at the end of our meeting (see Appendix B). I also asked parents for their consent to conduct a review of their child's clinical file, but this was not a requirement for participation. I wondered whether the assessment report or notes from the clinician would help contextualize the actions-interactions of the parents.

I generated information to enhance and assess the trustworthiness of my findings through a variety of methods. I kept a research journal with my field notes and my reflections on the research process. I jotted down my observations and thoughts after I left each participant interview. I tried to not filter these notes so that I would have a record of my initial reactions to compare to my later analyses. Toward the end of my (iterative) data generation and analysis process, I began member checking and peer debriefing interviews. For member checking, I reached out to parents who held family leader roles at the recruitment site and had young children with autism. For peer debriefing, I connected with the recruiting social workers as well as my colleagues and dissertation committee. I shared the results I was generating from my study and invited feedback from each group. These meetings were audio recorded for reference during analysis. I conducted member checking with parents who had more temporal distance from the feedback meeting, as these parents were at a different point in their emotional processing of the diagnostic news. I hoped that this would make member checking less burdensome and give me the opportunity to engage with parents who were interested in mindfully reflecting on my abstracted results. From my critical realist stance, I did not expect my results to fit perfectly with any parent's conscious experience. I was aiming to develop an interpretation that spoke to generative mechanisms in the real domain, beyond our direct observations (Danermark et al., 2002).

3.3.3 Initial and Theoretical Sampling

Theoretical sampling is an essential feature of grounded theory, but the earliest phase of my recruitment was open-ended to welcome the unexpected and see what would arise in my early analysis. When communicating with the social workers, I emphasized that I was looking to hear about a diversity of experiences from all types of families. I transitioned to theoretical sampling after open coding the first five interviews. Theoretical sampling involved making decisions around what data were sampled next in terms of both *who* I was recruiting and *what* concepts I was asking about in the interviews. To accomplish the former, I stayed in contact with the social workers to direct invitations to meet my sampling aims.

The purpose of theoretical sampling is to help flesh out the developing theory (Gentles & Vilches, 2017; Suddaby, 2006). My analytic process centered on asking questions of the data, and theoretical sampling helped *add* relevant data as I attempted to untangle my answers. For example, one of the early questions I asked myself was whether mothers and fathers had similar journeys – this led me to purposively sample fathers, as the majority of my referrals had been mothers. Another example of my theoretical sampling process involved exploring the relationship between co-parents. This was a topic that came up spontaneously from parents in all my early interviews, and the emotional tone of the conversation signalled that it was a meaningful topic. In response, I added a question about how the journey had affected the co-parent relationship to my interview guide. I also communicated to the recruiting social workers that I was specifically looking to reach co-parents who had both attended the feedback meeting. This was quite successful, and I was able to interview eight sets of co-parents and hear the perspectives of both partners in these dyads.

The process of theoretical sampling led me toward some types of data and away from others. For example, I initially asked several open-ended questions about how families accessed the autism assessment service and if they had experiences with any other assessment/intervention services. However, as I began defining the basic social process of this study and moving into axial and selective coding, the data these questions garnered did not seem to play an essential role in the action-interaction of the feedback meeting. Thus, I decided to stop prompting for this information in my interviews (as the interview was structured to follow the parents’ lead, parents could still bring up information relating to these topics and it would be coded). Another example was my decision to discontinue reviews of the children’s clinical files. While these documents corroborated some of the technical information parents offered in their interviews, there was a paucity of data related to the delivery of the diagnosis. As the files provided little new information to advance the analysis, I consulted with my research team and discontinued this data generation strategy after six reviews.

3.3.4 Data Management

All data management strategies were approved by the pertinent research ethics boards (REBs). I digitally recorded all interviews on a password-protected, encrypted audio recorder. I transferred and stored audio files on a secure network protected by a hospital-grade firewall. An external transcription service transcribed all interviews, after signing a data transfer agreement that outlined confidentiality and compliance with regional privacy legislation (Personal Health Information Privacy Act [PHIPA], 2004). We sent and received files via a secure file transfer protocol.

After receiving each transcribed interview, I read through the document and removed information that could be identifying (e.g., names of people or organizations, birth dates, etc.) before uploading it into my data management software, NVivo. I assigned an identification number and a pseudonym to each participant. I maintained a de-identified Excel file with the identification numbers, pseudonyms, demographic information, and details of each participant interview. I kept a separate, password-protected Excel file that linked the identification numbers with the names and contact information of the participants. All files were kept on a secure network protected by a hospital-grade firewall.

3.4 Strategies for Data Analysis

In this section, I describe the strategies I used when analyzing my data. In grounded theory, data analysis is the "act of taking data, thinking about it, and denoting concepts to stand for the analyst's interpretation of the meaning" (Corbin & Strauss, 2015, p. 85), and it is done in the service of developing a conceptual understanding of a social-psychological process. As reviewed in chapter two, both grounded theory and critical realism seek to explain why what happens tends to happen (Corbin & Strauss, 2015; Danermark et al., 2002). Following my research approach, my analytic aim was to speak to the underlying social-psychological mechanisms at play when parents receive a diagnosis of autism, and to do so with enough detail around conditions and consequences to try to make sense of some of the commonalities and differences in parents' journeys.

3.4.1 Sensitizing Concepts

Charmaz (2014) defines sensitizing concepts as the ideas a researcher has about a topic before beginning analysis, used to consciously guide the initial exploration of the data. While Corbin and Strauss (2015) do not refer to this term, I found it to be a valuable way of acknowledging the influences I brought with me to my analysis. I derived my sensitizing concepts from an extensive review of the clinical and empirical literature on the diagnosis of autism, as well as the wider field of childhood disability. Sensitizing concepts provided initial direction, but they needed to 'earn their way' from the data to be retained (Bowen, 2006; Charmaz, 2014).

Across the relevant literature, critical reflection on the feedback meeting is woefully lacking and there is a noticeable lack of attention paid to the social process of care. Sweeny and Shepperd (2007) reveal that this intellectual neglect pervades the delivering of medical 'bad news', where there is little of substance said about the goals of the disclosure process. While the field currently lacks basic theoretical arguments (grounded or otherwise) around the delivery of an autism diagnosis, I generated sensitizing concepts after synthesizing ideas from the most relevant resources I could identify – two qualitative studies of parents' experiences receiving a diagnosis of autism (Abbott et al., 2012; Mulligan et al., 2012), clinical practice guidelines (Autism Treatment Network, 2012; Missouri Autism Guidelines Initiative, 2010; National Institute for Health and Clinical Excellence, 2011; Psychological Society of Ireland, 2010; University of Connecticut, 2013), and studies of the disclosure of childhood disability (Cottrell & Summers, 1989; Cunningham, Morgan, & McGucken, 1984; Quine & Rutter, 1994). Based on review of these studies and guidelines, I identified and provisionally named three concepts relating to the care provider: clinician's style/manner, content of communication, logistics of delivery, and three concepts relating to the care receiver: emotional response, capacity to assimilate information, and action tendency. I also tentatively diagrammed the relationship I imagined between these concepts before beginning data generation (see Appendix C). As can be seen in my results chapter, the final diagram of my grounded theory departed significantly from this starting point. This is an indication that I remained open to my data and what my participants were saying, over and above my initial reflections on, and expectations about, this topic.

3.4.2 Open, Axial, and Selective Coding

As Patton describes, “the challenge of qualitative analysis lies in making sense of massive amounts of data” (2002, p. 276). Coding reduces the volume through a researcher-driven process of sifting through data, tagging segments with an interpretation of meaning, and organizing codes under categories with increasing levels of abstraction. I began the time-intensive process of coding data after my first parent interview. I continued coding and re-coding interview transcripts concurrent with data generation, using NVivo software to tag and organize my codes. I describe my open, axial, and selective coding under the same section because there was substantial overlap in the strategies I used for each. After the initial process of open coding, I rapidly switched between open, axial, and selective coding while building my theory.

Since I conducted all interviews, I was familiar with their content when I sat down to code. Regardless, I re-immersed myself in each interview by reading through the transcript before beginning line-by-line analysis. My goal while open coding was to stay close to the data and limit theorizing. Initially, I found this difficult, but regular meetings with my research team helped orient me and keep me grounded in my methodology. We individually coded sections of the first two transcripts, and then met twice via teleconference to review and come to consensus. At that point, I felt comfortable enough to continue, moving line-by-line and denoting my interpretation of what each participant was saying. My list of codes rapidly multiplied, and so I began tentatively collapsing codes and loosely organizing them under simple categories (e.g., talking about pre-feedback; talking about feedback; talking about post-feedback). These initial decisions were driven by practicality – namely, the limitations of my working memory to hold in mind hundreds of codes at once – and guided by the constant comparison method that is central to grounded theory (Corbin & Strauss, 2015).

In Table 4, I provide an illustration of an initial round of open coding from my interview with a participant I have called Reza. As can be seen here, I framed most of my codes using gerunds (i.e., -ing verbs) to help focus attention on action-interaction. In this segment, Reza is responding to my general prompt, “What was happening for you when the clinician said autism?” He is sharing his experience of his son’s feedback meeting and comparing the process to how things work in his business.

Table 4

Coding Sample from My Interview with Reza.

Interview Segment	**Initial Open Coding**
Reza: It’s so hard to concentrate, right; it’s very hard to concentrate when you're given a diagnosis like this. I was sort of half expecting it, and my mind was racing in twenty different directions. And that’s why I think that follow-up call or appointment, I think is going to be very important, because the reality is that, in my business, when I tell somebody that and I say, okay, you’ll need your time, I meet them again a week later or whatever, to start treatment. So, you develop that relationship. But with our psychologist, it sort of ends there.	*Struggling to concentrate* *Expecting but not expecting the news* *Mind racing* *Wanting follow-up after feedback meeting* *Needing time* *Comparing to other services* *Not developing a relationship with clinician*
Me: Yeah, right, when your mind is spinning?	
Reza: Correct, and then we don’t have a recourse to say that, you know, if we’ve got questions, can we come back to you? That bit wasn’t clear to me. She might have said it, that you're welcome back, but it may have just have flown out the window. I think a return appointment – you know, that can be an opt-out option, like, people can opt-out if they want to – will be very useful.	*Feeling like there is no recourse for follow-up* *Clinic leaving follow-up options unclear* *Not being sure what clinician said* *Wanting a follow-up appointment*

Coding one interview often led me to think differently about segments of earlier interviews, which I would go back to and re-code. I needed to be immersed in my data, spending much of my time coding, to help facilitate these connections. This iterative and emergent process allowed me to consider new insights into participant comments that I had previously laboured over without satisfaction. For example, my initial open coding of my interview with a father I will call Christopher led me to reflect on some of my earlier codes. Christopher’s remarks were rife with questions about the future, to the point that he talked about little else. When I prompted him to talk about the feedback meeting, he asserted that his diagnosing clinician should have been able to predict the likelihood that his toddler would develop anxiety or depression in adolescence and should have provided strategies for handling this possibility. Given the age of his son, Christopher’s comments sounded drastic, but as Danermark et al. (2002) contend, extreme cases can help elucidate mechanisms that are harder to see in regular conditions. Christopher’s interview led me to reflect on the painful discomfort of uncertainty, and I interpreted his deluge of questions, worries, and demands as part of a frantic search for certainty. Next, I returned to my earlier interviews and found new meaning in parents’ questions about the future. I also noticed just how pervasive those questions were across all my participants. As I continued axial and selective coding, I developed this idea into a higher-level category I labelled *swelling distress and uncertainty*.

Under the impetus of constant comparison, I continuously moved between the raw data and my concepts and categories, considering and re-considering my interpretive choices. I embraced the fluidity and tentative nature of coding, playing around with how I coded, labelled my codes, and organized my codes into categories. Constant comparison provided the freedom for creative exploration, because I could trust that I would keep coming back to the raw data to consider whether new insights really fit the stories and experiences of my participants. I incorporated a range of analytic strategies from Corbin and Strauss (2015) to help stimulate my thinking, such as looking at emotion, looking at language choice, and looking for negative cases. These strategies guided me to ask questions of the data and evaluate a variety of answers to these questions. For example, I often compared the way a specific topic was spoken about across parents. I pulled out the segment of each interview where parents first walked through their memory of the clinician's delivery of the diagnosis. I read these segments in sequence and asked myself questions such as: *In what way are these accounts similar or dissimilar? What evocative words or ideas show up across cases? What emotions are being expressed? Why is the word autism missing from most accounts?* I used memo writing to record my thoughts and reflections throughout the coding process.

As my coding became more abstract, I continued to ground my thinking using constant comparison as I considered the relationships between categories and their integration into a larger theory. For example, when developing categories I had labelled *swelling distress* and *swelling uncertainty,* I went back to my raw interview data to consider whether one followed the other in parents' accounts of the feedback meeting. My intuition was that the wave of uncertainty preceded and contributed to the distress – my job as a reflexive researcher was to question my intuition and compare it with my data. As I did not find evidence of a clear distinction or chronology, I merged these two concepts under one superordinate category and looked elsewhere for the generative mechanism.

Three strategies I found particularly useful during axial and selective coding (the phases where description becomes explanation) were constructing a mind palace, leveraging the conditional-consequential matrix from Corbin and Strauss (2015), and diagramming. My 'mind palace' was a table with columns for each of my participants and rows for my growing and changing list of key categories. I put different marks to symbolize how these categories presented themselves in each parent's journey. This served as a mnemonic device that facilitated my comparisons between cases when deliberating the relationships between action-interactions, conditions, and consequences. Along with my mind palace, I leaned on the conditional-consequential matrix as a scaffold to expand my thinking about conditions in the social strata of reality, such as gender, age, and power. I intentionally searched for evidence of the influence of various social structures, however, I only developed categories when I found pervasive support in my parent interviews. Finally, I relied on diagramming throughout my axial and selective coding process. I am a visual thinker, and diagramming allowed me to play around visually and ask questions about how different concepts related to each other.

3.4.3 Theoretical Integration

Theoretical integration was the final phase of analysis, when I focused on elaborating and honing my grounded theory in terms of density, abstraction, explanatory power, and trustworthiness (Corbin & Strauss, 2015; Danermark et al., 2002). It also involved selecting a core category – an attempt to capture the central social-psychological process in the data (Corbin & Strauss, 2015). The main strategies I used in this phase were diagramming, reviewing the extant literature for theoretical comparisons, member checking, and peer debriefing. I sought out literature to help me think more abstractly, borrowing established concepts from other contexts and evaluating how they resonated (or not) with my data. From a critical realist lens, personal experience and knowledge of the extant literature are vital components of a well-reasoned retroduction (Danermark et al., 2002). Importantly, concepts from the literature were used to stimulate my thinking and were not retained if not found to fit with what I was seeing in the data (as per Corbin & Strauss, 2015), as considered through careful memoing and ongoing consultation with my supervisory team – the predominant focus of the theoretical integration phase remained on the interview data. With member checking and peer debriefing, I presented my grounded theory in various states and invited feedback to help me refine and refute my ideas.

I was aiming to develop a coherent explanation of parents' journey through diagnostic feedback for autism, fallible – as all knowledge is (Danermark et al., 2002) – but grounded in my data. Part of theoretical integration was determining when I reached a point of *theoretical sufficiency* to justify ending theoretical sampling and data analysis (i.e., the themes and ensuing theory were well-developed enough to provide an answer to my research question). Based on the precedent set by previous doctoral dissertations that used a qualitative methodology, I estimated that I would need to recruit 20-30 participants to reach theoretical sufficiency (Mason, 2010). I made the decision to end my data generation and analysis in collaboration with my dissertation committee, after several presentations of my grounded theory across several months. In its final version, we agreed that I had explained and related the generative mechanisms underlying parents' experiences with sufficient detail to begin disseminating of my findings. I consider my results a "living theory", meaning that the ideas behind it should continue to grow and evolve with time and the accumulation of more knowledge.

3.5 Role of the Researcher

As discussed in chapter two, the ontological-epistemological stance of critical realism necessitates the recognition of the researcher as the primary instrument of analysis (Archer, 2010). My social position, life experiences, perspectives, and mental faculties all came to bear as I generated and made sense of my data. Thus, it was essential for me to be reflexive about the role I played in my research. Of course, any appraisal will be imperfect as I am without 'super-human self-consciousness' (Finlay, 2002), but it is important nonetheless. I used Bover's (2012) strategies for reflexivity to help guide my appraisal.

3.5.1 Researcher's Positionality

As the interviewer, I expect that my social position influenced the interactions between me and my participants. A few of my social identities that could have played a role include that I was young, white, female, neurotypical, middle-class, a native English speaker, an educated professional, a student, a diagnostician-in-training, and a person without the experience of parenting a child with or without autism. Further, my position as the interviewer/researcher yielded me power in relation to the parents I was meeting – they were choosing to take part in a study and share their experiences, but I had the power (and responsibility) to guide the interview, interpret their answers, and disseminate the findings.

Before conducting this study, I imagined that my professional identity would have the greatest impact on my interactions with participants. I thought that my affiliation with the recruitment site might make parents hesitant to disclose aspects of their experience that showed the clinic or clinicians in a negative light. I also thought that my role as an 'autism researcher' might lead parents to make use of the interview as an opportunity to access case management, clinical support, or information about autism. However, these aspects of my professional identity did not seem to garner much attention from parents in this context. No parent asked follow-up questions after I described the nature of confidentiality between researchers and clinical staff, and almost all parents chose to refer to their clinician by name without trepidation. No parent asked for information or advice regarding services or supports for their family, and the only question I received about autism was for a clarification around the levels of 'support needed' (e.g., How many levels are there and what do they mean?) requested by several parents. Having now completed the study, I am much less surprised by this turn of events. I think I underestimated how much parents valued the space to share their experience, even with a stranger for the purposes of a research study. Parents were focused on telling their story. However, the questions around levels of 'support needed' demonstrated that they were still relating to me as someone informed about autism.

Looking back on data generation, I wonder if my position as a young female student had the greatest impact on my interactions with parents. During the small-talk at the end of our interview, many parents took on a maternal/paternal tone with me: a father vocalized his worry about me waiting for the bus at night; a mother reassured me that I had plenty of time left to have children; and another mother offered me career advice. In each of these illustrations, the comments were unprompted by disclosures on my end. I think these interactions imply that many parents felt a connection with me and, in terms of power relations, they felt in a position to provide advice or assistance. Our society does not afford much authority to young females and, accordingly, I did not see evidence that parents – across social classes – felt intimidated by my presence. On the contrary, I remember one mother letting me into her apartment and casually motioning toward the couch as she finished up a phone call with her family from her home country. Interactions like this one display a level of comfort that may have helped facilitate a more candid and uninhibited conversation.

3.5.2 Researcher's Beliefs, Values, and Experiences

I expect my beliefs, values, and experiences surrounding my subject matter influenced my data generation and analysis. One major influence on my work was my background in psychological theory and practice: I was attentive to the intrapsychic and interpersonal aspects of parents' experiences, and I had an established knowledge base to draw from for theoretical comparisons. Bringing a psychological focus to my analysis was congruent with my research approach. In grounded theory, Corbin and Strauss (1996) encourage researchers to leverage their areas of expertise; in critical realism, Danermark et al. (2002) argue that due to the stratified and emergent nature of reality, researchers can study phenomena at any strata with meaningful results. As can be seen in the next chapter, my results have a distinctly psychological flavour (e.g., categories relating to shock, uncertainty, and distress) but they also include reflections on and integration with social structures and conditions.

I reflected on and journaled about my beliefs and values regarding my topic at various stages of the research process. Some of my core beliefs include the assumption that children with autism have difficulties that impair their daily life, but that they have lives very much worth living – and that parents play a crucial role in enabling their children with autism to live happy and satisfying lives. Following diagnostic feedback, I see parents as the change-makers: they are the ones who absorb and make meaning of the news, make new sense of their child's behaviours, tell other people the news, request support at school, access community services, take their child to appointments, and more. Especially with young children, parents shoulder the responsibility of taking action. I see the feedback meeting as a gateway – a single point in time where the clinician sets the parent on a new, unfamiliar path. The clinician opens the gate, but the parent walks through and into a bewildering new reality. I believe service providers have an ethical duty to help their clients through that gateway with a gentle, steadying hand. My research does not mean to imply that clinicians are not currently achieving this aim. Rather, I embrace the dialectical tension that clinicians are doing the best they can *and* that they (and I) can always do better. I hope that better understanding parents' experiences will enable clinicians to meaningfully improve the quality of care provided in the feedback meeting.

As my beliefs and values suggest, I decided to study a topic with which I had intimate experience, as I had grappled with it in my clinical training. This might have made it harder for me to let go of my perspective and step into the worlds of my participants (Peredaryenko & Krauss, 2013). Then again, I did not have experience as a parent of a child with autism. As I was attempting to build an in-depth understanding of parents' experience, my balance of proximity-distance may have served me well. My background helped me to build rapport and contextualize parents' stories, but I recognized that delving into their experience of receiving the diagnosis was unfamiliar territory for me. I approached my task with humility and curiosity. During my initial interviews with parents, I noticed that I was hypervigilant toward any mention of what the clinician was saying and doing. I often probed for details about the clinicians' actions rather than following the parents' lead in telling their story. Part of me was focused on placing ultimate responsibility on the clinician, and I was putting pressure on myself to develop a theory that could easily translate into clinical advice – for myself and others. Consultation with my dissertation committee and re-immersing myself in the theory behind my research approach helped me to let this go. I needed to have faith that working to deeply understand and explain parents' experiences would be enough. In fact, I came to realize that it would be more than enough, as this is where the real power of my study lay. Our world is complicated and nuanced, and I would be doing my research a disservice if I attempted to reduce my findings to a list of prescriptions for clinical practice.

3.6 Ethical Considerations

This study was approved by the pertinent university and clinic-affiliated REBs. Beyond satisfying regulatory ethics requirements, I reflected on the everyday ethics of my research process. The procedures of ethical review boards evolved from and are designed around positivist, quantitative traditions of research – while they play a critical role in safeguarding the well-being of participants, they can inadequately account for the nature of ethical considerations in post-positivist, qualitative research (American Association of University Professors, 2000; Guillemin & Gillam, 2004; Ramcharan & Cutcliffe, 2001). In the context of my study, three examples of this would be the emergent nature of grounded theory methods (i.e., I could not specify the precise details of my data generation and analysis in advance, as they were informed by the research process itself), the human-to-human nature of interviewing (i.e., I asked parents to talk with me about a sensitive topic; our conversation was dynamic and followed parents' lead regarding what we talked about), and the role of the researcher given the nature of my onto-epistemological position (i.e., as I believe it is impossible to objectively measure reality, I recognize the researcher as the main tool of analysis and ongoing reflexivity became essential to ethical conduct). Thus, it was important for me to be attuned and responsive to ethical issues as they emerged in my study.

In my efforts to maintain high ethical standards in my research practice, I leaned on the established literature in the social sciences around ethics-as-process/-practice, reflexivity, and micro-ethics (Archer, 2010; Bover, 2010; Guillemin & Gillam, 2004; Ramcharan & Cutcliffe, 2001). I also referred to the Canadian Panel of Research Ethics' Tri-Council Policy Statement for supplementary guidelines on ethical conduct in qualitative research (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014). Further, I considered Corbin and Strauss' (2015) statement that we have an ethical responsibility to our participants and to society to conduct our research with methodological integrity, to conduct the highest-quality analysis of which we are capable, and to disseminate our results. I tackle methodological rigour in the next section, and at the time of writing, I was in the process of actualizing my knowledge translation plan. I will contract a graphics designer to develop a user-friendly depiction of my results and present my grounded theory to clinicians, clinic managers, parents, researchers, and other stakeholders in Ontario and beyond.

Komesaroff (1995) coined the term micro-ethics to address the need to reflect on the complex dynamics that occur in relationships with intrinsic power imbalances, such as doctor-patient relationships and researcher-researched relationships. In this vein, I dedicated time to journaling and reflecting on my interactions with my participants. As described in the previous section (3.5.1 Researcher's Positionality), I believe that my presentation as a young female student may have lessened the intrinsic power imbalance between me and my participants. In addition, meeting my participants in a familiar location of their choosing (e.g., their home or local library, as was chosen in the majority of cases) may also have helped subvert the traditional dynamics between researcher and researched. However, I was still in the privileged position of the researcher and there is an ethical tension in generating data from and interpreting people's lived experiences (Guillemin & Gillam, 2004). I was mindful that I was approaching parents at a potentially tumultuous time in their lives, and I was asking them to discuss a sensitive topic. Gathering good qualitative data meant trying to create a space where participants felt comfortable opening up; however, ethically, it was more important that participants felt safe and felt able to determine how much to disclose. I believe my clinical training in client-centered approaches and reflective, empathic listening helped me to co-create a safe and connected space with my participants. I felt comfortable with and normalized the expression of emotion during interviews, but I followed each participant's lead in whether they wanted to continue discussing a vulnerable topic. In respecting their autonomy, I did not press for information if it was not forthcoming.

Guillemin and Gillam (2004) outline three elements of ethical conduct in the context of researcher-participant dynamics: (i) an awareness of micro-ethics in everyday practice, (ii) sensitivity to "ethically important moments" in everyday practice, and (iii) capacity to respond to ethically important moments when they occur. An illustration of how I responded to ethical considerations during my study follows.

An ethically important moment arose during my consent process with Angela, a mother of a preschooler with autism. She was uneasy about having her interview audio recorded, and she asked if she could proceed without the recording. In responding to Angela, I first considered the request from the standpoint of methodological rigour: for Angela's data to be fruitfully used in my analysis, I would need to capture her words verbatim. Second, I considered the request from the standpoint of micro-ethics: I accepted that Angela's feeling of uneasiness was valid, and I was aware that she may feel pressured to take part in the research study anyway. I shared my reasoning for why all my interviews needed to be audio recorded, and I asked Angela if she felt comfortable sharing the source of her trepidation. She shared that she was worried about having her child publicly identified as having autism. It was clear from her emotional tone that this was a significant concern for her. I normalized Angela's worry and reviewed the measures I had in place to ensure confidential transfer and storage of audio files. I assured her that it was perfectly valid to feel uncomfortable with audio recording despite these measures, and I encouraged her to take her time to think about what she would like to do. I was aware that Angela might still feel pressured to comply and go through with the study; I stepped out of the room to make sure she had time and space to make a decision. While I was waiting in the hallway, I considered that depending on how motivated Angela was to contribute to the study, she might feel undue pressure to agree to audio recording in order to have her voice heard. When I returned to the room, I offered Angela a third option: while conducting the interview without audio recording would mean I could not code and analyze her story in the same way as other participants, we could still discuss her experiences, and this would be informative to the research process. At this point, Angela confidently let me know that she was comfortable moving ahead with the audio recorder on. Afterward, I debriefed with my dissertation committee to explore their perspectives on how I handled the situation. One of the outcomes of their feedback was my decision to alert all future participants of the audio recording before meeting in person.

Chapter 4
Findings

In this chapter, I present the findings from my study of parents' journey through diagnostic feedback for autism. I begin by describing my data and the parents who generously agreed to take part in the study. Next, I provide an overview of the grounded theory itself, organized around a basic social-psychological process that I have labelled *protecting myself and my child*. Following this overview, I offer a detailed description of the categories and subcategories that underpin the grounded theory. I have also included a set of supplemental results in Appendix D, where I have collated quotes from participants who offered direct advice to clinicians communicating a diagnosis of autism. Lastly, I discuss the strategies I used to enhance the quality of my work.

As outlined at the start of chapter three, I have used several strategies to maintain the confidentiality of my participants and other people involved in my study. A note on writing style: I have used italics throughout the text to indicate category names, and I have adjusted pronouns and verb tenses of category names to fit grammatically when needed (e.g., *knowing something is different with my child* is also referred to as *knew something was different with his child)*.

4.1 Describing the Data

My primary sources of data were interviews I conducted with 27 parents of young children (ages 1-10) who were recently diagnosed with autism. Eight of these interviews were conducted with two parents present, while the remaining interviews were one-on-one. The majority of interviews (68%) were conducted within two months of the diagnostic feedback meeting. The remaining interviews (27%) were conducted within four months of feedback, except one case where the interview was completed within six months. All participants had attended their child's feedback meeting, which was carried out by a developmental pediatrician (53%), psychologist (42%), or nurse practitioner (5%) at the recruitment site.

4.1.1 Parent Sample

As can be seen in Table 5, the recruitment process was successful at enrolling mothers and fathers (as well as one grandparent) of a range of ages. It was also successful at capturing participants from a diverse array of sociocultural backgrounds, well-representing the diversity of the city in which I was recruiting. For example, almost half of the sample was first generation Canadian, matching the 51% of Torontonians who were born outside of Canada (Toronto Public Health, 2018). Four of the mothers I interviewed in this study were parenting alone, while the remaining 23 participants were co-parenting.

Table 5.

Characteristics of Parents Sampled

Characteristic	**Frequency counts**							
Relation to child	17	Mother	9	Father	1	Grandmother		
Age	9	25-39	16	40-54	2	55-69		
Generation Canadian	13	1st generation	6	2nd generation	8	3rd+ generation		
Family origins[a]	2	African	11	Asian	13	European	4	Latin American/ Caribbean
Language status	13	English as a first language	14	English language learner				
Educational attainment	7	High school or elementary	3	College Diploma	14	Bachelor's degree	3	Graduate degree
Work status	7	Full-time parent	3	Part-time employment	17	Full-time employment		

[a] *As the fields under family origins are not mutually exclusive, multiple fields were indicated for participants where applicable.*

One aspect of sociocultural background that is not included in Table 5 is religion. I did not routinely ask about religion; however, two parents spontaneously spoke about their faith during the interview. One parent spoke of a crisis in faith following the diagnosis while the other spoke of their faith as a source of strength and acceptance. One of these parents identified as Christian and the other identified as Muslim.

Table 6.

Characteristics of Households Sampled

Characteristic					**Frequency counts**			
Annual income	4	<$45,000	6	$45,000-90,000	9	>$90,000		
Number of children	5	1 child	6	2 children	6	3 children	2	≥4 children

Table 6 displays a summary of participants' household income and number of dependents. Forty-two percent of participating households (representing 52% of participants) earned under $90,000 annually – for comparison, the median income for families in Ontario was $81, 480 in the most recent population census (Statistics Canada, 2016). Some participants in this study were first-time parents, while others had several children.

Table 7.

Characteristics of Children Recently Diagnosed with Autism

Characteristic					**Frequency counts**					
Age at diagnosis	3	Age 0-2	10	Age 3-4	2	Age 5-6	2	Age 7-8	3	Age 9-10
Sex	5	Female	15	Male						
Level of support[a]	7	Level 1	3	Level 1/2	3	Level 2	5	Level 2/3	2	Level 3

[a]*Level of Support refers to the DSM-5 (APA, 2013) specifiers of level of support needed, as determined by the diagnosing clinician. Note that level 1 = requiring support, level 2 = requiring substantial support, and level 3 = requiring very substantial support.*

Table 7 displays characteristics of the children recently diagnosed with autism. The children who had been assessed for autism spanned the ages of 1-10 and their diagnoses spanned the full spectrum of level(s) of 'support needed' as laid out in the DSM-5 (APA, 2013).

Tables 5-7 demonstrate the diversity of the families who were interviewed for this study. Perhaps one of the richest sources of diversity in this sample does not fit in a table format – that is, the various pathways and perspectives from which parents came to the news their child had autism: there was a mother who worried about autism before she conceived; a father who has autism himself; a family who had fought for a diagnosis for their older child, and now went through the process again for their second child; a father whose daughter was diagnosed with autism in their home country but needed to be re-assessed in Canada; a mother who never considered autism until hearing it in the feedback meeting; a couple who both silently worried about autism for their son but never said it aloud, not even to each other; and a couple who only came to the clinic to prove their son's school wrong and that their son was developing fine – just to describe a few.

4.1.2 Parent Interview Process

I met with each parent once, in a location of their choosing. Parents chose to meet in their home (42%), at the clinic (32%), or a public library in their neighborhood (26%). Interviews that took place at parents' homes tended to have a more relaxed feel to them – children were usually playing in the same room and parents would pause the conversation to respond to the child or complete household tasks. All meetings began with an informed consent process and ended with the collection of demographic information. The interview portion generally lasted about 70 minutes and ranged in length from 50-100 minutes.

Across interviews, parents did not need much encouragement to share their experiences and perspectives of their journey through diagnostic feedback. This was a topic on which they had things to say; they seemed engaged and earnest. Several participants disclosed that their reason for taking part in the interview was the opportunity to talk to someone about what had happened. The conversations were alive with emotions such as shock, worry, frustration, and sadness. Most parents cried or teared up at some point in the conversation, often as they recollected the moment when they heard the diagnosis or described their worries for their child's future. Some of these parents fought against or brushed aside the tears, while others acknowledged that tears had become a common occurrence in the weeks or months following the feedback meeting. While many participants were emotionally activated, no one appeared overly dysregulated and no one indicated a desire to end the interview or to divert away from discussing a particular subject. Many expressed appreciation for having a space to tell their story.

Overall, participants were willing to answer all my questions; however, I did more following than guiding. I focused on minimizing my side of the conversation, offering encouraging sounds or saying 'yeah', 'of course' or repeating a part of what a parent had said to ask for further clarification. On several occasions, parents were invested in sharing their experiences and reflections on topics that went beyond the scope of this research project. Frequently, this featured parents' frustrations trying to navigate and access services for their child following the diagnosis. It was clear this was another important issue for parents at this stage in their journey. Due to the open-ended, emergent design of my study, I did not foreclose these topical departures. I considered anything parents brought into the discussion as meaningful. The boundaries of my research question and the social process I was attempting to explain would be subject to change based on what I found in my data. Comments that I interpreted as extraneous at one point may, later in analysis, be interpreted as a crucial condition or consequence of action-interaction related to my core category. I allowed parents to direct the flow of conversation, but when a particular subject had run its course, my open-ended questions would draw us back toward the diagnostic feedback meeting.

4.1.3 Findings from Complementary Sources

In addition to interviews with parents, I generated data and assessed the trustworthiness of my findings from clinical record reviews, journaling, member checking, and peer debriefing. All 27 participants opted to provide consent for their child's clinical record to be reviewed; however, I only undertook six reviews. The clinical records contained the following materials: clinical consent forms, intake questionnaires, assessment measures, copies of any correspondence with parents, and the final assessment report. While these documents corroborated some of the technical information parents offered in their interviews, they provided little new information to advance the analysis. Perhaps the most revealing aspect of the clinical records was the absence of references to the feedback meeting or to parents' experiences or perspectives of the diagnostic process. With this firmly established after six reviews, I discontinued this data generation strategy.

In contrast to the clinical record reviews, my research journal helped supplement my analyses throughout the research process. I used the journal as an informal record of my reactions to participant interviews and my reflections on the research process. The examples I drew on in section 3.5.1, *Researcher's Positionality*, are an illustration of how I incorporated my research journal into my reflexive analysis. The comments parents made about my trip home, my prospects of bearing children, and my career all struck me as surprisingly intimate, and I wrote about each occurrence well before considering that they might be emblematic of power dynamics and my social position. Having my research journal as a record allowed me to confidently revisit and reflect on experiences like these.

Another helpful source of data came from member checking and peer debriefing interviews. I undertook these consultations toward the end of the study, at which time I described the results I was generating from my study and invited feedback. It was reassuring to hear that my grounded theory resonated with parents of children with autism as well as clinicians and researchers with methodological expertise. In one of my member checking interviews, a parent expressed the following:

> "Trust your results. The fact that I can come in here and say, 'yes, yes, yes, that resonates with my experience' is powerful. Someone needed to do this work, and I'm so glad that you did."

Another parent reflected on how the theory provided new insight into her own experience. She was intrigued by the category *obtaining the right support* (described further in the following sections) and the power of having a connection to someone who is comfortable with autism. When she had been trying to absorb the news of her son's autism, she had reached out to a close friend who worked with children with special needs. She expressed that although this connection did not play a significant role in her narrative of receiving the diagnosis, looking back now she could see the many ways their conversations had influenced her perception of autism and her son. This was the level of resonance that I was hoping for with my results – a level that fit with parents' experiences but pushed beyond any one person's account to provide new insight into generative mechanisms (Danermark et al., 2012). This in keeping with Corbin and Strauss' approach to grounded theory, as the authors state: "The relationships between micro and macro conditions are not always visible to individual research participants […] It takes listening to many voices to gain understanding of the whole" (2015, p. 162).

Like my experience with member checking, my peer debriefing interviews with the social workers from the recruitment site encouraged me to trust my results. One social worker expressed the following:

> "You're capturing it so well. It's so good to hear these stories being presented in this way and given the weight that I think they deserve […] I feel like it's so wonderful to have data to support what, anecdotally, I hear all the time."

My peer debriefing interviews with my colleagues, dissertation committee, and other methodological experts (e.g., the Grounded Theory Club research group) helped me to refine the integration of my theory. As I discussed and answered questions about the relationships between my categories, I could see where there was insufficient explanation or where I struggled to articulate the evidence behind an assertion. This was an invaluable process, as it brought me back to my data and the constant comparison method to refine or refute my interpretations.

4.2 The Grounded Theory of Protecting Myself and My Child

This study aimed to build a conceptual understanding of parents' journey through diagnostic feedback for autism, grounded in interviews with parents and advanced through my knowledge of the literature, general theory, and clinical experience. While the process of building a grounded theory is primarily bottom-up (i.e., it starts by breaking down and reassembling the raw data with increasing levels of abstraction), I present my results top-down. Specifically, I begin with the overview of the polished grounded theory before delving into the details and providing examples. This is the order recommended by Corbin and Strauss (2015) and it resonated with me as the clearest way to articulate my findings.

4.2.1 Presenting the Core Category

Grounded theories coalesce under a core category that attempts to capture the central social-psychological process in the data. That is, the core category is an abstract representation of the central activity that all participants are engaging in, in response to the events or phenomena under study (Corbin & Strauss, 2015). The core category I identified in this study was *protecting myself and my child*, and it indicated that parents rapidly make meaning of, feel, think, and respond to the delivery of the diagnosis as signalling a hazard from which they must protect their family. One mother described her perception of threat and her response to the threat in the following series of quotes:

> "Like the fight or flight mode, that… right, like I'm under attack."

> "You've destroyed my image of what my family is. My family up until that day was like my loving partner-husband-dude and my two beautiful perfect children, and now I don't have that anymore, and it's your fault. You know, that's sort of… which is… I realize it's not true, but, yeah, it was a real… You're threatening me, you're telling me something is wrong, and I need to fix it."

> "There is so much to be done, and I think part of my feelings of being threatened are 'oh my god, it's like oh my god, what do I do?' like, that sort of instant helplessness. Like that was an instant feeling, like 'shit… I can't… I don't… I'm stuck, I don't know what to do, I don't know what to do.' And so maybe that was part of it too, that – like I said the urgency to leap into action and just sort of move on, and, I don't know, to restore the stability of my nice little family, you know?"

Another mother explained her need to protect her son in the following series of quotes:

> "It's just that, like, for example, why you're saying that my son is like this but he's not? So sometimes, you know, it's like a defense mechanism for the parents."

> "I remember that-- no, my son did not do that, because it's my defense mechanism, that my son is not, because I don't have the diagnosis yet and it's my first time to deal with this speech pathologist. But now I totally understand, because... so there is lots of correction on her diagnosis because I contradict what's her diagnosis, but now I totally understand they know better than me and I was telling... I'm defending my son -- that he's not -- he did not do it. Did you not see that my son followed your instruction? Why are you saying that he did not? And yeah, there are some corrections, but I think with that is you just have to explain. Be patient with the parents especially, explaining why they have to do it, why the diagnosis is like that"

> "Because you know that parents are defending these [kids]"

These excerpts help to illustrate how parents quickly organize themselves around protecting their families from what they perceive as a threatening situation. They are suddenly facing an uncertain and daunting post-diagnosis world. The other categories in my grounded theory tie into this overarching explanation for how parents are responding. The primary categories of action-interaction I identified under this core category included an *undercurrent of anticipating* in the lead-up to the feedback meeting, *sounding the alarm* when hearing the official pronouncement, followed by *swelling distress and uncertainty*. Depending on a complex interplay of conditions, parents dealt with their situation in three ways: *protective maneuvering, instrumental responding,* and/or *processing-oriented advancing,* which, in turn, affected their swell of distress and uncertainty.

4.2.2 Presenting the Grounded Theory

The grounded theory *protecting myself and my child* begins, chronologically, with the category *undercurrent of anticipating.* The *undercurrent of anticipating* establishes that parents' journey worrying and wondering about their child's differences starts well before the feedback meeting. However, no matter how much or how little parents seem prepared for a diagnosis of autism, *anticipating is not the same as hearing* the news. Hearing the diagnosis is the flash point, the point at which parents *sound the alarm*. The alarm is a warning of potential danger to their child and their family. Part of this alarm-response is *going into shock,* which includes visceral experiences such as feeling like a bucket of cold water has been dropped on them, feeling dazed, checking out, or things going blurry. For some parents, this includes *experiencing a release that the alarm is real.* This doesn't necessarily mute the alarm, but for this subset of parents there is a sense of relief, vindication, or outpouring of emotion that the alarm is real – they are not crazy.

Sounding the alarm, signalling potential danger to their child and their family, leads to the *swelling of distress and uncertainty*, and no wonder! Parents connect with feelings of being crushed, like the situation is too much and a heavy weight on their shoulders. Their distress also centers on how their child will have to deal with this diagnosis – how they want the best for their child and for their child not to have any struggles. Inextricably linked with the swelling distress is the sense of *being engulfed in new uncertainty.* Parents are consumed with unrelenting questions about what the future will hold – will their child ever talk, be safe around cars, live independently, become depressed – suddenly, the future feels like a big uncertain blank. The distress and uncertainty seem to swell together like a wave in the ocean. The analogy of a wave captures that gravity and dynamism of the experience.

People are agents that give meaning to events: they have feelings about them, think about them, and respond through action-interaction. In my grounded theory, I see the primary conflict as parents' attempts to deal with the alarm and the ensuing wave of distress and uncertainty. I identified three main categories of responses, which I have labelled *protective maneuvering, instrumental responding, and processing-oriented advancing.* Any individual parent may engage in any distribution of responses across these three categories. However, it seems that the larger the wave of distress and uncertainty is for a parent – that is, the louder the alarm and the more threatening the situation – the more parents' actions are constrained to *protective maneuvering.* These parents have less space, less safety, and fewer resources to support them through taking other actions. Conversely, the smaller the wave of distress and uncertainty – the quieter the alarm and the less threatening the situation – the more parents are enabled to respond with *processing-oriented advancing.*

The relationship between each of these three categories and the wave of distress and uncertainty goes both ways. The actions parents take have consequences that impact back on the wave. *Protective maneuvering* can be thought of as a search for control and certainty by avoiding or obscuring feelings or ideas. In this category, parents are trying to get rid of the alarm any way they can (e.g., push it away, bury it, fight with it, distract themselves from it, avoid it, pretend it isn't there). Meanwhile, it seems like the wave of distress and uncertainty keeps growing and hanging ominously overhead. *Instrumental responding* entails the tangible actions – and the focus on preparing for action – that parents take to protect their child. In this category, parents are responding to the wave of distress and uncertainty by acting to protect their child and family. It is like they are learning how to stay afloat in the storm – how to surf on the wave. *Processing-oriented advancing* involves parents experiencing and moving toward accepting their feelings, as well as reflecting on and integrating the news. In this category, parents are processing the potential threat, metabolizing their distress, accepting the uncertainty, and, in so doing, calming the wave.

So far in this overview, I have walked through the actions-interactions of parents' journey through diagnostic feedback. Now, I turn to the conditions that help make sense of the complexity and variation in parents' journeys. Conditions answer questions about when and why action is taken (Corbin & Strauss, 2015). First, I consider the impact of parents' perceptions of autism, which are derived from their own ideas and experiences as well as societal norms and messages. The different perceptions parents have can dial up or down the volume of *sounding the alarm,* which in turn affects the amount of *swelling distress and uncertainty* and, thus, constrains or enables the resources parents have to respond to the situation. On the 'down' side of the figurative dial, parents are *reacting to autism as comfortable*. On the 'up' side of the dial, parents are r*eacting to autism as unfavourable*.

Another important condition is *obtaining the right support*. Parents highlighted that support is critical during this traumatic time, but not just any support meets their needs. The support parents valued and craved was that provided by people who 'get it' – people who understand the world of autism. Parents who found this support accessed it either from the diagnosing clinician or by reaching out to people in their lives who had firsthand experience and comfort with autism. When parents were able to access sufficient support, it helped to pull them down from more *protective maneuvering* to *processing-oriented advancing.* It provided the space, safety, and resources to facilitate a different kind of response to their situation.

The final category in my grounded theory is *deferring to clinician-as-expert*. This category speaks to the structural level of social norms and power dynamics between clinicians and parents (Danermark et al., 2002; Vandenberghe, 2014). Clinicians and parents share expectations for the clinician to play a certain 'expert' role, and this, in turn, constrains and enables their actions-interactions. The 'expert' role can be soothing for parents, as they may be able to follow the clinician's lead and put faith into the diagnosis they deliver. However, the expert role also comes with expectations that parents will perform to a norm – that they will listen attentively and rationally to what the clinician says. In *deferring* *to clinician-as-expert,* parents often muted their distress and quieted their appeals for emotional support.

My grounded theory is an interpretive rendering that attempts to make the most credible, useful sense of my data. While there was complexity and variation in parents' journeys, no parent experienced the diagnosis as a non-event and the conceptual categories I identified transcend individual cases. The theory attempts to capture and explain dynamic shifts – the swell and calming of alarm and distress as parents act to *protect themselves and their children* in the face of an uncertain and daunting situation. A final note before delving into the details: the interplay of conditions is different for different parents, and thus, when a couple goes through this process together, they may have disparate experiences.

Figure 2 provides a visual representation of the main categories and their interrelationships under this grounded theory, which I consider more in-depth in the following section. While the diagram is static, it is meant to represent a process that is dynamic and can be thought of as a "rhythm, as well as the changing and repetitive forms of action-interaction" (Corbin & Strauss, 2015, p. 172).

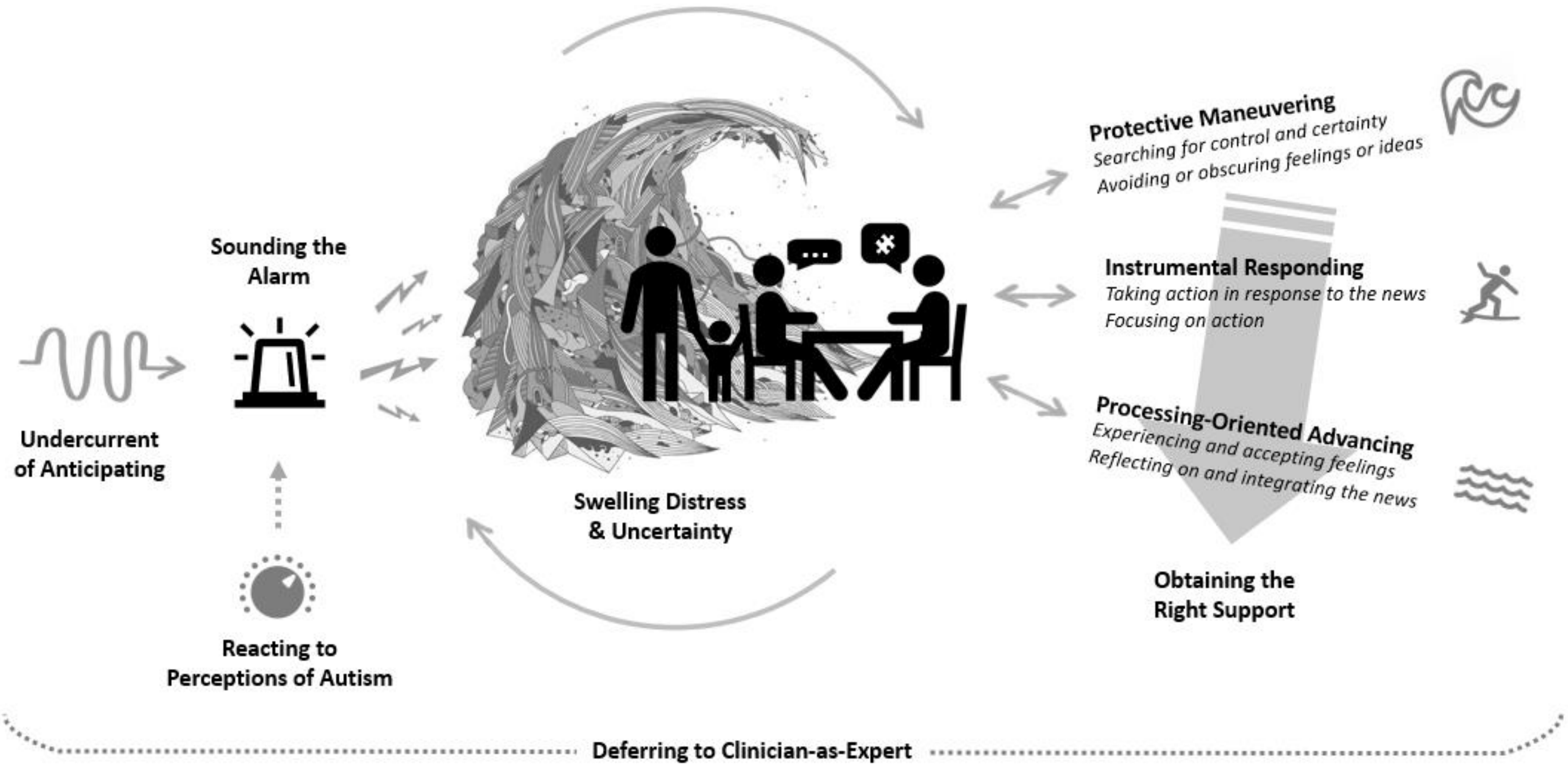

Figure 2. A grounded theory of parents' journey through diagnostic feedback for autism.

Table 8.

Summary of Categories under the Core Category of Protecting Myself and My Child.

Category	**Subcategory**
Undercurrent of anticipating	Knowing something is different with my child Using alternate explanations Fighting for concerns to be heard
Sounding the alarm	Hearing is the flash point Going into shock Experiencing release that the alarm is real
Swelling distress and uncertainty	Swelling distress for myself and my child Being engulfed in new uncertainty
Protective maneuvering	Doubting the assessment or results Pushing away the implications of autism Avoiding thinking, feeling, talking about it Blaming self or co-parent
Instrumental responding	Focusing on action to protect Taking action to protect
Processing-oriented advancing	Accepting emotions and unknowns Moving toward accepting autism Reflecting on my child and autism
Reacting to perceptions of autism	Reacting to autism as unfavourable Reacting to autism as comfortable
Obtaining the right support	Valuing emotional support from the clinician Valuing connections with others who ‘get it’
Deferring to clinician-as-expert	Following clinician’s lead Quieting appeals for emotional support

4.3 Exposition of Categories

In this section, I provide an in-depth explanation of the categories I identified in the analysis, weaving data from parents' stories and quotes to enrich and contextualize my findings. Density in explanation helps to account for variation and increase the trustworthiness of results (Corbin & Strauss, 2015). In Table 8, I offer a list of all the subcategories and categories I identified under my core category, *protecting myself and my child.* A list sacrifices the ability to convey the relationships between categories (an essential feature of any grounded theory or critical realist account), but it is an effective means of condensing information.

4.3.1 Undercurrent of Anticipating

Parents arrive to the feedback meeting from various pathways and with various perspectives on their child's difficulties; however, what is consistent across families is that this event is not the start of their journey. The category *undercurrent of anticipating* describes the time spent worrying and wondering about their child's development, which can stretch upwards of several years. All the participants in my study spoke about this disquieting period of anticipation. Sameer, a father of a school-aged child with autism, puts it thus:

> "And you're basically waiting. And you've been waiting. So, although it seems like you've been waiting for three appointments for this diagnosis, you've actually been waiting for two years for this diagnosis. And you've been through speech and language therapy. You've been to everything. You've talked to other people. You've seen other kids. You've done the whole bit. So, we've been waiting for two years for this."

For many parents, there is a strong feeling that their child's differences need to be figured out, but they are unsure what the 'figured out' will be. Sameer, for example, reported not feeling prepared for his son to be diagnosed with autism. When I interviewed him, he was still struggling to absorb the news and was not quite sure that he believed the results of the assessment. He had been waiting for two years for an answer – but waiting can provoke anxiety over equanimity.

I decided on the word *undercurrent* as it evokes a sense of dynamic movement beneath the surface – the anticipatory anxiety flows beneath the surface of parents' everyday life, and its strength can wax and wane. This category is made up of three subcategories: *knowing something is different with my child, using alternate explanations,* and *fighting for concerns to be heard.* The first subcategory was present across all study participants, while only some parents engaged in *using alternate explanations* and *fighting for concerns to be heard*.

4.3.1.1 Knowing Something is Different with My Child

A key part of the *undercurrent of anticipating* for parents is *knowing something is different with their child.* Whether it is their first child or a later-born child, whether their child is a toddler or a grade-schooler, and whether they talk about it freely or avoid acknowledging it to others, parents have a sense that something is different. This came up consistently in all my interviews – parents shared, "I know that there is something wrong," "I knew that something was wrong," "I had a feeling that something was off." One mother described this *knowing* as a dependable gut instinct: "I think most parents know if their child is, not so much on the spectrum, but with personality -- I think it's really your gut instinct and you're never really wrong with it."

For some parents, the intuition that *something is different* is a diffuse feeling and not specific to concerns about autism. Below, three different parents describe how they recognized differences and delays in their child's development but were unsure how to make sense of them:

> "We just didn't know if he was just really terrible twos or if there was kind of something more going on than just he was having a speech delay and then tantruming a lot. So, we didn't really know what we were dealing with."

> "I did think about [autism], but then I was thinking maybe autism or maybe just like a learning delay. I wasn't sure. But I did think about it."

> "Well I guess I had just thought of the typical autistic child was the one who just kind of is alone and twiddles his hands or does repetitive activities and doesn't

> socialize at all, is kind of in his own world. So I thought – well I could see [my son] had problems with making friends, but he didn't have all those typical signs of autism – that made me think maybe he's got something else."

Other parents are tuned into autism well before they are referred for an assessment. Below, three different parents describe how the prospect of autism lingered in the back of their mind, in the shadows, and slowly came into focus:

> "[My son] was like, 'Do I have autism, mummy?' Because he was listening to some of the protestors that were outside [City Hall] about funding and stuff like that. So, I said, 'No,' but I kind of wasn't sure myself when I said it, so it's always been kind of in the back of my mind that this could be it."

> "Yes, I was worried. Yes. I think, I mean, he has, you know, aspects of other ASD-like signs and all that. Yes. I go through some of the items and I saw, you know, certain shadows."

> "Like in terms of the non-verbal. In terms of the tantrums. In terms of the non-socializing. In terms of like phasing out or-- I'm like, yeah. It was becoming more and more of a reality that this was going to be his diagnosis"

For many – but not all – parents, whether their child has autism has become a central question on their minds by the time they approach the feedback meeting. Service providers have often alerted parents that their child has signs of autism and that the assessment will be trying to figure out whether they meet criteria for the diagnosis. Below, three different parents describe, in hindsight, the outlook with which they arrived at the feedback meeting:

> "For me it was yes/no because I had done my own research and kind of researched some of the science of autism, the behaviours and stuff like that. So, for me it was, 'Okay, is this going to be what it is or is it possibly something else?'"

> "I know it. When I read about autism, all the characteristics, they have it […] so, I know that the diagnosis would be like that."

> "We went for the results -- I was, kind of, like prepared and expecting that that was going to be a yes, like, yes, he has autism."

A note that *knowing something is different* is an internal experience and does not necessarily imply that parents are sharing their intuition with others. For example, I interviewed a husband and wife who shared that they were anticipating that their son was going to be diagnosed with autism; however, they had not acknowledged this idea to anyone before the feedback meeting – including each other.

4.3.1.2 Using Alternate Explanations

The *undercurrent of anticipating* is not a comfortable position for parents, and *using alternate explanations* seems to be an action some parents take to try to ease their mind. Even though they *know that something is different with their child,* it is hard to fathom the prospect that it could be something pervasive and lifelong like autism. They very much want things to be okay for their child, and so they hold onto alternative explanations that allow for a future where their child is typically developing. Perhaps their child has a speech delay they will overcome soon, or their behaviours are simply quirky and will fade away, or they are spoiled, lazy, or unmotivated. Often, these explanations are appropriated from family, friends, or professionals:

> "We've heard people that say, 'You know what, my son had a speech delay,' or he did this, did that and then was talking and now he does… you know, it's just amazing, just normal. And I thought, okay, that's what's going to happen, he's just going to start talking and everything's going to be great."

> "I have always kind of felt… but again, I didn't want to, though. I didn't want to think that's what it was, so when the behavioural therapist says no we don't need to have him assessed, it's like okay good, great, I won't go there."

> "They just thought that he had behavioural issues that he had to deal with. A lot of the people thought he was just spoiled, so we give him everything and so when it comes to playing fair, he doesn't know how to play fair and he doesn't know how to give up things and he would just get angry at things that other kids wouldn't get angry at, because again he's just getting his way let's say. So, the aggression and all that stuff yes and all the little- like I said the hand flapping and the eye gazing, again you do so much research, you're like that could be related to lots of different things."

Parents are resourceful and able to generate alternate explanations themselves as well:

> “[His] dad didn't start talking until he was four. And his dad is a genius. Like, he's very, very smart. And he's an engineer and he's, like, one of the smartest - like he's one of the smartest graduating, but he didn't talk till he was four. So, I thought okay, maybe [my son]'s just super smart.”
>
> “But the only thing, he’s lazy. That’s why, lazy and stubbornness, the problem with him.”

As parents wrestle internally with their concerns, there is often reluctance to assume that these concerns are due to something that could mean lifelong challenges for their child. *Using alternate explanations* does not necessarily dispose of the worry or sense that something bigger is going on. Dayana, a mother of a school-aged son with autism, reflected that this seemed to be her husband’s experience:

> “Yeah, no, I think [my husband] knew in his heart of hearts that something was happening or not happening for [our son], but I think as a dad he never – you know, he was like, ‘Whatever you think, I’m good to go but I’m not going to – I’ll support you with whatever the findings are, but I think he’s fine as well.’”

Dayana’s husband aligned with the onlookers who wished to assure him and his family that their son would be fine. Parents *know something is different with their child,* and *using alternate explanations* appears to be one way they can manage this period of anticipation.

4.3.1.3 Fighting for Concerns to be Heard

Fighting for concerns to be heard is another action that parents take in response to the *undercurrent of anticipating.* In my sample, parents who did not engage in *using alternate explanations* were the ones who were *fighting for concerns to be heard.* In these cases, parents are rejecting the alternate explanations being offered by family, friends, and professionals due to a gut feeling that “there’s more to it than that.” It’s a tough position for parents, as they are insisting that something is wrong when they want that to not be the case. Below, a mother describes how she disagreed with her friends, family members, and husband regarding her concerns:

> “They were saying [my kid] was okay. And they said send him to daycare. Once he talks, he will talk and -- yeah, I said no, there's something wrong. Sometimes you feel good because it's, like oh, maybe I'm just paranoid that there's something wrong with my kid, but no.”

Other parents were *fighting for their concerns to be heard* by their family physician. In Ontario, the family physician is the gatekeeper for referrals for specialized assessments. Below, two different parents describe their efforts for their concerns to be taken seriously and acted upon by their child’s doctor:

> “For me, it was his formulation of his communication skills that I noticed right away. And so, I brought it up when he was three. And the doctor basically -- typical -- he's a boy. Because he can communicate, and he would -- he could stay relatively on topic, it wasn't easy to pinpoint unless you spent time with him, at that time. So, he could be seen as just, like, eccentric or quirky or whatever, but I was like, ‘No, there's more to it than that.’”

> “Like, [the pediatrician]'s got so many kids, like, she hardly has time to spend but then, although we will give her those milestone sheets, I doubt that she looked at it. […] Yes, we bring it forward and then it's, doctor, you know, like, these are the milestone points that he missed, and then no resources. We would like a developmental pediatrician to look into it. […] So, that's why I needed to see some more reference and then further, like, you know, I raised, you know, to see whether we can contact Holland Bloorview to do a, kind of, diagnosis this year, and that goes well, you know, and that's how we get the diagnosis.”

This fight was further complicated for parents of school-aged children, as it often meant trying to persuade professionals that other diagnoses their child had accumulated (e.g., Attention Deficit Hyperactivity Disorder (ADHD), Learning Disabilities), did not fully explain the challenges parents were seeing in their child.

> “But when I spoke with teachers and tutors and other family members, everyone seemed to think he was fine. So, I think after his diagnosis of ADHD and a learning disability and having a psychological assessment done through the school and getting the results back and still not feeling like that was quite right… it’s a mother’s gut, a mother’s feeling.”

> “Because definitely, the ADHD thing -- it was just I don’t know, it didn’t really fit a style. I mean she definitely has it but there's definitely more to her than the ADHD.”

During this period of anticipatory anxiety when parents are worrying and wondering about their child's differences, some parents have such a strong gut feeling that they are drawn to fight for their concerns to be heard. They struggle to be heard by family and friends as well as by professionals who are reluctant to concede that something more may be going on.

4.3.2 Sounding the Alarm

Parents have been anticipating some explanation for their child's differences for years, and the answer arrives abruptly when clinicians deliver the autism diagnosis. As one parent put it, "it's big, right? Like it's big to hear that about your child. The next category, *sounding the alarm,* describes parents' intrapsychic response to the news: parents sound an alarm, signalling potential danger to their child and their family. One mother described the experience as, "Like the fight or flight mode, that… right, like I'm under attack." She went on to explain,

> "[The doctor] gave me a lot of information during that meeting, and a lot of it was just like -- because my head was buzzing, and I was like, what, what, what, alarm bells going off and everything, so I'm sure there's a whole lot of stuff that I actually don't remember her saying."

Represented in Figure 2 by a siren, *sounding the alarm* is made up of three sub-categories: *hearing is the flash point, going into shock,* and *experiencing release that the alarm is real.*

4.3.1.1 Hearing is the Flash Point

Something that came across very clearly in my interviews with parents is that anticipating a diagnosis of autism is not the same as hearing a diagnosis of autism. The subcategory *hearing is the flash point* describes how it is the moment that the clinician delivers the verdict that sparks the *sounding of the alarm.* Parents proclaimed: "Knowing in your head and being told are two different things;" "Hearing it and believing that it might happen are like two different things;" "I'm expecting it but, of course, it's different when it's legal and on paper;" "So we went into there, the meeting, kind of knowing what she - what she was going to say. I just didn't know - that's where - we didn't know..."

Hearing is the flash point was a message that was repeated over and over. Even if parents had been anticipating and wondering about autism for years or *fighting for their concerns to be heard,* the pronouncement of the diagnosis ignited *sounding the alarm* and a new course of action-interaction. Below, a mother and a father (unrelated) describe how their expectations did not prepare them for the reality of the feedback meeting:

> "When she gave that one that [my son] is, in the back of my mind I have an idea that he will - she will answer that word - he will have autism. Before we went there I think I, there's a time that I thought that [my son] had it, so. But in reality, when [the clinician] told me, it's just like, you know, I'm just shocked."
>
> "We weren't prepared, just -- we weren't prepared, that's the reality. [...] I don't think anyone is really. It's like one of those things that you just, kind of, like -- you have an idea, but you're really never prepared."

Hearing the diagnosis of autism is a momentous event for parents. A father of a school-aged child with autism explained, "Even if we know that a child is having abnormal behaviour -- if somebody say 'autism,' it's a big thing for the parents." *Sounding the alarm* at this flash point is linked to *going into shock* and, for some parents, *experiencing release that the alarm is real.* These subcategories are described next.

4.3.1.2 Going into Shock

A dependable part of parents' alarm response is *going into shock*. Psychological shock refers to a strong surge in our emotional and physiological systems that leave us feeling stunned and temporarily unable to react, reflect, or otherwise organize ourselves (Koopman, Classen, Cardefia, & Spiegel, 1995). This is the experience I saw described in my participants' interviews. Indeed, shock was a word they frequently used to describe how they felt in response to the diagnosis: "I was really shocked to hear that she had autism." "I, yeah, I was shocked;" "I think I was stunned;" "It's a big shock;" "The result, that's a shock." I understand *going into shock* as a visceral experience, not mediated by the rational parts of our minds. Below, two different parents describe their reaction to hearing that their child has been diagnosed with autism:

> "Well, for me it was like -- I don't know, like, someone put, like, -- just dropped a -- like, a bucket of cold water over me, I mean. But then I was like I knew, like, within me it's, like, okay, kind of knew, knew, knew, but it's just hearing it."

> "I'm sure I said a bunch of stupid stuff after and that's okay 'cause sometimes people babble and whatnot. But yeah giving them time also just to sit there and be like okay -- silence and let them, yeah…"

The intensity of shock varied as a property of this category. For example, the mother I quoted last experienced a much milder and time-limited shock, while the mother I quoted immediately before described feeling hijacked by shock throughout the feedback meeting and beyond.

Another property of *going into shock* is a felt sense of being disconnected. Parents described the experience as a blur, as leaving without your head, as not being awake: "It's a bit of a blur because emotionally it was a shock, it was like a blow;" "Kind of leave without your head, when you leave there;" "I don't know, maybe they give you time to wake up from it all. But you're not awake until you have your child in the right track in the right program. You're not awake." A fundamental part of *going into shock* seems to be having difficulty processing new information. Below, four different parents describe the difficulty in processing what the clinician is saying following the pronouncement of autism:

> "Like, I just feel like after you get that news, like, even though going in I knew she was going to say that, it was just very hard for me to process anything else."

> "Because you listen, but the state we're at, you listen but you actually don't listen because it's something that you don't expect. Or - it's new. It's something totally new."

> "I don't know. It's a message that I think no matter how it gets delivered, you need a lot of time, because people are going to need to react to it. So, if you are going to deliver the message, I think they've got to be conscious about the fact that most of what they say for probably the next five minutes aren't going to be absorbed by the people when they're sharing the diagnosis."

> "Cause, you know, when you're listening to this, you hear certain things, and you kind of check out a little bit. And you start thinking about that thing that you just heard, and you kind of half miss some of the other stuff."

As these parents indicate, the clinician kept talking and sharing information after delivering the word autism in the feedback meeting. However, parents reliably struggled to stay present. As one mother stated, "it is a traumatic piece of information."

4.3.1.3 Experiencing Release that the Alarm is Real

Some degree of *going into shock* emerged consistently across my participants when *sounding the alarm*. A subset of parents, however, also *experienced release that the alarm is real.* The release was a concurrent flood of positive emotion linked with receiving an answer to stem the *undercurrent of anticipating.* There was a sense of relief that came after worrying and wondering for so long:

> "Like kind of like a bit crushing, like oh god. But at the same time there was -- half of me is relieved to know that there is something to blame […] there was absolutely a feeling of oh, okay."

> "You know you're always hoping that it's not. Part of me was like well it's good because finally you have an answer as to why my child is like this; on the other hand you're like wow…"

For parents that had been *fighting for their concerns to be heard,* a significant part of this release involved receiving validation that they are "not crazy". I can imagine that it is hard to feel settled when you *know something is different with your child,* but you are not sure what the threat is or how to protect your child – and others are telling you not to worry, there is nothing there. Below, three different parents describe the sense of relief that followed the confirmation that their concerns were valid:

> “So that's why when you have someone who says to you based on everything this is what we think, then you just go okay we're not crazy. We're not crazy 'cause everyone else thinks we're crazy. But we're not.”

> “It was emotional for me -- not because I didn't know what it was. It was emotional, because I felt like I'd been holding my breath for over a year and a half and nobody believed me. So, hearing the information was actually like, oh, my God, thank God, almost.”

> “Quite frankly depending on the parent they might just have said, “Okay, well then he’s fine.” And he’s not fine. So, when I did get the diagnosis, I was relieved. I wasn’t upset. It’s like, “I’m not crazy.”

For the subset of parents who *experience release that the alarm is real,* it is important to recognize that the alarm is still real. It does not seem that they avoid the *swelling distress and uncertainty* (described next) that flows as they respond to the alarm and try to protect themselves and their child. Their path just includes an inundation of relief following the *undercurrent of anticipating.*

4.3.3 Swelling Distress and Uncertainty

The next category in the psychological strata is *swelling distress and uncertainty.* When parents sound the alarm signaling threat to their child and family, the energy from the alarm is rapidly transferred into this turbulent and stormy mix of distress and uncertainty. One parent said succinctly, “Everything that comes, you know, it's just too much.” Another parent explained, “I think it's just more fear, because you don't know.” A third parent, speaking about his son, shared,

> “You kind of wonder like what's the rest of his life going to be like, given that he's got a permanent diagnosis that's going to follow him for whatever he does as he gets older. And I think all that you want is the best for your kids. And everyone has got this vision of how their kids will grow up and what they'll be able to do, and the first thing you start doing is questioning are they are going to be able to do that.”

I symbolized the category *swelling distress and uncertainty* with a wave made up of a mosaic of different objects and patterns. The parents who took part in the member checking process reported that the symbol of the wave resonated strongly with their experience as well as the stories they have heard from other parents. As one of these parents shared, the mosaic is a good fit as “there is so much in that wave, it’s not just one thing or one worry”. Further, the wave implies dynamic movement – waves come and go and swell bigger and smaller. When you’re in the water, small waves may feel manageable, but the big waves can grow so ominous that it seems like they are hanging overhead, waiting to wash you away. Represented by the wave, this category is made up of two closely related subcategories: *swelling distress for myself and my child* and *being engulfed in new uncertainty*.

4.3.3.1 Swelling Distress for Myself and My Child

The subcategory *swelling distress* represents the inchoate pain that parents experience in response to the alarm. I chose the amorphous term ‘distress’ to capture the various dimensions of expression: emotional, cognitive, behavioural, and somatic. Below, five different parents share their feelings of swelling distress in the time following the feedback meeting:

> “When you're in this parent moment of – you're agitated, you're frustrated, you're angry, and then you wait. It's like – oh, a ton – a ton of bricks on your shoulders.”
>
> “So, it’s just a lot of little things – just, very overwhelming. So, then, I get sad. I'm not going to lie to you. Yeah. It gets really rough sometimes.”
>
> “Like at night I couldn’t sleep, especially when I heard the news. I can’t help but cry.”
>
> “That span of, sort of, six weeks I would say was not a very good time, it was really emotionally turbulent and really upsetting, and the kids were upset because we were upset.”
>
> “This is going to be hard. There's -- it was almost like there's so much hardship ahead of you kind of feeling. Like, I don't – I can't deal with that.”

These parents speak to their distress using words like emotionally turbulent, overwhelming, upsetting, sad, agitated, rough, and hardship. For some parents, the distress can be so intense that it feels incapacitating. Below, a mother describes her sense of devastation following the feedback meeting:

> “I was very angry with myself. With God. With everything. I said, why me? Why does she have to have this diagnosis? Why is she going to go through this, right? I was very sad about it. I don't know, I guess I was devastated. Like, everything was just a negative for me. I was feeling very low. I was not happy at all for months. Every time I'd think about it, I would just tear up. On that particular day when she actually told me straight up, I don't think I spoke to anyone that day. I was just upset that when I came home, I didn't eat, I didn't sleep that night.”

Many parents also focus on their child when they speak to their distress. Meena, the mother of a school-aged boy with autism, shared,

> “I felt… I was very sad for my child that now he has to deal with this, like this is something that he's going to have to deal with for the rest of his life. I mean, he was already dealing with this, it's not like putting a name to it makes it any different, but at the same time – I don’t know… You never want to put your child in that category, it's terrible […] Anyways the emotions were… I was crying not for me, I was crying because my child had this thing.”

Parents, quite naturally, are driven to protect their children. Meena is an example of a parent who centres her distress on the thought of her child struggling. Distress for herself and her husband is secondary. Meena continues,

> “I think the first thing was I was sad for my child – it wasn’t about me. It was about, well, you don’t want your child to have any difficulties in life, like you give everything to your child, so anytime that this challenge presented to them, it's like you don’t want that for them. So, I think that was the first thing, I was literally so sad […] and then I thought a little bit about what that meant for us, like oh…”

Another mother echoes this sentiment regarding her son:

> “I think it was more of just like I was -- are things going to be hard for him? Like it wasn't about are things going to be hard for us. It was like I don't want him to struggle. Like I just want him to have -- not that he wouldn't have a wonderful life, but would he struggle? Like would he feel like he fits in? Would he feel all of those things? And I think that was kind of probably the -- like I can't -- there's a bit of a fog.”

Distress centered on their child was one of the most common topics that prompted tears (spilt or welling up) from mothers and fathers during the interview process. Below, two different parents express their swelling distress for their child following the diagnosis:

> "I have this fear where it's like, okay, maybe she's not going to go to school. So now I'm just stressing out about working because I want to make sure I make enough money so that just in case she can't work she's going to be okay. Like, after I die – like, I'm thinking about all these things, right? Because I just want to make sure everything's set up for her so that if I do die, or like something happens to me and I can't work, at least she can, like, survive.

> "Oh, it was like – because I'm crying at that time, like when I heard it. I'm crying and – that [my son] had it. We just thought it – he was just delayed like in talking and everything, so. As a mom, I thought he's a normal, he's perfect, so there's nothing wrong with him […] like I love my kid, I love, like I love my family, I want my family to be perfect – like all my dreams for my kids, especially now, like crushed."

The intensity of distress experienced by parents is variable based on their context, just as waves in the ocean can be big or small depending on a number of interrelated conditions. However, for many parents, their distress was alive and palpable at the time of the interview, as I witnessed in the weight of their words as well as their tears. Theresa and Reza, parents of a preschooler with autism, describe the process of anticipating-but-not-anticipating autism, followed by their swelling distress:

> *Theresa begins,* "I knew, like, within me it's, like, okay, kind of knew, knew, knew but it's just hearing it. For me, it was just like… because you always want not to have any problems, right, or anything--" *Theresa is overcome with emotion and struggles to keep talking. Reza finishes the thought,* "We just want the best for him. We don't want him to struggle."

Parents' swelling distress is wrapped up together and occurs simultaneously with swelling uncertainty. Alliyah, a mother of a preschooler with autism, appeared stoic throughout our interview – until she began speaking about her worries for her daughter's future. At that point, she struggled to respond to my questions and maintain her composure. After a few minutes and a few tears, she was able to share,

> "Knowing that she has autism it's like, okay, well maybe she's not going to have a boy - like, reality. You know. So maybe she won't ever have a boyfriend, and maybe, like, she won't go to university and then maybe she'll be that girl that no one wants to talk to at school. You know what I mean? I just worry about the future, whereas before I was just more excited about it. I was planning it. Now I'm, like, worried and I'm - it's planning but it's, like, making sure that everything is set."

The distress and uncertainty are intertwined with each other and a drive to protect their family.

4.3.3.2 Being Engulfed in New Uncertainty

Sounding the alarm unleashes a new breed of uncertainty for parents. During the period of anticipating, uncertainty was focused on whether anything – and if anything, what – is different with their child. Getting an answer provides no refuge. Instead, parents seem to tumble down a much deeper rabbit hole of uncertainty. Jayson, a father of a preschooler with autism, describes it thus,

> "Now what do we do, and how is it, and what's going to be… how are our lives going to be with him and how is he going to develop? It was just, like, a big blank. […] So, you just start questioning everything."

This uncertainty is not limited to parents who are unacquainted with autism. Hannah, a mother with plenty of firsthand experience with autistic people, asks herself,

> "Okay, what does this mean? What am I going to do? What does it mean for me, what does it mean for my child, what does it mean for our life? Is it going to change? […] Like what is it going to mean for his life? Is he going to get treated differently? How are his friends going to respond as he grows?"

Hannah understands, "there's no 'this is autism.' There's this is autism, that's autism, there's so many different things," and so many unanswerable questions. Jayson, Hannah, and a chorus of other voices speak to being enveloped in a "big blank" of new uncertainty regarding the future.

The swelling of uncertainty entails questioning things that were previously taken for granted. For example, in the first years of their child's life, parents had not wondered whether their child will ever live independently. Now, as the alarm blasts, they lose their footing and the safety to rely on their previous assumptions about their child and family's trajectory. Below, four different parents share their swelling uncertainty, each unprompted by me (as my mind was far from the concept of uncertainty at the time):

> "[The diagnosis] meant to me that she wouldn't be able to live normally like the other two girls. Like, is she ever going to be able to go to school? Is she going to be able to do without me? Am I gonna have to always be there with her? I mean, is she going to be able to grow up, get a job, married, or have kids? Or, just like, what's gonna happen to

> her? Is she is going to be in a home if I die? Like, I thought about a bunch of different stuff."

> "Are they going to be independent? Are they going to live by themselves? Like, I'm also asking will they improve in the years to come. Because I always keep on asking, so what would be the future?"

> "Like how can [my son] achieve his dreams and go to school or whatever? How can he, of course, I want him to be, when he grow up, to have fun, to have kids. I'm thinking his future, I'm thinking what about all the – his sister, like how can she, how can he live, how can he live? That's all my questions."

> "[My husband's] primary concerns are about [our daughter]'s future and so his questions for the doctor were things like can she have a normal life, can we expect mental illness down the road, can we expect super screw-ups? What can we expect? And of course, [the clinician] doesn't really have an answer, like, no one could really have a solid concrete answer to those questions."

As seen at the end of the last quote, parents acknowledged that no one could have the answers they were seeking. Regardless, there was a sense of urgency, and many parents felt a strong need to ask the clinician about the future.

While a degree of uncomfortable uncertainty was ubiquitous, the intensity varied as a property of this category. Uncertainty is more acutely felt by parents who sound a louder alarm as well as parents with children who are in earlier developmental stages. A mother of a non- or pre-verbal preschooler asked, "Is he going to talk?", while her husband asked, "When he grows up, like how is he in school or how will he walk through the street, with cars?" This couple have many more developmental milestones to wonder about than a parent who receives a diagnosis of autism for their gregarious 9-year-old, so, it makes sense that their sense of uncertainty is heightened.

For some, the intensity of the uncertainty was almost all-consuming and remained so months later. I felt this in my interviews with parents where questions about the future seemed to fill their mind and attention no matter what subject we were discussing. One illustration of this is Christopher, a father of a toddler diagnosed with autism,

> "I was, kind of, oh no. Like, it was, kind of, awful. Like, I don't know how much time that I need to delegate, I need to give to him, because I'm the only one. Like, I'm working but then my wife is not because nobody is helping us and she's the only one that's taking care of the kid. […] Like, what do we expect? Is he going to have epilepsy? Is he going to have anxiety? What are the studies, you know, into teenage kids having autism and, you know, do you develop anxiety and what do we do?"

While Christopher's son is very young, questions about how to respond to anxiety in adolescence feel urgent – the list of unknowns are overwhelming. Christopher also links uncertainty with the pressures of planning and allotting limited resources for an unknown future. He continues,

> "And I know that this is only the beginning and I don't know how much is coming down, like, for us, you know, down the road. I mean, it could have been a lot of time that we need to - I mean, it's both physically and financially as, kind of, potentially devastating to us. You know, like, do you know how much money that we will put in?"

For parents like Christopher, the *swell of new uncertainty* was the most prominent aspect of their interview.

4.3.4 Protective Maneuvering

Following the delivery of the diagnosis of autism, parents rapidly organize themselves to protect their family from a daunting and uncertain future. With their internal alarm bells signaling threat and the ensuing distress and uncertainty, parents engage in three main categories of responses, which I have labelled *protective maneuvering, instrumental responding,* and *processing-oriented advancing*. *Protective maneuvering* describes parents organizing themselves at the most rudimentary level of protection. It is made up of four subcategories: *doubting the assessment or results; pushing away the implications of autism; avoiding thinking, feeling, talking about it;* and *blaming self or co-parent.*

Almost all the parents in my sample engaged in at least some *protective maneuvering* in the aftermath of the news. For over half of my sample, the bulk of their responses fell into this category, and parents spent more time describing this category of responses than any other across all my interviews. It was clear that what I classified as *protective maneuvering* represented a common and important way that parents of managed their situation. I noticed that parents who experienced the news of autism as more threatening were the same parents who responded with more *protective maneuvering*. It seems as if the overwhelming degree of threat constrained parents' actions to this more rudimentary category of responding. Below, a mother articulates just how incapacitated she felt by her child's diagnosis:

> "I'll be honest. Like, with everything that I'm going through, personally. It's like I can't have… I can't have an autistic child. It's like I just can't. […] like, I don't know if I can f*cking handle it. Like I don't know if I can get a diagnosis. Like I'm wishing, that this is just -- like, it will go away. Like, I don't know what I'm going to do."

When things feel so overwhelming and threatening, it is hard to imagine calmly reflecting on and integrating the news. One mother described her initial response and refutation of the clinician's diagnosis as, "Like a barrier. You don't officially go with it because -- I didn't have any assumptions, anything like that. But it's, I guess, a defense mechanism in a way." I delve into the four subcategories of *protective maneuvering* next.

4.3.4.1 Doubting the Assessment or Results

The first subcategory of *protective maneuvering* is *doubting the assessment or results*. Hearing the clinician's verdict that their child has autism is "a big thing for the parents;" "it's big to hear that about your child." As one father offered, "maybe the permanence of it is what I was upset about." It makes sense that it would be challenging to take in the ramifications of an autism diagnosis. Alternatively, if the information was faulty – if your child maybe did not have autism – that would be an effective way of managing the alarm. There would be no need to go into overdrive to protect yourself and your child, if the threat is not real. Below, two parents describe their instinctive rejection of the diagnosis:

> "So, when I heard about it, my immediate thought was, like, that's not my son because that's not -- like that is not autism. Like that is not what I've seen."

> “I said to [the clinician] ‘He’s not like that. Those diagnoses that you told me, I don't agree.’ That’s why my husband, the only thing you can ask is us, because we know [our son] better than those psychologists, because they meet him only once. And this teacher too. That’s why I said to him ‘Those answers of that teacher, I don't agree.’”

Parents found themselves dissecting the assessment and struggling to have faith that it was a trustworthy process. A mother reported, “Well, I think for [my husband] it was -- he found it hard to accept that just this one interaction with [our son] was enough to make this diagnosis.” A father shared, “But to make a diagnosis that fast. It also felt like it was -- how you can get to something that quickly?” The same father went on to explain, “I felt myself feeling like I don't necessarily know if I agree with what a doctor who's spent a total of three hours.” Another parent ruminated on the clinician’s style and approach to the assessment:

> “You don’t know how to play with kids. You’re looking for symptoms. That’s my overwhelming feeling—was like you’re just interested in seeing a sickness. [...] So, technically on these questionnaires that I answered for [my daughter], I could have ticked the crazy box for me too, and for [my husband], and [my other child].“

A mother of a toddler agonized over the clinician’s disclosure that her son was younger than most children they had assessed. The mother shared, “Because then it's almost like, all right, so this is, like, based on what we're observing and then you don't really see kids this age either, so how, like, accurate is this?”

Parents who engaged in *doubting the assessment or result* in my sample were often preoccupied by their doubt, but it remained *doubt* rather than a conviction that their child did not have autism. Their doubt and their faith continued jockeying for position in the months following the feedback meeting:

> “Like I trust the medical profession and I'm really thankful that we have specialists that can help to evaluate and diagnose. But he's two years old, he's still developing. A three-hour session where you kind of get to experience the one extreme of his behaviour and not necessarily the -- a greater feeling about the boy. For a diagnosis which is somewhat interpretive by nature. Like I said, it's not a tumour. I just, I found it very difficult to take those findings and so quickly apply a label to someone that they carry

> permanently for the rest of their life. Not that I disagree with it. I just want to make that clear. It's not that I disagree with it. It's just it's very difficult to rationalize in the moment."

> "I kind of questioned it to be honest with you, because even though I was looking for that answer and I took him there thinking maybe it is, I'm like I don't know that he's-- […] I'm sure the assessment is done because they've developed it over you know many years and lots of research and that's why the assessment is done -- But really, I don't know that the assessment is that accurate, because even though she did all the things she was supposed to do, and she was lovely, because it's not in a real-world environment, it's you know behind one-way glass, it's with someone he doesn't know, it's not real -- I don't know, I don't think that it was that real."

> "It's just like, if you're going to give me that information, you have to be able to talk about the fact that you know my child. And it -- I was in no shape or form in denial. And neither was [my husband], once he was -- Once he was given the information, he was not in any kind of denial. But I think that that -- you fall into that trap with parents, especially if they fall higher on the spectrum, that you met my son for an hour and a half. I'm not quite sure that you know what you're talking about -- could very well be the reaction of a parent. And I know that I realized after the fact that I don't doubt he's autistic. It's not a question, but you're not giving me enough to hold on to."

I find the end of the last quote to be quite provocative: "you're not giving me enough to hold onto." It speaks to the idea that what the clinician needs to make a diagnosis of autism may not be the same as what a parent needs to take in a diagnosis of autism.

4.3.4.2 Pushing Away the Implications of Autism

The second subcategory of *protective maneuvering* is *pushing away the implications of autism.* I interpreted this category as working in the same vein as *doubting the assessment or results,* with a twist: it is not the diagnosis that is faulty, but it is the long-term implications of the diagnosis that are not that to be believed. If parents could persuade themselves of this fact, this would serve as an effective way of managing the alarm. At the end of my interviews, I routinely closed by asking parents what they hoped for in the future. One father answered with the following:

> "I hope that he will overcome this ASAP [as soon as possible], right. I mean, we don't want to have this lingering on for the rest of his life because that will impact through his

> personality and down the road and a host of other things, you know, his jobs, you know, his life, you know, later on through his life."

This quote came from a father who was relatively well-informed about autism. He had been anticipating the diagnosis and researching it extensively before his child's assessment. However, when he came face-to-face with the prospect of his son's autism, he *pushed away the implications* that autism is a lifespan diagnosis that affects a person's personality, job, and life.

Other parents indicated that the clinician played a role in facilitating them *pushing away the implications* of the diagnosis. They interpreted the clinician as reassuring them that their child's diagnosis was "non-significant" or "nothing". Below, a mother of a school-aged child shared:

> "I don't know if [the clinician] used the word mild. No, I think she was just trying to be encouraging in the sense that like you know it doesn't mean anything, like -- Not that it doesn't mean anything, but that for him again because he's such a bright child that he could outgrow it [...] But we didn't think at all that it was important to tell [the school] about the autism, because it was so mild -- I don't know if she ever used that word, that's in my head like mild and non-significant -- So, we didn't tell the school."

This quote is even more poignant when considered in context, as the mother reported that her son encountered tremendous social and behavioural difficulties at school – still, if the diagnosis "doesn't mean anything", then it is easier to dismiss the prospect of sharing the news with the school (who might have a different interpretation). Below, a mother of a preschooler shares the long-term outlook she is trying to hold onto for her daughter:

> "[The doctor] made me feel like it was nothing. Just, as long as you have the treatment, you'll be fine. That's how I felt. I don't know like, I should be feeling that way. But, that's what I'm -- I'm just, I have this treatment now. She's just like, well she is still very young. With early intervention she'll be fine. As long as she has intervention [...] I don't know if I'm thinking IBI's [intensive behavioural intervention] going to be something -- a miracle treatment or something. But, I feel like I'm just waiting for that treatment to kick in."

Pushing away the implications of autism appears to represent an implicit strategy to manage the turbulence that follows the delivery of the diagnosis. However, as with the other subcategories of *protective maneuvering,* it does not effectively quell the distress and uncertainty. As an illustration, all three parents quoted in this subsection remained ambivalent about the long-term implications of autism and agonized over the daunting and uncertain future for their family.

4.3.4.3 Avoiding Thinking, Feeling, Talking About it

The third subcategory of *protective maneuvering* is *avoiding thinking, feeling, talking about it.* This subcategory describes the approach of trying to manage the alarm, in part, by acting as if it is not there. One father who was fairly quiet throughout the interview (he took part with his wife, who led the conversation) commented, "Yeah, just we're not, I don't like to think about it." He went on to share, "I don't know about the medical condition. I don't talk to anyone else." I asked him if he thought this would change with time, and he said, "I don't want to believe now, and I don't want to think about it for now." Another father reflected that his focus and insistence that things will be just fine was, "a positive but actually sometimes can be a negative because I'm, kind of, brushing it underneath the carpet instead of saying, you know?"

Avoiding thinking, feeling, talking about it was a common response taken by fathers that I interviewed, as well as by fathers as described by their partners when they were not able to participate in the study. Below, two mothers depict their husbands' style of not talking about the diagnosis in the weeks and months following the feedback meeting:

> "[My husband] never even mentions it, like it's not even a part of the conversation."
>
> "[My husband] took it pretty well, I think so. I mean he went, 'Wonderful.' And I'm like, 'Are you that shocked?' He goes, 'Not really.' So, we didn't speak a lot. Like you said I explained the spectrum and stuff to him, but it wasn't something that we had this long ongoing conversation about."

This response style can have a polarizing effect on co-parents if one parent *avoids thinking, feeling, and talking about it* and the other does not. One father portrayed the contrary responses between him and his wife as, "She went into, like, boom-mode and I was, like, relax-mode." Below, a mother describes the painful sense of disconnection between her and her husband in the immediate aftermath of the feedback meeting:

> "I cried all the way home. And actually, it might have been nice to have had that conversation in front of [the clinician], now that I think about it, because I was crying all the way home. He got upset with me, because his attitude was 'We knew this was -- like, this is what we knew, so what the hell are you…' 'Cause he perceived my crying to be that I was upset; whereas I explained to him afterward, first of all, it's just a sign of emotion. And that was me and not him. But secondly, I explained to him it was because I had been fighting for this for so long that I felt validated, and it was kind of a release of something. So, I think, had we been sitting in front of some professionals and they'd asked us that question […] Because we're not looking for counselling, but it's such a traumatic -- it is a traumatic piece of information."

I heard similar stories from other couples in my study. In each case, it was the father who was *avoiding thinking, feeling, and talking about* the ramifications of the diagnosis. However, this subcategory represents a style of responding and was not limited to one gender. For example, Jolene, a mother of a preschooler, made several comments that demonstrated her tendency to minimize her emotional response to the news: "Let's not fuss and fume;" "Now's our time to be sad but this stops tonight, like we will always be sad about it but not self-indulgent about the whole thing;" and "You can't sort of wallow around." In some cases, co-parents joined together in *avoiding thinking, feeling, and talking* about the implications of the autism diagnosis, as illustrated by the quote below:

> "I was given a book by [the clinician] afterwards that I'd never finished, but I started reading it and [my husband's] like you got to stop reading that book, because I think it made it -- I don't want to say worse […] I think it also made me very anxious because I was like, 'Oh we talked about all the things in the future and the troubles that even adults have that, have this,' and so he's like I don't want you to become -- He's still the same kid, we're doing the right things, so I eventually put the book down. Yeah, I didn't want any more information at that point."

One feature of this subcategory is the practice of not sharing the diagnosis with other people. Parents in my sample reported, "I'm not sharing. I'm not ready;" "I am not planning yet to disclose the report, honestly. I don't want to." In the aftermath of the feedback meeting, many parents chose not to share the diagnosis with friends, their child's day care or school, or other professionals – at least not yet. A mother of a school-aged child with autism reported that this extended to not sharing the diagnosis with her son: “I think I also thought in that moment I'm not telling anybody, I'm not even telling [my son]. And to be honest with you, I haven't told him.” Below, three parents describe not feeling ready to talk about their child’s diagnosis:

> “Because my sister's boss, one of her bosses, I think her two kids have autism. So, she knows that her eldest has autism. So, when -- I don't know, but I haven't talked with her yet, because -- but she gave me her number and she said whenever I'm ready to talk with her, talk to me -- and every time I attempt to call her I hang up the phone. Because I'm not yet ready.”

> “Like there are groups on Facebook and stuff, but when you join the groups, it shows up like in everybody's newsfeed. Like, hey, [I] joined a group -- ‘Parents of Children with Autism’. So, I don't -- I feel like I don't want to join those groups because I'm not ready to like make this giant announcement”

> “For like a week or two it was like I can’t tell anybody about this, like I had to really get my head around it. Because there was -- absolutely there was a bit of shame, there was like a weird shame-y thing. What did I do to my kid? Did I do something wrong?”

Sharing the news is an act that would entail acknowledging the meanings the parent is making of the diagnosis and coming face-to-face with their distress and uncertainty. In many situations, it feels like too much. The last quote, above, also highlights the role of shame as a motivator for not sharing the diagnosis – the parent asks, “What did I do to my kid? Did I do something wrong?” This type of response is elaborated on next, under the subcategory *blaming self or co-parent*.

4.3.4.4 Blaming Self or Co-Parent

The fourth subcategory under *protective maneuvering* is *blaming self or co-parent.* This subcategory describes parents’ attributing their child’s autism to something they or the other parent did or did not do. A mother described her husband’s instinctive reaction to the news as, “‘Oh yeah, that’s my fault then. It’s all my fault.’” Below, two mothers describe how they became preoccupied with the sense that they were at fault for their child having autism:

> “But when the doctor told me like, well, I felt like – I felt guilty, I felt just guilt on my, I felt so guilty, because like I’ve been wrong -- but my pregnancy was very healthy […] I

> felt guilty, like I asked myself what I do wrong. Like I'm asking that, like why my child, I said I would be a nice person and I say everything."

> "But yeah, you do blame yourself as a parent. You did something wrong, for sure. […] And then – not deliberately – but the other partner starts to blame you too. Like, can you imagine you blame yourself and then on your shoulders you have the partner's blame? It's not okay."

Another aspect of *blaming self or co-parent* is attributing fault around how and when families received the news of their child's autism diagnosis. Below, two parents describe how they felt blamed by their co-parent around aspects of the assessment process:

> "My wife kind of threw it in my face a little bit that I was too relaxed. And that we could have taken care of this sooner if we had -- but she always say, 'Oh, you always kept saying he'll be fine, he'll be fine.' I said, 'Yeah, he'll be fine. Just, you know, I've talked to people, he'll be fine.' And she's like, 'Well, you know, I shouldn't have listened to you and you -- we could have already had him diagnosed earlier,' and already done this and already done that."

> "I don't know. I think I was frustrated with -- I just feel like her dad and me weren't on the same page and a lot of it was just, like, I think it was just the way it [the assessment] was done. Because her dad was upset that I - like, I just went to the doctor and told her everything that [my daughter]'s not doing. But a lot of the questions that she was asking, I'm not going to lie about it. And then when he went in for the two days he was just trying to tell the doctor, she could do this, she could do that."

It seems likely that the mother and father referred to in these excerpts were upset and directing their upset at their co-parent.

In my sample, participants engaged in *blaming* even when they knew on an intellectual level that parents do not cause autism. This action-interaction is not simply the result of misinformation – it is part of an attempt to manage in difficult circumstances. Blame can help to discharge discomfort; it can provide a sense of control and counter helplessness. One mother reflected on this explicitly: "I have to be honest. Like, there's -- sometimes it makes me feel okay if I'm blaming somebody. This is not right, but I'm blaming [my husband] a lot;" and another mother explained, "I mean I said to [the doctor] - and she said, there's nothing - it's not your fault. That she told me right away. She said please don't feel like that. But I said, you know, it goes helplessness with it. Because you don't know what to do."

4.3.5 Instrumental Responding

The next category is *instrumental responding*. As parents attempt to deal with their alarm signals and the ensuing distress and uncertainty, many organize themselves and orient toward taking action to protect their child. Taking action is like learning how to surf on the wave of distress and uncertainty: a parent can climb up on a surf board to stay afloat in the storm, and it can feel empowering to gain a sense of control in an otherwise uncontrollable situation. However, learning to surf is an intensive, challenging process, made more so when the waves are large and choppy. In the context of diagnostic feedback for autism, parents who take the path of *instrumental responding* must navigate their internal tumult as well as the bewildering unknowns of how to take effective action to protect their child. One father put it thus, "Now we know; now we can do something. So that I think for me was the most – empowering was what I felt, was like now we can finally do something;" while another father countered, "The helplessness wasn't from the diagnosis; the helplessness is the --- what to do next?" Both fathers here express a focus on doing, on a desire to take action to achieve some tangible goal. The category *instrumental responding* is made up of two closely related subcategories: *focusing on action to protect* and *taking action to protect*.

4.3.5.1 Focusing on Action to Protect

The subcategory *focusing on action to protect* describes how parents rapidly orient toward thinking about action. Below, a mother describes the shock of the diagnosis and how she responded with a desire to take action:

> "We are quite shocked with the results, but once it sinks in and we wanted to know what's next, this is where even -- and while I'm trying to sink in also, I just say, okay, what do I do next? I do not know what I do next."

Genevieve, the mother of a preschooler with autism expressed, “Okay, I need to help him and how I’m going to help him and -- yeah, for me that was it when I heard [autism].” Genevieve’s husband, Jun, used the analogy of being on a starting line:

> “When the information comes to you you’re just, like, still kind of thrown back and then you think, okay, now I have to really step it up and really, kind of, figure this thing out and see, let’s get informed [...] It’s almost like you, kind of, like -- you’re on the starting line, you’re waiting for someone to go and then, okay, now we know, now let’s like...”

In Jun’s analogy, I can imagine the clinician communicating the diagnosis of autism as the sound of the starting pistol, signaling him to hurtle forward. However, there is no visible race track, as partly reflected in how he trails off at the end of this sentence – it is hard for him to say exactly what he should do next. Many parents *focus on taking action* and want to be directed in what action to take: “I said, perfect. Where do we start? Right, what happens next?” “Yeah for me it was like, okay, where do we go now?” “Tell me exactly how this pertains to my child and what to do today.”

Parents’ focus on action is in the service of protecting themselves and their child. Feeling capable of taking action can help stabilize parents’ internal tumult and provide reassurance regarding their child’s well-being. Feeling incapable of taking action can leave parents deep in the turbulent and stormy mix of distress and uncertainty. Below, two parents describe their *focus on taking action* and how they felt stymied and disabled by the ambiguity over what steps to take:

> “I want to be able to [...] work hard to fix something, and I realize that this can’t be fixed like that. But yeah, yeah, my need to put things in place as quickly as possible so that he doesn’t have a harder time than necessary. [...] Let’s actually move, let’s get some action plan in place and let’s do whatever we can. But then we were completely stymied because we had to wait, and wait, and wait, and wait, and wait for that stupid report and to find out what I’m supposed to do.”

> “Having the knowledge empowers the parents to say, this is what you can do now, right? And I think it’s that sense of loss of direction, is very disabling for us. I mean, you're used to directing every aspect of your life, and now perhaps something major for your kid happens, and you're not really sure the direction that you take.”

4.3.5.2 Taking Action to Protect

The previous subcategory described parents' orientation toward action, while this subcategory captures parents' follow-through in the weeks and months following the feedback meeting. Parents described a variety of goal-oriented actions, such as accessing wait lists for services, contacting service providers to get more information, and trying to learn behavior management strategies from the internet. One parent shared, "As soon as I found out she had autism, I finally went out and got life insurance." Another parent shared that she contacted her son's school to share the news, "I just sent the email and said private and confidential, please do not share with anyone other than his teachers. And then I got an email back saying that they're going to be scheduling an IPRC [Identification, Placement, and Review Committee meeting] or something meeting, yeah."

As discussed in the earlier section on *undercurrent of anticipating,* some parents arrived to the feedback meeting with diffuse worries about their child's development, while others were honed in on the yes/no question of autism. In cases of the former, parents now *took action* by trying to learn more about autism. A mother shared, "I went, and I googled what autism was [...] I also went to Instagram and hashtagged autism to see what came up, to get a better understanding." A father shared, "When [the clinician] diagnosed him, I'm now reading about autism. That's why I get the app right now. I want to download eBooks to read more books about autism."

4.3.6 Processing-Oriented Advancing

A third way parents manage the swell of distress and uncertainty is through *processing-oriented advancing*. In contrast to the avoidance involved in *protective maneuvering,* here parents engage in experiential approach of their thoughts, feelings, and memories relating to the diagnosis. An oft-repeated word in my interviews with parents who took *processing-oriented* action was "okay" (e.g., I don't know, and it's okay; I'm upset, and it's okay; My child has autism, and it's okay) – they were making sense of their situation with a tone of acceptance. Below, a mother of a preschooler with autism describes her path from anxiously focusing on the uncertain future to becoming more grounded in the present:

> "But, I think it is just also -- like just it is a big unknown, right? But then I realized, like, you know what, my other kid's life is a big unknown too. Like I don't know what she's going to do or what she's going to be or where she's going to go to school. And when I started thinking about it like that, like, yeah, I don't know what he's going to be or where he's going to go to school, but I don't know that about her either. So, it really -- it became more of a, okay, let's slow a little bit and just take it one step at a time. And we'll worry about high school when we get to high school, and we'll worry about college when we get to college, and all of those kinds of steps. But at first it was just like – like, I have a tendency to like, okay, let's research the accessibility issues at George Brown College. Like what kind of options is he going to have when he's -- okay, he's three, right? Like let's just slow down."

Processing the diagnosis of autism is likely a lifelong journey for parents (see Nicholas et al., 2016), but in some conditions, parents like this mother are enabled to begin moving in this direction contemporaneous to the feedback meeting. *Processing-oriented advancing* is made up of three subcategories: *accepting emotions and unknowns*, *moving toward accepting the diagnosis*, and *reflecting on my child and autism*.

4.3.6.1 Accepting Emotions and Unknowns

The subcategory *accepting emotions and unknowns* describes parents coming to terms with their emotional reaction and the inevitable unknowns of their child's future. Parents who are *accepting emotions* self-validate that their feelings in response to the diagnosis – whatever they are – are understandable and okay. Below, a mother expresses her belief that feeling sad in response to the diagnosis is entirely acceptable:

> "Right and I would say it's okay to grieve. It's totally okay. […] And then you know you're not the first one. The Kleenex are there. I'm not the first parent who's going to cry. And that's the important thing. And I would tell parents you're not the only one."

My sample included parents who ranged across the spectrum of *accepting emotions,* as I interpreted based on how they responded to their emotional expression during my interviews. For example, some parents talked openly about feeling sad, while others insisted that they were not experiencing sadness as their eyes filled with tears. One mother sagely pointed out, "You would have to also deal with that, with your emotions. And, you know, okay, you need to have them in order for you to keep going on and just to have, like, your mind where it has to be."

Parents who are *accepting unknowns* are turning toward and reflecting on the unknown future without being swept away. Like the mother quoted in the introduction to this section, parents are acknowledging uncertainty while staying grounded in the present. Below, three different parents describe *accepting unknowns:*

> "I want to hear the therapists or the doctors telling me they're going to be okay, but the truth is it's not sure. But [the doctor] didn't give me an assurance that they're going to be okay. She told us that the future can only tell, but we're doing the best and we will reassess them."

> "As long as I'm able to provide the right resources for her and the right therapy, I think that it's -- it will be okay. Is it going to be perfect? I don't think so. But at least I will be equipped with tools and people to help her in any way I can."

> "[The diagnosis] means that I don't know how he's going to manage in school, but I think he'll be okay"

4.3.6.2 Moving Toward Accepting the Diagnosis

The subcategory *moving toward accepting the diagnosis* describes parents' process reflecting on and accepting the clinician's verdict that their child has autism. Below, a mother describes how she and her husband are in different places regarding accepting the diagnosis:

> "[My daughter] started in daycare. There's, like, a question where it's like, do you think - or, are there any, like, anything that we should know about with [my daughter], whatever-- and [her dad] got so mad at me that I put [autism] in there. Because he's just like, we don't - he doesn't want her to be labelled and he doesn't want her to be different. He just wants, you know, her to be like everybody else. But she's not, you know, and that's fine."

Notice how this mother pairs the acknowledgement that her child is different with the acceptance-oriented statement, “and that’s fine.” Developing acceptance seems to be a gradual process that occurs in increments. Below, three different parents reflect on how they are moving toward absorbing and accepting the news of the diagnosis:

> “I think the more I talk about it the more the acceptance is because, honestly, I'm not in the acceptance period yet. But I think the more I talk with somebody, I believe, to a professional that knows about this, the more I can accept it, earlier than I expected”

> “We’re still absorbing everything. With us, it’s only one son and he is the first born, so we expect him to be perfect, almost. But you know, science, we can’t explain it. We need, got to accept it, we just need to accept and love him that much and his sister, that’s all he needs right now, all our love and support.”

> “In my first reaction receiving the diagnosis -- I’m getting a second opinion because I see this report, it’s bullshit. And then I was like -- no, first of all, no, because there are things here that are absolutely accurate, and we know that, and that’s just -- I’m just being silly and in denial about that.”

In many ways, this subcategory is the antithesis of *doubting the assessment/results,* described under *protective maneuvering*.

4.3.6.3 Reflecting on My Child and Autism

The subcategory *reflecting on my child and autism* describes the actions-interactions of parents integrating the news of the diagnosis and making sense of what it means for their family. The diagnosis offers a new frame for parents to understand their child’s behaviour and needs. Below, three parents explain how they have come to new conclusions about how to communicate with their child and how to make sense of their child’s repetitive behaviour and social difficulties:

> “But I'm like, people need to know so that they understand, you know, why. And they need to know as well because then they know how to, like, speak with her because you can't speak to her the same way you would a kid who doesn't have autism. You know what I mean? Like, she has her own way.”

> "Another thing that he would do but we weren't, kind of, like -- I was always puzzled, it was always a question in mind, like, why is he rocking on the chair or is he -- he would, like, rock on, like, a -- we had, like, a bench and he would just, kind of, be rocking on it to the point he would start sweating. And we're kind of, like, oh, he's just bored, right, I'm thinking to myself but he's doing it a lot. And then now I've realized what it is, it's he's looking for an outlet."

> "He doesn't really say too much, but he is quite social sometimes but he's kind of nervous. So, I think he actually needs to be taught how to make friends, but I think once he is taught he'll do it. He kind of just doesn't know what to do, right?"

Some parents also begin drawing new conclusions about what it means to be autistic:

> "You see it as a disease. You don't see it as a condition. That's the problem as a parent. And I now try to see it as a condition and I try to find ways for her to -- be able to manage and maneuver with it for her life. […] Because it's a behaviour -- it's a mental state, the way the brain is programmed."

Along with reframing how they see their child and autism, another dimension of this subcategory is decentering the diagnosis. In relation to the three overarching categories of responding to their *swelling distress and uncertainty*, it is as if *protective maneuvering* is trying not to see autism, *instrumental responding* is seeing autism and taking action, and *processing-oriented advancing* is seeing autism but also seeing beyond it – parents are aware of the implications of the diagnosis but shift it away from the exclusive focus of their attention. One mother explained, "[Autism] gives me like sort of a glimmer into his mind but, at the same time, autism is so different with everyone that I'm going to have to find what works with him." At the end of my interview with this mother, she asked me to share the following message with other parents about receiving the diagnosis: "Let them know that it's not an ending to a story, it's the beginning for their child or their teen." Marissa, a mother of a preschooler with autism, initially felt devastated by the diagnosis but later processed it as "not the end of the world." Farah, a mother of a school-aged child with autism reflected:

> "So, it doesn't really change anything, you know? I'm not heartbroken about anything; he's the same person he was and he's maturing in his own way and we'll get through it […] If this is going to get him the help that he needs, then who cares what the label is?"

Farah went on to describes her new outlook on her son's future, one that acknowledges and accepts his social difficulties but also sees beyond that to a world of possibility and adaptation:

> "And eventually he'll have some friends. Maybe it'll be the Dungeons and Dragons friends; it won't be the friends from school, but he'll find a group of people that he can hang out with. That's from me, just find a group of people that understand you and get you and you'll be fine. That's what it's about, right?"

4.3.7 Reacting to Perceptions of Autism

The next category, *reacting to perceptions of autism* – as well as the final two categories – represent conditions that are part of the equation of explaining the commonalities and differences in experiences across parents. Two subcategories represent the polar dimensions of this category: on one end there is *reacting to autism as unfavourable* and on the other end is *reacting to autism as comfortable*. When parents *react to autism as unfavourable,* they interpret the diagnosis as a bigger threat to their child and family. Thus, they sound a louder alarm and, in turn, experience a more volatile swell of distress and uncertainty. When parents *react to autism as comfortable,* they interpret the diagnosis as less of a threat to their child and family. Thus, they sound a quieter alarm and, in turn, experience a calmer swell of distress and uncertainty. In the former case, parents are often paralyzed by the perceived danger and are impelled to engage in *protective maneuvering* to manage the distress. In the latter case, parents have more resources to engage in *processing-oriented advancing*.

Parents' *perceptions of autism* are informed by social and psychological mechanisms, such as the disabling stigma of others and the challenges people with autism encounter functioning in daily life. Parents are attuned and sensitive to how the world may respond to their child's new label:

> "There is still an unnecessary amount of stigma around a diagnosis with autism, right? People assume it's a cognitive disorder only whenever folks are diagnosed and don't necessarily understand there are social aspects that are tied in with it."

> "I don't think the world is ready for that yet because they're not educated enough, so I don't want him going up to people and saying, "Hi, my name is ____, and guess what? I have autism."

In my sample, the more firsthand experience a parent had with autism, the more they *reacted to autism as comfortable,* and vice versa. Below, Emma describes her early perceptions of autism and how it changed when her close friends' son was diagnosed with autism:

> "The understanding is that they can't be independent, that was my first understanding. Then I have friends here [in Canada], and this is where I knew, because we knew them before the kids got diagnosed with autism. So, we've heard of autism, so just a very shallow understanding of it. I thought, okay, the kids might not be able to function […] But then [their son is] making communication with us, it's like, oh, there's a lot of changes – you see the changes and it's like, okay. Well, I think that back home, we don't have the support, so the kid is so still dependent. And then I said, okay – and I knew that he's – their kids are smart kids. He loves numbers, you know, he spells long words at the age of, like, four, he spells the words, and so he loves numbers, and so he's very smart. And it's just that he's not able to – you know, to behave as normal around people, like, the social part of it."

In this excerpt, I hear how Emma began to shift from seeing autism as unfavourable toward seeing autism as comfortable. Due to her experience with her friend and her friend's son, Emma started making this shift years before her own child was diagnosed with autism. Next, I will describe the two subcategories of *reacting to perceptions of autism* in more depth.

4.3.7.1 Reacting to Autism as Unfavourable

Reacting to autism as unfavourable appears to be a driving force underneath *sounding the alarm* – this perception is signalling threat and the associated need to protect their family. One mother described her gut reaction to the news as: "I was like, oh my goodness, that's her life?" Most of the parents in my sample fell more toward this end of perceiving autism than the *comfortable* end. Below, three different parents candidly describe their reactions to autism as unfavourable:

> "Well, because I noticed, you know, autism is a very detrimental syndrome, you know, to a family […] I saw some autism examples, you know, in a subway car, and then, you know, outside, you know, the sign. They're just devastating, right?"

> "In the beginning the moderate to severe really hit home. It was like really, like, oh my God, like is my kid that bad? Right? Like that's what you get from that diagnosis. Like, oh my God, like my kid's like…I don't want to say the words to you, because it's so horrible."

> "So, there was absolutely a feeling of oh, okay, but, shit, my kid's life is ruined. That was the -- like oh no, it's ruined forever, it's just going to be awful, life is going to be terrible for her, oh no, like that feeling."

Other parents focused on how the nature of autism put their child at-risk of harm at the hands of others and society at large. In my sample, these parents often had some exposure to people with autism through friends or work. They described being worried about their children being treated differently, excluded, or bullied. One mother shared, "And then there was a – holy crap. I know what the world looks like for these kids. And I don't want this for my son." Another mother explained, "I'm fine with her being different, I just don't want her to be teased." Below, two parents reported being worried about the risks their children will face at school, in interactions with teachers and peers:

> "About her being singled out. Definitely. Maybe the teacher -- sometimes you're not an expert but they might determine, oh, [my daughter] won't be able to do that. Like, assumptions, and I don't want that."

> "I'd lost -- had particular -- had a situation with a student who was very high functioning, but horrible bullying going on. And that's where my head went immediately, so I was obsessed with how do I give my son the tools to not have that happen, because, particularly at that time, he was not communicating with us about his day when we asked him. And it terrified the crap out of me that my son could not relay what was happening during the day, because I was witnessing stuff at school. And knowing that that boy wasn't able - he was doing similar things."

4.3.7.2 Reacting to Autism as Comfortable

At the opposite end of *perceptions of autism* is *reacting to autism as comfortable.* Parents who *reacted to autism as comfortable* did not come across as unmindful of the challenges or stigma associated with autism, but they spoke of autism with positive overtones. Below is an excerpt from Naomi, a mother who was very comfortable with autism:

> "The world we live in isn't the greatest to people with disabilities as it is. Hopefully that changes by the time he's older enough to know that he has different qualities than other kids."

Naomi went on to advocate:

> "A lot of people who know [my son] are like 'He's so normal' and I'm like 'You can't tell-' Normal is a watchword. There's no 'This is autism.' There's this is autism, that's autism, there's so many different things that come from it and so many different behaviours and so many different good things."

Parents like Naomi who see so many different good things about autism still engaged in the actions-interactions that were described in the previous categories. They still describe feeling stunned and *going into shock* when they receive the diagnosis. However, their comfort with autism seems to dial down the alarm and the ensuing distress and uncertainty. Below, two more parents demonstrate their comfort with autism:

> "But [my sister]'s like, "Oh, he's going to be labeled now." Like they just don't get it. [...] I don't know. I mean she must see it as a disability in a negative but not really understanding the diagnosis."

> "We're proud of our little kid, right, and we know autism is not something that you should shy from, right. It's a learning disorder, it doesn't mean that he's in any way incapacitated by it, you know. You know, this kid, if we take appropriate measures, is poised to contribute to the community, you know, better than we could, for all we care, right? [...] By knowing what the disease is, really, you know. Knowing that, you know, probably half of the people I work with have got autism spectrum disorder and they are very successful people, you know."

Only a subset of parents (6 out of 27) in my sample *reacted to autism as comfortable.* During analysis, I asked questions of my data regarding what set these parents apart from those who *reacted to autism as unfavourable.* The only consistent feature that I identified was that all these parents had significant firsthand experience with people with autism – for example, they had a sibling or child already diagnosed with autism:

> "But if we would have known [about my brother], we would have treated him differently. And things would have been different, so yeah that's why we're very aware of it with our kids. So, I started to see it differently then and then I started to teach at [school] and we

> had a lot of kids, but everybody would say oh that kid's definitely got high functioning autism."
>
> "I have friends that have ADHD. Some have been diagnosed with the [PDD-NOS[2]]. Yeah. I've been around people that have learning disabilities and different severities my whole life I guess."
>
> "This was round two for us [...] Like in the moment I remember we just looked at each other and we just smiled and went yep. Like that's exactly what we thought it was and so now it's been confirmed."

Amongst these parents, the more firsthand experience they had with autism, the more *they reacted to autism as comfortable*. The remaining parents – even those who were expecting an autism diagnosis, fought for their concerns to be heard, or had some cursory exposure to autism – reacted more in the direction of autism as unfavourable, and, in turn, interpreted the diagnosis as a bigger threat to their family. It seems that the lived experience of knowing people with autism is more powerful for changing perceptions than a more intellectual 'knowing about'.

4.3.8 Obtaining the Right Support

Whether a parent can *obtain the right support* is another condition that contributes to the variation in experiences across families. When parents are faced with the turbulent mix of distress and uncertainty following the delivery of the diagnosis, certain kinds of support become a powerful lifeline. The *right support* manifests from connections with people who are intimately familiar and comfortable with autism. It seems that these connections offer understanding and reassurance that calms the sense of overwhelming threat with which many parents grapple. When parents can *obtain the right support* and quiet their alarm signals, it facilitates a shift in responding away from *protective maneuvering* toward *processing-oriented advancing.*

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[2] Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) is a diagnosis that fell under the autism umbrella in the earlier editions of the DSM.

It is not just any emotional support or reassurance that holds the potential to allay parents' fears – it is when it is sensitively delivered by people who 'get' autism. This makes sense from the perspective that these are the people whose knowledge can be trusted. Imagine being on a ship with your family during a storm, and you notice that the deck is rapidly filling with water. You might start to panic and look for life jackets for your children who cannot swim. Your brother's or sister's reassurances that the ship will be just fine would do little to alleviate your concern – but the voice of the ship's crew who have weathered many storms might help calm your sense of alarm. *Obtaining the right support* is made up of two subcategories: *valuing emotional support from the clinician* and *valuing connections with others who 'get it'*.

4.3.8.1 Valuing Emotional Support from the Clinician

The clinician is well-positioned to offer support, as they are present during the pivotal diagnostic moment, are intimately familiar with autism and that child in particular, and they have witnessed many parents receiving diagnostic feedback. The first subcategory is *valuing emotional support from the clinician,* describing parents' desire to feel understood, to have their reactions accepted and normalized, and to receive reassurance from the clinician. Some parents obtain this kind of emotional support in the feedback meeting, and others are left feeling like something is missing. One mother described the value she placed on the interaction with the clinician as such: "I just want to know if the doctor cares and, like, she kind of understands how we feel. Because it means a lot. That is, like, you know, something that's going to stick." Another mother shared, "We were like, yeah, exactly that's how we feel. You know, this impacts [our son's] day-to-day life. We were really appreciative of having [our clinician] understand what we were going through."

Parents valued when the clinician made time in the feedback meeting to listen and attend to their reaction to the news. One mother shared,

> “Then when she told me that, it's like I'm melting down, so she had a break and she just listened and -- a good listener, and that's very important. A doctor should be a good listener [...] She listened, and she stopped talking. And she gave us a break. That action meant a lot.”

A father spoke highly of having “time to vent” during the feedback meeting, and another mother reported that she was only able to cry in the feedback meeting because the clinician paused and gave her time to process the news. Parents were affected by and grateful for authentic connections with their clinician, in cases where they felt cared for and treated with dignity. Below, four different parents describe how meaningful this was to them:

> “So, I felt that she was very nurturing, very kind and generally interested in the welfare of my child. It was great! And it’s not very often that happens.”

> “We're very lucky to have her as [our daughter]'s doctor actually. She could very closely relate to us. This was much on a deeper level connection. That I never experienced before. So. We're thankful for that. Really are.”

> “I know the parents have lots of questions lots of times and millions of questions and – [the clinician was] very patiently answering. Even if there's no ‘answer’ sometimes -- it's like, you know, out of nowhere you are asking, but just make them feel that you're entertaining everything that the parents ask. It's a big -- yeah. It's a big hell for the parents as well. It's like you don't feel ignored.”

> “Yeah. Like we actually left there saying, okay, it's way later than we wanted it to be, like our son needs to go to bed, but we've gotten answers to the questions that were on our mind. We both felt like we had had a chance to speak, be heard, and also get responses. So, like I did appreciate that about the appointment. I didn't feel like we were just a ticket. Like you were in for 30 minutes and then here's your diagnosis, see you later.”

Another indication of the significance of emotional support during the feedback meeting is that parents yearned for it in its absence. One father, who did not find a space to express or process his reaction to the diagnosis, suggested that the clinician should, “Maybe ask the parents, “How do you feel about this?” Another mother echoed this sentiment, “Having been asked how we were feeling about it in that moment might have helped.” Below, three parents describe being disappointed in the tone of the interaction with their clinician:

> “She didn’t have any kind of -- I don’t want to say words of wisdom or sympathy – it wasn’t like ‘I do this with a lot of parents, I understand, and I know what you’re going through and it’s this or it’s that’ -- she didn’t -- She told me the trajectories but there wasn’t a lot of -- And that’s why maybe my husband should have been there to provide the emotional support.”

> “But even how they did it, it was very clinical and very detached. It wasn't -- You know, like, you can't expect everybody - someone who's so good at what they do sometimes isn't always the best person to communicate. That's the reality.”

> “Because it's a warm person who you know has – and this is going to be a really bad way of putting this – actually has feelings about what they're about to -- you know, they're connecting with you on it, as opposed to just, I'm here and I'm delivering this message to you. Okay. Did you get it? Great. You know what I mean? As opposed to, how are you feeling about it? How does it make you -- It could be that interaction, as well.”

One parent described the clinician’s delivery of the diagnosis as “wincing” and another as “apologetic” – both found this tone to be aversive. It seems that parents were not looking for a distant, dispassionate delivery or for expressions of sorrow. Instead, they valued a warm, personal connection to a clinician who was able to make space for and resonate with their situation.

4.3.8.2 Valuing Connections with Others who ‘Get It’

The second subcategory is *valuing connections with others who ‘get it,’* describing parents’ desire to have access to people who are intimately familiar with the world of autism. Ideally, this means connecting with another parent who has had the experience of raising a child with autism, as they can offer a very personal level of understanding, reassurance, or direction for next steps. Sometimes it means connecting with someone who has worked with children with autism, such as a specialized teacher – “[This teacher’s] been like my rock, our rock, throughout all of this. She's our go-to.” A mother explained, “Because I think that's the first thing you want to know is, like, other families that are going through it too. Because you just have so many questions.” A father suggested, “[The clinician] could connect the parents to some other parent who have the same child, so they can share the experience.”

Parents who had someone to reach out to tended to do so soon after receiving the communication of the diagnosis: “I called up my girlfriend right away. Her step-daughter is autistic;” “I did call my colleague first before I called [my husband]. I called him when I was in the parking lot -- my friend whose son has autism.” Below, three different parents describe the impact of connecting with others who ‘get it’:

> “I was connected with a mother whose son is nine. And honestly, like, the thing -- that's -- I learned along the way that parents are the ones you talk to, because they know more. I'm sorry. They know more. And the way they speak is more sincere. And they're in it, and they understand. You know, there's some things she said to me when I'm like, ‘And then I'm worried about this and this and this.’ She's like, ‘One step at a time. I did the same thing.’”

> “Immediately after we got – after we knew, we told them immediately that, you know … So, because it is nice to have someone who we can connect, yeah, and then knowing that they are also able to relate to how we feel. […] To have someone that we can reach out, so that helps a lot. And I felt that they are – they’re comforting was really – you know, some people --- who is not there, they will comfort us --- okay, we don’t really, but with somebody who has gone through it, we know they really meant it and they know our frustration, know the feeling, the emotion we’re going through.”

> “It was helpful. So, a friend of mine who -- her son also recently had a diagnosis of ASD […] We connected and talked about -- like we just talked about the whole process. Like what was her experience, what was my experience, like what are we worried about, what -- like just some things that it was nice to have someone who really completely understands what you're talking. Like everyone else, people can understand your concern for your child, but they don't necessarily get it, right? Like that kind of difference in being in the same situation is good.”

Connections to these people are powerful, because “they’re in it” and can “relate to how we feel” and “really completely understand.” They are a source of comfort and help calm the swell of distress and uncertainty. In comparison, below, a mother describes how it is difficult to talk with her sister about her experience:

> “If at home, like with my sister, when we do, like before, like one, she’s asking me what happened to the workshop, what happened to doctor, check-up – so, I share to her and she’s -- just that’s it, she just, she don’t want to elaborate everything because I, she knows that I will cry, she does – so she doesn’t want to you know, go deeper in those issues.”

Parents *value connections to others who 'get it'*, but not all parents have access to people who meet this description.

4.3.9 Deferring to Clinician-as-Expert

The final category in my grounded theory is *deferring to clinician-as-expert*. This category describes some of the ways in which parents relate to clinicians in the context of diagnostic feedback. Whether arising primarily from ideology or interpersonal experience, *deferring to the clinician-as-expert* can be soothing and/or silencing. As one father put it, "We don't know because we're not the doctor." A mother who held strong and ambivalent feelings toward the clinician who assessed her child, drew the line at questioning the clinician's expertise: "We didn't question her diagnoses. And there's no way I'm going to question her." Another mother reflected on her needs during the feedback meeting, but dismissed the idea of the clinician meeting her needs as "not her role,"

> "She didn't provide a lot of emotional kind of consoling or anything like that. I don't know if everybody needs it, I'm pretty strong too, so I don't know that I necessarily need it, but maybe a little bit more time to kind of give me maybe reassurances -- I don't know what kind of reassurances you can even give to be honest with you, I don't know what I'm looking for, but I remember at the time thinking I needed someone to make me feel better right now and she didn't necessarily -- That's not her role, but that's, you know--"

Deferring to clinician-as-expert is a condition that constrains and enables parents' actions-interactions throughout the diagnostic journey. This category is made up of two subcategories: *following the clinician's lead* and *quieting appeals for emotional support.*

4.3.9.1 Following the Clinician's Lead

The first subcategory of *deferring to the clinician-as-expert* is *following the clinician's lead.* Irrespective of whether parents engaged in *protective maneuvering, instrumental responding,* and/or *processing-oriented advancing,* parents indicated that the clinician's verdict had weight and was – at least on an intellectual level – to be trusted. "[The clinician] is knowledgeable of what she says. And whatever she gave us, those ideas or those words, I know I trust her." Parents recognize the clinician as the expert in autism and seem to want them to own that authority when delivering the news. Below, two parents who struggled to process their children's diagnoses contend that the clinician must take the lead:

> "A lot of it is emotional too. It's how we feel, and I just feel like if you're going to diagnose someone it should be based on what the doctor sees and not, like, how the patient -- or how the family members feel."

> "But not to the point, like you're following the parent's instinct, because you know that parents are defending these [kids] but, you know, as the point of view as a doctor, as the one who knows better than the parent, so you know that the parent is wrong, so you just have to explain--"

Parents also *follow the clinician's lead* by allowing the clinician to structure the interaction in the feedback meeting. Parents perceive their part in the social script as one where they sit in rapt attention, rationally taking in what the clinician rationally explains. The clinician steers the conversation and has power over how long it lasts. Even narratively, we describe clinicians as *delivering* the diagnosis and parents as *receiving* the diagnosis. These verbs – which I have not been able to avoid using throughout this paper – construct clinicians as active and parents as passive in the interaction, even though parents respond, act, and make meaning throughout the process. Below, two parents explain their perspective that they should *follow the clinician's lead*, inhibiting impulses to direct the conversation or ask questions that may take up too much time:

> "Well sure, sure because you know she's the professional and she has her way of doing things, so I didn't want to, you know, step on her toes and say, 'Well I don't want you to do it this way, I want to do it this other way.'"

> "But definitely, I think I didn't take enough time and I'm a bad person like that, I don't want to take anybody's -- too much time, you know she's a doctor, she's busy, she had other patients to go to, I knew that I had a limited timeslot too. So -- I don't know why I knew that, but I knew she had another meeting or appointment with somebody else right after, somebody might even come into the room to say somebody was waiting -- I think that happened. So, I definitely didn't feel like I had enough opportunity to kind of think and then ask questions."

Below, another mother describes feeling at a loss when the clinician invited her to guide the information exchange by asking any questions she would like:

> "She was very nice, and she said, 'Do you have any questions,' right? But at the time honestly that, 'Do you have any questions?' I was like -- I'm like, okay, pretty much everything, like, right, so…"

Following the clinician's lead may be an example of joint action between parent, clinician, and ideological expectations, serving to help parents navigate through the tumult of the feedback meeting.

4.3.9.2 Quieting Appeals for Emotional Support

The second subcategory is *quieting appeals for emotional support.* Many parents interpret the 'expert' role of the clinician as precluding emotional discussion at the feedback meeting. The expert is there to deliver their expert opinion and knowledge, not to deal with the troublesome responses that arise when parents hear the news:

> "You know the doctor can just deliver the diagnostic criteria and maybe someone else is there that's there to provide the emotional support."

Part of the dynamic of *deferring to the clinician-as-expert* can involve muting distress, especially if there are no signals from the clinician that it would be welcome to express in the feedback meeting. Below, a mother describes how she avoided asking questions to better contain her feelings:

> "When she told us the diagnosis, I wanted to cry but I didn't. […] And that's why, like, with the doctor I didn't really want to say anything because I knew once I started talking that's it. So, I just kind of sat there and didn't really ask as many questions as her dad. But her dad is not emotional, so like, he was fine"

Something comes up for parents in their interactions with clinicians that leads them to *quiet appeals for emotional support.*

Next, I include a longer excerpt from my interview with Sofia and Caleb, a mother and father who go back and forth discussing their needs immediately following the communication of the diagnosis as well as their expectations regarding the role and capacity of the clinicians delivering the news:

> Sofia: So, I was just in this mode of, okay, I need to do something now. So, it was like -- but, you know, like, I noticed for my husband he was still a little bit, like, on denial, like, no. So, I just find, like, maybe to talk to someone before we leave that just -- other than the doctor, just even to give us, like, a pause and just, I don't know, help us, like, emotionally, like, you know? Okay, the doctor, not -- other than the doctor maybe that, okay, just were given the diagnosis, okay --
>
> Caleb: So, it's -- I guess for couples and sometimes maybe -- I'm not saying they have to be, like, a counsellor but at least maybe say, "You know what, just calm down, you're going to be fine," and for me, like, "Maybe you're a little too relaxed," I don't know.
>
> Sofia: Because sometimes, you know, I find maybe doctors they don't see more, like, the emotional part of it, more like, more -- I would say more objective. But in real life, like, you would have to also deal with that, with your emotions. And, you know, okay, you need to have them in order for you to keep going on and just to have, like, your mind where it has to be. So, yeah, that would be it for me. So, with the doctors sometimes -- not all the doctors they have, I find, that ability. Others they do but some others they don't, if they have their social skills are very [laughs] --
>
> Caleb: Well, maybe sometimes they deal with so many people that they have to put on that --
>
> Sofia: No, exactly, exactly, right?
>
> Caleb: They can't get emotional with every situation they deal with, so it's -- yeah.
>
> Sofia: You know, I agree. I agree.
>
> Caleb: Yeah.
>
> Sofia: But, yeah, that's why I think maybe someone else…

Sofia and Caleb perceive that the clinician's role is to be objective, an impassive authority informing them of their child's situation. However, they also identify a time-sensitive need for reassurance and help processing their emotions. Sofia and Caleb reflect that clinicians may not have the capacity to provide the help they needed, creating a deadlock.

Sofia and Caleb were not the only participants who came up with the solution that "someone else" could provide the emotional support they needed in the moment:

> “So maybe, I don’t know besides having a doctor there and maybe it's good to have somebody like a psychologist there who deals with kids -- Because I went home and again we didn’t do anything for a few weeks, like nothing happened until a social worker and even out of that meeting nothing happened. So, I think the emotional support would have been better and again I think you should come with your partner. That was stupid on my part not to come with my husband.”

> “Someone who's so good at what they do sometimes isn't always the best person to communicate. That's the reality […] the realities are that you're not talking to a machine; you're talking to two people about something that is the centre of their universe. And just from a purely empathetic standpoint, you want to present that information in the most effective and empathetic way. So, you need someone in there that has a bit more of that”

Quieting appeals for emotional support when *deferring to the clinician-as-expert* may hide some or most of parents’ turmoil from their clinician. While the participants focus on the clinician in the room, many structural and systemic challenges likely play into this action-interaction.

4.4 Quality of Findings

Having presented my grounded theory of the actions-interactions and conditions surrounding parents’ journey through diagnostic feedback for autism, this section will address the quality of findings. Research is the systematic investigation of our world for the purposes of generating knowledge; however, not all knowledge is created equal. Researchers must be able to demonstrate the quality of their work for our results to have merit. This is not a simple process – establishing and evaluating quality cannot be separated from our basic assumptions around what we can know and how we can know it (Morrow, 2005; Patton, 2002). For example, a positivist may try to demonstrate that there was a high degree of inter-rater reliability in her measurements while a constructivist may try to demonstrate that her results resonated with the meaning-making of her participants. Flipping these expectations would be incompatible with each researcher’s beliefs about the nature of reality and knowledge. The positivist scientific community expect to see evidence of validity, reliability, generalizability, and objectivity (Patton, 2002; Winter, 2000). In contrast, researchers who operate from a non-realist epistemological position – as I do – have written extensively on how to strengthen a study's rigour (e.g., Chiovitti & Piran, 2003), trustworthiness (e.g., Morrow, 2005), credibility (e.g., Tracy, 2010), resonance (e.g., Charmaz, 2014), applicability (e.g., Glaser & Strauss, 1967), and transferability (e.g., Lincoln & Guba, 1985).

In their grounded theory text, Corbin and Strauss (2015) provide a thought-provoking and evocative definition of quality:

> "Quality qualitative research is research that makes the reader, or listener, stand up and say things like 'wow,' 'I'm touched,' 'now I understand,' 'that has power,' 'I feel like I've walked in those participants' shoes,' 'there is so much depth in the study that it covers detail that I never knew about this subject and more,' 'this is something I can use in my practice, in my life.' In other words, quality qualitative research is research that resonates with readers' and participants' life experiences. It is research that is interesting, clear, logical, makes the reader think and want to read more. It is research that has substance, gives insight, shows sensitivity, and is not just a repeat of the "same old stuff" or something that might be read in a newspaper. It is research that blends conceptualization with sufficient descriptive detail to allow the reader to reach his or her own conclusions about the data and to judge the credibility of the researcher's data and analysis. It is research that is creative in its conceptualization but grounded in data. It is research that stimulates discussion and further research on a topic. In other words, it is research that is both scientific and creative." (p. 346-347)

Paired with this definition, Corbin and Strauss (2015) propose nine conditions of quality: methodological consistency, clarity of purpose, self-awareness, training in how to conduct qualitative research, sensitivity to participants and data, willingness to work hard, ability to connect with the creative self, methodological awareness, and a strong desire to do research. As I followed Corbin and Strauss' (2015) methodology, I applied their conditions of quality to strengthen the merits of my results. In Table 9, I summarize how I addressed each of these nine conditions during my study.

Table 9

Applying Corbin and Strauss' (2015) Conditions of Quality to the Current Study

Conditions of Quality	**Applications in the Current Study**
Methodological consistency	- I implemented the quintessential features of grounded theory (e.g., constant comparative analysis, developing concepts from the data, identifying a core category around which the theory is integrated, theoretical sampling, theoretical sufficiency, memoing, and diagramming) - I articulated the internal consistency between my theoretical paradigm, methodology, and the decisions I made while generating and analyzing my data
Clarity of purpose	- My intention was to develop a social-psychological conceptualization of parents' journey through diagnostic feedback for autism - I developed a theory that offers an explanation of how actions-interactions are related and the conditions under which events occur
Self-awareness	- I kept a research journal to record my thoughts, experiences, and responses to the research process to aid my self-analysis - My dissertation committee supported my critical assessment of the decisions made during data generation and analysis, helping me to reflect and question my tacit knowledge and assumptions - As I believe that we cannot objectively know reality, reflexivity was an essential component of my role as a researcher; I integrated examples of my reflections throughout my methods chapter as illustrations of my process
Training in how to conduct qualitative research	- Along with independent study and readings, I took two graduate-level courses in critical qualitative health research methodology through the University of Toronto and attended methodology workshops through the International Institute for Qualitative Health Research - I leveraged the expertise of my dissertation committee, who helped prepare me and guide me through data generation and analysis - I also benefitted from regular videoconference meetings with the Grounded Theory Club, a group of grounded theory researchers in Canada who provide peer consultation on methodological issues
Sensitivity to participants and data	- I felt sincere admiration for each of the parents that I interviewed in this study; my background working with families with children with autism helped me to build rapport and contextualize parents' stories, but I recognized that delving into their experience of receiving the

	diagnosis was unfamiliar territory for me – I approached my task with humility and curiosity - Throughout the various stages of coding and theory integration, I returned to the raw data – going back and reading through interviews to get a sense for how my abstractions fit with each case
Willingness to work hard	- I took this endeavour seriously and did not undervalue the amount of work that would be involved in learning and applying a new-to-me research approach (e.g., to improve my facility in thinking and talking about grounded theory and critical realism, I offered a series of workshops to my research lab and taught it to others) - I took on all aspects of study design, ethics approval, participant recruitment, interviewing, coding, and theory integration, to facilitate my immersion in the data
Ability to connect with the creative self	- Retroductive reasoning requires creativity and imagination, and I believe my grounded theory demonstrates this creativity as it offers new thinking about aspects of parents' journey through diagnostic feedback for autism
Methodological awareness	- I have framed chapter two, *Research Approach,* to demonstrate my understanding and application of both critical realism and grounded theory; I included illustrations in chapter three, *Methods,* to demonstrate my methodological reflections during the conduct of my study
Strong desire to do research	- I was driven to produce and disseminate rigorous research with clinical applications – to better myself as a clinician and researcher, and to develop new knowledge to influence wider clinical practice

When describing the quality of qualitative research, Whittemore et al. (2001) argue that, "Elegant and innovative thinking can be balanced with reasonable claims, presentation of evidence, and the critical application of methods" (p. 527). Throughout these chapters, I have attempted to provide sufficient indications of each.

Chapter 5
Discussion

In this final chapter, I summarize the main findings from this study and integrate them with the extant literature. Next, I consider some of the limitations of this study as well as directions for future research. Lastly, I explore the clinical implications of this work.

5.1 Summary of Main Findings

Receiving a diagnosis of autism is a pivotal event in parents' lives. However, parents' experiences of this event remain poorly understood and insufficiently attended to by clinicians and researchers. The objective of this study was to develop a social-psychological conceptualization of parents' journey through diagnostic feedback for autism. Corbin's grounded theory methodology, as interpreted through the lens of critical realism, provided the structure and guide for all aspects of the research process (see Corbin & Strauss, 2015, and Danermark et al., 2002). Theory development was anchored in data generated from in-depth interviews with parents as well as clinical record reviews, journaling, member checking, and peer debriefing. The primary source of data was interviews with 27 parents of young children who had been diagnosed with autism at a publicly-funded clinic in Toronto, Canada. I interviewed parents within six months of their diagnostic feedback meeting – the events were still vivid in their minds, and they had much to say about their experiences. Parents came from a wide range of sociocultural backgrounds, well-representing the diversity of the city from which I recruited. Their children with autism (ages 1-10) spanned the spectrum in terms of the DSM-5 levels of 'support needed' classification assigned by the clinician as well as parent's descriptions of their developmental stage (e.g., minimally verbal to highly verbal).

Through an iterative process of constant comparison and retroductive reasoning, I developed the grounded theory *protecting myself and my child*. The crux of the grounded theory is that parents rapidly make meaning of, feel, think, and respond to the news as signalling a threat from which they must protect their family. While parents have been worrying and wondering about what is different with their child for an extended period of time, hearing the diagnosis is the flash point for sounding the alarm. The surge of the alarm ignites a sense of shock and, for some, relief that their concerns have been heard and validated. Depending on the intensity of the alarm, parents have a corresponding swell of distress and uncertainty and rapidly organize to protect themselves and their child. Parents orient toward three different types of responses: protective maneuvering (i.e., turning away from the news by doubting, pushing away, avoiding acknowledging, or blaming), instrumental responding (i.e., focusing on or taking tangible action), and processing-oriented advancing (i.e., turning toward the news by reflecting, integrating, and accepting).

Although these actions-interactions are laid out in a linear fashion, this is an artefact of writing: the theory attempts to capture and explain dynamic shifts in the swelling and calming of the sense of alarm and distress as parents act to *protect themselves and their children* (see Figure 2 for a visual depiction). Processing-oriented advancing contributes to a calming of the sense of alarm and distress; instrumental responding helps parents keep their head above water; while protective maneuvering does little to attenuate the tumult. These response types are neither sequential nor mutually exclusive. Many parents engage in all three, and varying conditions constrain or enable their ability to respond in different ways. Three such conditions are identified in this theory.

One influential condition is parents' perceptions of autism. The act of diagnosis does not occur in a vacuum – the discourse of disability as well as firsthand experience with people with autism tempers parents' perceptions of autism. When parents perceive autism as unfavourable, they sound a louder alarm than when they perceive autism as comfortable. The more overwhelming the sense of threat, the more parents are constrained to try to handle their swell of distress and uncertainty with (the more rudimentary) approaches of protective maneuvering. The more manageable the sense of threat, the more parents are enabled to acknowledge and approach their (correspondingly smaller) swell of distress and uncertainty with processing-oriented advancing. Another condition that varies across parents is whether they obtain the right support from others. Parents value support from others who ‘get it’ (e.g., an attuned clinician or a colleague who has a child with autism) but only some have access to people who can offer this type of support. The experience of being understood and validated by others who get what they are going through helps create calm within the tumult, providing the safety for parents to move toward processing-oriented advancing. The final condition identified in this theory touches on how power relations between parents and clinicians influence the journey through diagnostic feedback. Conventionally, clinicians take on the role of structuring and setting the tone of the interaction, and parents follow their lead. Many parents interpret an unspoken expectation that their role during feedback is passive listener and that handling emotional expressions is outside of the role of the clinician. These social dynamics can occlude parents’ in-the-moment experience of receiving the news.

The tenets of a critical realism maintain that while we can never directly access an objective reality, we can use judgmental rationality to draw tentative and critical conclusions about how our world works. Thus, I approached the task of theory building with the recognition that the researcher is the primary instrument of analysis and acted accordingly. I applied Corbin and Strauss’ (2015) conditions of quality in qualitative research to strengthen the merits of my work. I reflected on and attempted to make explicit how my beliefs, values, experiences, and social position affected the conduct of the study. My dissertation committee supported my reflective process during study design, data generation, and analysis. Moreover, the processes of member checking and peer debriefing helped to refine the developing theory and fostered my confidence in the final results. Please see Appendix D for a set of supplemental results, where I have collated quotes from participants in response to the interview question, “What advice would you give a new clinician about how to deliver the news of a child’s diagnosis of autism?”

5.2 Integrating Findings with the Extant Literature

In this section, I situate my findings in the wider context of the extant literature. I focus on three different fields of research: (i) parents' experience of diagnostic feedback for autism and developmental disabilities; (ii) psychological responses to threat and distress, and (iii) validation and relational resilience. This literature served a variety of functions before, during, and after the analytic process. I drew on some of this literature for directions to explore as I generated data (i.e., sensitizing concepts), others for theoretical comparisons in the final stages of theory integration, and the remaining for post-hoc formulations of how the grounded theory *protecting myself and my child* fits with existing conceptualizations. This approach is consistent with the stance of critical realism, which argues that strong retroductive reasoning requires knowledge beyond what can be produced in a single study:

> "Nobody manages in a simple empirical investigation to collect the experience needed for a well-grounded retroduction. Naturally, it is important to collect, by well-reasoned choices, new material for one's procedure and to apply scientific methods in the data collecting. However, scientific method is at least equally concerned with what the researcher makes of her data and her experiences." (Danermark et al., 2002, p. 139)

While the literature played an essential role during the analytic process, its role was subordinate to that of the raw data. Theoretical comparisons followed rather than led the interpretation of data; the superseding consideration was always whether a concept fit with the data (Strauss & Corbin, 2015).

5.2.1 Diagnostic Feedback in Autism and Developmental Disabilities

The current study represents the first known attempt to develop a social-psychological conceptualization of parents' journey through diagnostic feedback for autism. Nonetheless, several studies of parents' experiences offer insights relevant to the results herein. Firstly, the themes described by Mulligan et al. (2012) and Abbott et al. (2012) resonate well with the present findings. All three studies have demonstrated that diagnostic feedback for autism is an emotionally-arousing and anxiety-provoking experience for parents. Mulligan et al. (2012) and Abbott et al. (2012) call attention to parents' difficulty absorbing and assimilating information when hearing the news of their child's diagnosis. The grounded theory *protecting myself and my child* offers a conceptual explanation for this finding: parents perceive the news as threatening and respond accordingly, sounding an alarm and experiencing shock. Although parents have been waiting, wondering, and worrying about their child's situation for a period of time, the delivery of the diagnosis serves as the flash point for igniting the sense of threat – since "knowing in your head and being told are two different things". The perception of threat impedes the assimilation of new information (this will be discussed in greater detail in the next section).

The present findings around how parents *defer to the clinician-as-expert* resonate with an earlier study by Avdi et al. (2000). Avdi et al. used discourse analysis to explore power in the parent-clinician relationship. As in the current study, the authors interviewed parents soon after they received a diagnosis of autism for their child. Avdi et al. (2000) frame modern diagnostic practice as pulled by the polar tensions of egalitarianism and authoritarianism (see Billig et al., 1988 for a description of the 'liberal expert'), and their aim was to analyze how parents construct expertise and authority in this paradoxical context. They found that parents' dialogue about their clinicians was ambivalent – they constructed their clinicians as friendly, supportive, and helpful as well as powerful, controlling, and potentially dangerous. Parents construed that they needed to be compliant and present as a 'good' parent to ensure they received the best care for their child. Avdi et al. (2000) contend that much of their findings can be understood at the ideological level rather than the intrapersonal level, for, no matter how well-intentioned and approachable a clinician may be, the authoritarianism of diagnostic practice will remain. The authors conclude that clinicians should be aware and reflective of the power that is inherent in their position. The current study supports this conclusion and suggests that part of this process is being thoughtful and responsive to the ways in which parents may follow the clinicians lead during diagnostic feedback and quiet appeals for emotional help.

Another study with related findings is Potter's (2016) thematic analysis of father's responses to a web-survey about the diagnosis of autism. Potter's main conclusion is that a child's diagnosis of autism profoundly impacts fathers. Likewise, the findings from this study indicate that the diagnosis of autism profoundly impacts parents – both mothers and fathers. Throughout the analytic process, I asked questions of the data around the role of gender and other demographic characteristics in the actions-interactions of diagnostic feedback. One query was whether fathers more readily engaged in *avoiding thinking, feeling, or talking about the diagnosis* when they had a strong alarm and distress response. As the current study did not centre a gender lens and other conditions appeared to contribute more to the variation in parents' experiences, I did not flesh out a clear answer to this question. However, it is something to be curious about. In a grounded theory of fathers of children with juvenile rheumatoid arthritis, McNeill (2004) theorized that fathers were deeply affected by their child's condition, but they tended to inhibit emotional self-expression due to a perceived need to be strong for others. In the current study, I wondered whether parents' proclivity to *avoid thinking, feeling, or talking about the diagnosis* could be related to a style of coping with distress that is influenced (but not determined) by gendered socialization. Irrespective, the present study supports that both mothers and fathers are greatly impacted by the news of their child's disability.

As detailed in chapter one, there has been limited work done to build a conceptual understanding of parents' experience of diagnostic feedback for autism. Regarding suppositions of researchers studying developmental disabilities more broadly (e.g., Cunningham & Davis 1985; Drotar et al., 1975; Emde & Brown, 1978; Kennedy, 1970), the current study provided some support for bereavement as a conceptual parallel. Aspects of *doubting the assessment or results, pushing away the implications of autism,* and a*voiding thinking, feeling, talking about it* could fit with the denial phase in Kubler-Ross' (1969) model of dealing with loss; *blaming self or co-parents* could fit with anger; *processing-oriented advancing* could fit with acceptance. Rather than the loss of the wished-for child, parents in this study seemed to speak to a loss of 'normative' certainty that most major life milestones will be met.

Lalor et al.'s (2012) grounded theory of parents' experiences of antenatal diagnosis of fetal abnormality may be the most pertinent to the current study, even though the nature and timing of the diagnosis is relatively dissimilar. Lalor et al. (2012) suggest that parents avoid or seek information about the fetal abnormality as a way of coping with the news. It was only upon rereading this study at the end of the current project that I noticed that these authors link their results with Lazarus and Cohen's (1977) work on two styles of responding to perceived threat: blunting (linked with information-avoiding) and monitoring (linked with information-seeking). Conceptualizing parents' responses as related to perceived threat strongly resonates with the core process identified in the current study. In the grounded theory *protecting myself and my child,* the action-interactions of *protective maneuvering, instrumental responding,* and *processing-oriented advancing* are interpreted as responses to the sounding of the alarm and ensuing swell of distress and uncertainty.

5.2.2 Psychological Responses to Threat and Distress

In this section, I integrate the grounded theory *protecting myself and my chid* with the related literature on psychological responses to threat and distress. It is well-acknowledged that when we evaluate something as threatening, we experience a strong surge in our emotional and physiological systems that is meant to prepare us to act to keep ourselves safe (Hellhammer et al., 2009; McEwen, 1998; Ursin & Eriksen, 2004; van der Kolk, 2006). Part of this wired-in response is a reduction in our higher-order cognitive functioning, language facilities, and awareness of our surroundings (de Kloet, Joëls, & Holsboer, 2005; Elzinga & Roelofs, 2005; Koopman et al., 1995; Schoofs, Preuss, & Wolf, 2008). The evolutionary understanding is that when we are facing a saber-tooth tiger, for example, our survival depends on our quick escape rather than our thoughtful reflections on the nature of predator-prey relationships. Commonly known as the fight-flight-freeze response, the limbic system in our brain temporarily hijacks us, leaving us with a sense of being in a daze. The current grounded theory proposes that this is part of the process that occurs when parents hear the news that their child has autism. Parents *sound an alarm* as they perceive that there is a need to *protect themselves and their child.* This seems to launch their mind and body into something akin to the fight-flight-freeze response, making it exceedingly difficult to take in, understand, and remember complex information or reflect on their in-the-moment experience.

The intensity of our psychological response to threat depends on several conditions, including our perception of the degree of danger – the greater our perception of threat, the greater the intensity of our response (van der Kolk, 2006). Fonseca, Nazare, and Canavarro (2013) demonstrated this relationship in their study of the disclosure of a diagnosis of perinatal congenital anomaly: parents who perceived the diagnosis as more threatening experienced higher-intensity emotional reactions. I observed an analogous pattern in the current study. Some parents responded to the news of their child's diagnosis with an intense sense of alarm and shock, followed by a strong swell of uncertainty and distress. Other parents responded with a more nominal and manageable sense of shock. What seemed to differentiate the intensity of parents' responses was the degree to which they perceived autism as unfavourable or comfortable. This makes sense, as perceiving autism as unfavourable would contribute to a greater sense of threat – the situation seems more formidable. Our psychological response is based on our perception of threat rather than an objective truth, and different people perceive situations differently. When parents spoke of autism as unfavourable, they spoke of something unfamiliar and ominous, of the disabling effects of stigma, and of the difficulties with function associated with the diagnosis. In contrast, parents who were intimately familiar with autism tended to perceive it with more confidence and comfort and, in turn, they responded with a less intense sense of alarm and shock.

The current grounded theory proposes that parents respond to the *sounding of the alarm* and *swelling distress and uncertainty* with three types of actions-interactions: *protective maneuvering, instrumental responding,* and *processing-oriented advancing.* The literature on psychological responses to threat and distress offers insights relevant to the nature and consequences of these actions-interactions. First, *instrumental responding* represents parents' orientation toward taking action to protect their family. The importance of being able to "do something" in response to the news permeated my interviews with parents. Taking action likely fosters a sense of control in a situation that is otherwise out of their control, and a sense of control contributes to positive outcomes such as optimism, persistence, and coping (see Skinner, 1996). Likewise, facing a threatening situation but being unable to take action leads to worse psychological outcomes (van der Kolk, 2006, 2014). Van der Kolk, a renowned trauma researcher, contends that it is the experience of being immobilized in the face of threat that produces a trauma response. Being able to "do something" to protect ourselves has a resounding impact on our well-being. In the context of the current study, this would suggest that parents who are able to undertake *instrumental responding* are better able to 'surf' the swell of distress and uncertainty.

Next, I integrate the literature on psychological responses to threat and distress with the nature and consequences of *protective maneuvering. Protective maneuvering* and its subcategories – *doubting the assessment or results; pushing away the implications of autism; avoiding thinking, feeling, talking about it;* and *blaming self or co-parent* – represent actions-interactions of parents disengaging from the news that their child has autism. Disengaging is a common part of our psychological response to threat, understood as an attempt to eschew painful thoughts and feelings while we get through whatever circumstance we are in (Koopman et al., 1995). This psychological process is referred to by several names in the literature, such as experiential avoidance (Hayes et al., 1994; Hayes, Wilson, Gifford, Follette, & Strohsahl, 1996), emotion avoidance (Ford, Lam, John, & Mauss, 2017; Greenberg, 2008), or numbing (van der Kolk, 2006, 2014). Just like the fight-flight-freeze response, this type of response can be adaptive for brief periods of time when we are handling intense stress. However, when we depend upon it as a longer-term or inflexible strategy, it can become more problematic than helpful. Trying to avoid our distress can interfere with life goals (e.g., avoiding thinking about our child's diagnosis can interfere with our goal of getting them optimal support in school) and is ultimately ineffective at resolving the distress (Ford et al., 2017; Greenberg, 2008). This resonates with the pattern of *protective maneuvering* identified in the current study: when parents engaged in a high degree of *protective maneuvering,* the *swell of distress and uncertainty* continued to rage.

In many ways, actions-interactions categorized as *protective maneuvering* appear to be the inverse of *processing-oriented advancing.* The latter involved parents turning toward their thoughts and feelings about the news – reflecting on what the diagnosis means for their child and their family, acknowledging the uncertainty of the future, expressing and accepting their emotional reactions. As one mother commented:

> "You would have to also deal with that, with your emotions. And, you know, okay, you need to have them in order for you to keep going on and just to have, like, your mind where it has to be."

The current study identified that parents who engaged in more *processing-oriented advancing* presented with less intense *swells of distress and uncertainty* than other parents at the time of the research interview. This finding resonates with research on acceptance and emotion processing. Acceptance, or the willingness to experience your thoughts and feelings without judgment, leads to greater psychological health and less negative affect (Ford et al., 2017; Hayes et al., 2006; Leahy, 2002). Ford et al. (2017) concludes that "when people accept (versus judge) their mental experiences, those experiences run their natural – and relatively short-lived – course, rather than being exacerbated." Although it may sound counter-intuitive to some, it is argued that "the only way out is through" when it comes to changing our emotional reactions (Hunt, 1998; Pascual-Leone & Greenberg, 2007). Greenberg and Pascual-Leone theorize that turning toward our emotions and articulating our needs fosters the experiencing and resolution of primary emotions (i.e., fundamental reactions to a situation, such as experiencing fear in response to perceived threat) and the transformation of secondary emotions (i.e., reactions to emotions, such as experiencing shame in response to experiencing fear) (Greenberg & Pascual-Leone, 2006; Pascual-Leone & Greenberg, 2007).

5.2.3 Validation and Relational Resilience

In this section, I link the present findings with the related literature on validation and relational resilience. Validation is an interactional process in which a person shares thoughts and feelings and a listener communicates understanding and acceptance for that person's experience (Linehan, 1997). Humans are relational by nature – being seen and accepted by others has a powerful effect on our ability to connect with, express, and regulate our internal states (Elliott, 2004; Greenberg, 2008). It is well-established that the interactional process of validation facilitates arousal reduction, emotional regulation, and psychological processing of our reactions (Bohart & Greenberg, 1997; Fruzzetti & Shenk, 2008; Greenberg, Auszra, & Herrmann, 2007; Linehan et al., 2002; Shenk & Fruzzetti, 2014). In studies where validation is experimentally manipulated, people whose stressful and painful experiences are validated report more positive affect, less negative affect, and less physiological reactivity compared to people whose experiences are invalidated (Linton, Boersma, Vangronsveld, & Fruzzetti, 2001; Shenk & Fruzzetti, 2011; Vangronsveld & Linton, 2012). For example, Shenk and Fruzzetti (2011) had participants complete a series of difficult and frustrating tasks. Randomized to condition, participants were met with either validating or invalidating responses from the experimenter (e.g., "Most other participants have expressed the exact same feeling" compared to "There's no need to get upset"). Those who received validating responses had decreased heart rate and skin conductance as well as decreased negative affect compared to those who received invalidating responses.

In the face of life's stressors, we can be left feeling immobilized and isolated without the support of empathic connections to others (Jordan, 1992). The current study proposes that *obtaining the right support* is a condition that helps enable parents to shift from *protective maneuvering* toward *processing-oriented advancing* following the shock and distress of diagnostic feedback. The nature of support that parents valued strongly echoes the interactional process of validation. In the moment of receiving the news, they valued support from clinicians who made time to listen and attend to their emotional reaction. They valued support from clinicians and other people who “get it”, “relate to how we feel”, and “really completely understand.” One parent spoke of the significance of validation explicitly:

> “I mean, the realities are the parents are going to be the people that are going to advocate for those children, so their emotional state towards this needs to be checked in with -- We’re talking about the moment when you’re talking to them, it’s – validate them. Ask them how they’re feeling – be sincere. Make them understand that what they’re feeling, whatever that looks like, is very much okay. Take the time to actually look at the parents and ask how they’re feeling.”

Diagnostic feedback for autism is an emotionally-arousing and anxiety-provoking experience for parents. Validating responses from the clinician and other people who ‘get it’ may help facilitate arousal reduction, emotional regulation, and psychological processing of parents’ reactions. This could be the underlying mechanism that enables parents to shift from *protective maneuvering* toward *processing-oriented advancing*.

The importance of empathic, affect-oriented communication has been highlighted before in research on disclosing diagnoses of developmental disability. Quine and Rutter (1994) suggested that the clinician’s affective behaviour (e.g., communicating that they understand the parents’ concern) is more important to parents’ experiences of diagnostic disclosure than whether parents understand and remember the content of the meeting. Sharp et al. (1992) analyzed the preferences of 189 parents of children with developmental disabilities, and parents’ top preferences were for the clinician to express caring, to be allowed to talk, and to be allowed to show their feelings. The results from these studies resonate with the grounded theory *protecting myself and my child.* The present study offers a tentative explanation that *obtaining the right support* – having our experiences understood and accepted by others – contributes to a reduction in the alarm and distress response that swells when hearing the news of the diagnosis.

The literature on validation and relational resilience has implications for another condition in the current study, *deferring to the clinician-as-expert.* Validation is an interactional process. In its simplified form, there are two parts: (i) the self-disclosure of vulnerable thoughts, emotions, or desires, and (ii) a response that communicates understanding and acceptance of the person's experience. *Deferring to the clinician-as-expert* can impede the self-disclosure aspect of this interactional process. *Deferring to the clinician-as-expert* involves *following the clinician's lead* and *quieting appeals for emotional help,* meaning that parents are likely to be reticent to disclose their inner turmoil if the clinician does not create a space that encourages and normalizes this expression. When we are feeling under threat, we require a sense of relational safety to show our vulnerability (van der Kolk, 2014). As Jordan (1992) states, "acknowledging vulnerability is possible only if we feel we can reach out for support. To do so we must feel some confidence in the relationship" (p. 5). Conforming to traditional clinician-client roles would be expected to hinder open communication (St. Claire, 2004), constraining parents' ability to *obtain the right support* during diagnostic feedback.

5.3 Limitations and Future Directions

This study provides an empirical foundation for an innovative theoretical understanding of parents' journey through diagnostic feedback for autism, and tentatively links this understanding with broader knowledge on the psychological response to threat and distress as well as validation and relational resilience. As with all knowledge, the outcome of this study is a fallible interpretation; however, the careful and critical application of grounded theory methods and retroductive reasoning builds confidence in the results. The grounded theory *protecting myself and my child* is intended to be a living theory, meaning that the ideas behind it will continue to grow and evolve with time and the accumulation of more knowledge. Additional research is needed to critique and advance the ideas presented herein. Moreover, future research may identify new conditions that impact on parents' journey through diagnostic feedback for autism. The conditions identified in this study were those that appeared most prominently in the data, and they are not considered exhaustive. As reality is an open system with an interminable number of complex conditions influencing people’s actions-interactions, there would be other social-psychological processes with causal tendencies to explore.

The nature of critical realism and grounded theory led to a focus on developing knowledge about concepts rather than on a description or analysis of specific cases. As such, I would consider the central process of this study, *protecting myself and my child,* potentially to have generic transferability to other populations and contexts – similar to how I applied concepts from Lalor et al.’s (2012) grounded theory on antenatal diagnosis of fetal abnormality. The conceptual underpinnings of *protecting myself and my child* could transfer to a variety of situations where parents receive diagnostic or other health information about their child. Future research could explore these applications, refining and refuting the theory as needed.

When considering the transferability of these findings, I would be mindful of the context in which information was generated (e.g., a specialist clinic) and how this may appertain to other contexts. I would also be heedful that this study explored the experiences of parents of young children up to age 10. This age range encompasses the most common period of autism diagnosis (Baio et al., 2018; Public Health Agency of Canada, 2018); however, identification during adolescence and adulthood still occurs. I would expect there to be distinctive aspects to the experience of diagnostic feedback in the context of late diagnosis. By this advanced developmental stage, a diagnosis may fuel less uncertainty about the future – it may ignite less of a visceral sense of threat and more of a threat (or a welcome catalyst) to identity formation. This is an area ripe for future research. Research tackling this area would be wise to explore the experiences of the adolescents and adults receiving the diagnosis, as they would be important agents in the diagnostic process.

A strength of this study is the diverse representation of parents from different sociocultural backgrounds, spanning the gamut of education levels, income, immigrant generation status, and family origin. This is regrettably still rare for research studies in this field. Some studies do not report on this information at all, revealing that it was not a consideration, while others describe samples that are overwhelmingly white and/or of high socioeconomic status (e.g., Abbott et al., 2012; Nissenbaum et al., 2002). As this study took place in a large city, one aspect of diversity that was not captured was non-urban parents. While fathers and single parents were represented here, their voices could be amplified in future research, as mothers and co-parents were more prevalent. Future in-depth examination could continue to query whether there are social conditions relevant to these groups that affect the actions-interactions of diagnostic feedback.

Another social group that was not captured in this study was parents who did not speak English, the language in which the diagnostic service was delivered. Any level of conversational English was welcomed for participation; however, I am only fluent in English and was not able to provide translation services. This means that parents who received feedback through an interpreter were not represented in this study. As one of the first forays into conceptualizing parents' journey through diagnostic feedback, I believe this study has much to offer without the added complexity of including non-English speakers. At the same time, there is a need for future research to listen to the voices of this marginalized group and explore any distinctive aspects of their journey through diagnostic feedback. The impact of linguistic barriers would be underestimated in the current results.

5.4 Clinical Implications

Much of the emphasis in clinical training is on how to *determine* a diagnosis and stops short of addressing how to *communicate* a diagnosis (Barnett et al., 2007; Braaten, 2007; Fallowfield & Jenkins, 2004; Merker et al., 2010). While there is growing acknowledgement that a diagnosis should be delivered sensitively, we still have little insight or explication as to what, exactly, that would look like in the clinical encounter. The current research was explicitly motivated by a desire to generate knowledge to help fill this gap. By advancing our understanding of parents' experiences, the findings from this study hope to advance our understanding of how to provide high-quality, compassionate care when communicating a diagnosis of autism. In this section, I reflect on the clinical implications of the current findings.

The grounded theory *protecting myself and my child* identifies an emotion-laden process, handling perceived threat to self and child, as the core process of parents' journey through diagnostic feedback for autism. Let us return to a pertinent quote from a Canadian parent advisory group as well as the words of one of the parents in this study:

> "Clinicians and researchers sometimes forget they are dealing with real families who are going through difficult times [...] The process of assessment is not just about symptoms and questionnaires, but concerns [our] tears, fears, joy, relief, anguish, and hope."
> (Miriam Foundation, 2008, p. 6)

> "When you're given a diagnosis like that, and it's life-altering in many ways, you want a little bit more humanity to it."

At a fundamental level, I believe the findings from this study call for us to uphold the humanity of diagnostic feedback. The rest of this section will consider how this might be done.

The language around the act of diagnosis tacitly conveys that the focus is on information-sharing: the clinician delivers the news; the parent receives the news. The focus is on information, and the flow of information is one-way. However, the present findings problematize the wisdom of information-sharing as the sole or even primary focus of feedback. This grounded theory suggests that we may be presenting information to parents at a time when they are not psychological prepared to integrate new, complex information. We may be expecting parents to listen attentively at a time when they are emotionally-aroused and anxious. It seems as if the clinician and parent are at cross-purposes: the clinician has a cognitive purpose (i.e., deliver information) and the parent has an emotional one (i.e., handle threat response, protect self and child). As they are, these cross-purposes would hamper a synchronous interaction. A father in this study contrasted his ideal and actual experiences of feedback in a way that underlines these cross-purposes:

> "Because it's a warm person who you know has – and this is going to be a really bad way of putting this – feelings about what they're about to -- you know, they're

> connecting with you on it, as opposed to just, I'm here and I'm delivering this message to you. Okay. Did you get it? Great. You know what I mean? As opposed to, how are you feeling about it? How does it make you -- It could be that interaction as well."

Considering these cross-purposes, the present findings invite clinicians and service providers to think deeply about our role and how we can best use our expertise to facilitate parents' journey through what is, primarily, an emotional process. What are our objectives during diagnostic feedback and why? What would it be like to shift the focus from delivering information toward attending to and validating parents' reactions? What presumptions have we made about what is going on for parents? What stirs up our own discomfort during diagnostic feedback? Who are we as clinicians, sharing this visceral struggle with parents? How can we be present in a human-to-human way, belly-to-belly with the parent in front of us? Certainly, these are tough issues to grapple with, and there are no simple answers.

One way forward is to reflect on and design our services in a way that values what parents need to take in their child's diagnosis and thrive. We know that hearing that their child has autism is a big deal. Especially when parents are not intimately familiar with autism, the news ignites a sense of threat and shock. The current findings, as well as the broader literature on psychological responses to threat and distress, suggest that we can expect – and prepare for – parents to feel a surge in their emotional and physiological systems, have difficult absorbing new information, and experience swelling distress and uncertainty when they are presented with the diagnosis. The higher their degree of perceived threat, the more we can expect – and prepare for – parents to disengage, push away the news, or embattle. The current findings, as well as the broader literature on validation and relational resilience, suggest that the opportunity to talk with someone who 'gets it' has a powerful effect on parents' distress. Having someone communicate understanding and acceptance of their experience can help them connect with and process their reaction to the news.

This study does not offer a one-size-fits-all solution; instead, it urges services providers to think critically and creatively about their practices as well as the individual family in front of them. In this vein, Table 10 translates aspects of the grounded theory *protecting myself and my child* into a series of clinical reflection questions intended to help us recognize and uphold the humanity of the diagnostic encounter.

Table 10. *Considering Theory in Practice: Clinical Reflection Questions*

Aspect of Grounded Theory	**Clinical Reflection Questions**
Undercurrent of anticipating	- How can I be mindful that this parent has been wondering and worrying about their child for a long time?
Reacting to perceptions of autism	- What are this parent's perceptions of autism? Do they have any close relationships with people with autism? - What might this mean for how they take in the diagnosis (e.g., the degree of perceived threat and intensity of their emotional reaction)?
Sounding the alarm; Swelling distress and uncertainty	- How can I be mindful that announcing the diagnosis is likely to trigger a surge in their emotional and physiological systems – even if they are half-expecting the diagnosis? - How can I accommodate the likelihood that it will be very difficult for this parent to absorb and assimilate new, complex information during this high-stress meeting?
Obtaining the right support	- Do I feel comfortable creating a space to listen, attend to, and validate this parent's in-the-moment reactions? Is there another member of my clinical team who can help with this part during diagnostic feedback? - Am I able to offer timely follow-up contact to check-in with how this parent is handling the news? - Does this parent have connections to other people who are comfortable with autism? If not, how can I facilitate those connections?
Deferring to the clinician-as-expert	- How can I be aware and reflective of typical dynamics of the client-clinician relationship (e.g., parents may follow my lead and quiet appeals for emotional help)? - How can I create a space where this parent feels safe, comfortable, and welcome to share their reaction to the news?

Protective maneuvering; Instrumental responding; Processing-oriented advancing	- How can I normalize any distress or uncertainty this parent may be feeling (e.g., almost all of the parents I see feel stunned, it is hard to process; it is common to feel overwhelmed with uncertainty)? - How can I communicate understanding and acceptance for however this parent is handling the news? - How can I help this parent maintain some sense of control? Are there clear, simple steps I can share so that they can take action to help their child?

Note. Due to the dynamic and interwoven nature of the grounded theory, some questions would fit well in more than one category but have been placed in one as a matter of course.

5.5 Conclusion

Receiving a diagnosis of autism is a pivotal event in parents' lives; however, parents' experiences of this event remain poorly understood and insufficiently attended to by clinicians and researchers. Moreover, the literature on the act of diagnosis in autism is predominately atheoretical, making it hard to generalize findings or generate hypotheses about parents' experiences. The current study attempted to fill this gap by building a social-psychological conceptualization of parents' journey through diagnostic feedback. The theory building process was grounded in constant comparison with interview data from twenty-seven parents in Ontario, Canada. These parents came from a range of sociocultural backgrounds, held a range of expectations about their child's assessment, and experienced a range of reactions to the news that their child had autism.

The result was a grounded theory centered on the dynamic process of *protecting myself and my child,* offering new insight into parents' experiences anticipating, hearing, and dealing with the life-altering news that their child has autism. The study offers an account of the mechanisms that underlie the action-interaction of diagnostic feedback and the conditions under which they occur. Thus, the theory addresses three interrelated questions: How are parents responding? Why are they responding this way? When do they respond differently? Answers to these questions can help clinicians and other stakeholders think deeply about their role and how they can best use their expertise to facilitate parents’ journey through diagnostic feedback. At a fundamental level, the findings from this study problematize the wisdom of information-sharing as the sole focus of the diagnostic encounter and call for us to uphold the humanity of diagnostic feedback – it is, after all, an emotional process.

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Appendix A
Sample Interview Guide

This guide offers questions to prompt the exploration of parents' experiences in rich detail. The interviewer's role is to listen, clarify, and follow the parents' lead regarding topics of importance.

Opening

Today we will spend much of our time talking about your experience of the feedback meeting when you first heard that [child's name] was being diagnosed with autism.

First, I'd like to hear a little bit about your family and [child's name].

- Could you tell me what he is like, what his relationships are like, what he enjoys doing?
- What do you notice as far as his challenges?

Before you had [child's name]'s assessment, what was your experience of autism?

- Did you know anyone with autism, or learn about autism from anywhere?

Telling the Story of Diagnostic Feedback

Now, let's focus on the day when you heard that [child's name] was being diagnosed with autism.

- Could you walk me through your experience of that day?

Further Exploration

People think and feel all sorts of things when hearing the news that their child has autism.

- What was it like for you?
- What was going through your head?

Was there anything the clinician did that was helpful or not helpful?

- Was there anything the clinician said that stood out – or was confusing?

How did the news impact you after you the meeting?

- How has the news and your reaction to the news impacted your relationship with your partner?

What does [child's name]'s autism diagnosis mean to you?

Have you shared the news of the diagnosis with other people? What has that been like for you?

What advice would you give a new clinician about how to deliver the news of a child's diagnosis of autism?

Closing

Is there anything we else that you would like to share?

What do you imagine or hope for your child/family in the future?

What drew you to take part in this study?

Appendix B
Demographic Questionnaire

We want to understand more about the diversity of people taking part in our research study. Please fill out the questions below about yourself. Let us know if anything is unclear.

Your Gender: _______________________ **Your Age:** _______________________

Language(s) Spoken at Home: ____

Generation Status:

☐ 1st generation Canadian	*You moved to Canada*
☐ 2nd generation Canadian	*Your parents moved to Canada*
☐ 3rd + generation Canadian	*Your grandparents, great-grandparents, or beyond moved to Canada*
☐ N/A	*Indigenous people of Canada*

Family Origins – Check all that apply:

☐ African origin	*(e.g., Nigeria, Ethiopia, Zimbabwe)*
☐ European origin	*(e.g., Ireland, France, Poland)*
☐ South Asian origin	*(e.g., India, Pakistan, Bangladesh)*
☐ South-East Asian origin	*(e.g., Philippines, Malaysia, Vietnam)*
☐ East Asian origin	*(e.g., China, Korea, Japan)*
☐ Middle-East/West Asia origin	*(e.g., Iran, Uzbekistan, Israel)*
☐ Latin American origin	*(e.g., El Salvador, Colombia, Chile)*
☐ Caribbean origin	*(e.g., Jamaica, Guyana, Trinidad)*
☐ North American aboriginal	*(e.g., First Nations, Métis, Inuit)*

☐ Other: ____

In the last year, have you been employed outside the home?

☐ No, I'm a full-time parent
☐ Yes, part-time
☐ Yes, full-time

What was your job?

____
____

Household Income:

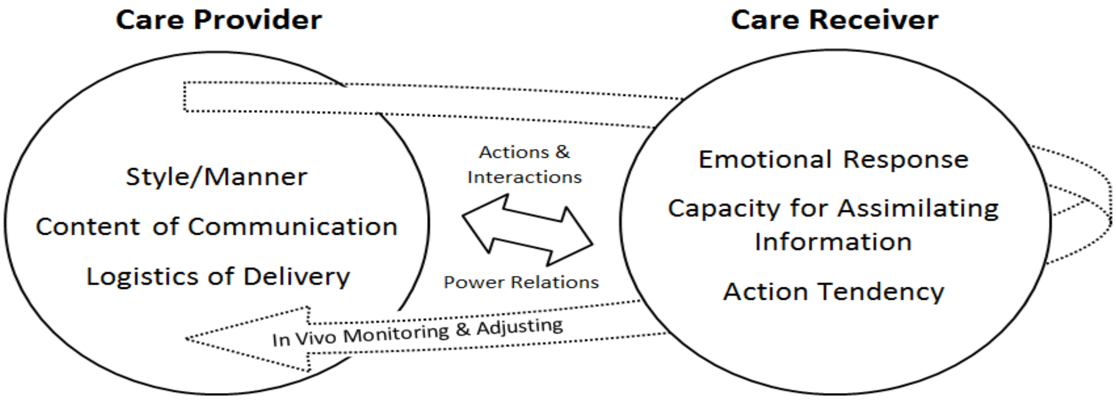
☐ < $45,000
☐ $45,000-$90,000
☐ > $90,000

Educational Background:

☐ High school or elementary school
☐ College diploma or equivalent
☐ Bachelor's degree
☐ Master's degree
☐ Doctoral degree (Ph.D., M.D.)

Appendix C
Conceptual Diagram Before Data Generation

Before beginning data generation, I identified sensitizing concepts and diagrammed the relationships I imagined between these concepts. These ideas provided initial direction, but they needed to 'earn their way' from the data to be retained (Bowen, 2006; Charmaz, 2014).



Appendix D
Dear Clinicians: Advice Offered by Parents

Near the end of each interview, each parent was asked, "What advice would you give a new clinician about how to deliver the news of a child's diagnosis of autism?" Some parents gave one piece of advice and others offered a couple ideas. All have been included here and roughly grouped together by topic.

- **Suggest parents bring someone with them**

  "Tell them to come with somebody."

- **Be responsive**

  "Giving the parents some time to kind of -- giving them time also just to sit there and be like – Okay. Silence."

  "Be a good listener."

  "I mean, the realities are the parents are going to be the people that are going to advocate for those children, so their emotional state towards this needs to be checked in with -- We're talking about the moment when you're talking to them, it's – validate them. Ask them how they're feeling – be sincere. Make them understand that what they're feeling, whatever that looks like, is very much okay. Take the time to actually look at the parents and ask how they're feeling."

  "Seem like you're sincere and that you – you sympathize with the family and that you're giving them time. Because I think for me that's one of the biggest things. Like, if they seem like they're rushed, or it's just like, they just give the diagnosis but don't really care, it's just their job."

  "Gently -- Just lots of empathy."

  "Validating the parents."

  "Not argue with the parents."

  "It's a sensitive issue – and the parents, we're going to be like devastated. So, being careful and being determined in disclosing this kind of -- Like be sensitive in that."

  "This is a difficult time for the families, right? Usually they will be nervous but [the clinician] has to handle them in a proper way."

  "Know your audience."

  "If I were interviewing doctors for this place I would definitely be looking at somebody who has a nurturing, kind, understanding personality."

  "Be genuine and kind."

  "Just listening and answering questions."

- **Check-in before delivering the news**

  "I strongly recommend, what they did with us, and that is to find out where their mindset is at, before they go in. I feel like that like, is so small, but so important, right."

  "I just think the doctor needs to understand or have the question, 'What brought you here today?' Maybe getting a feeling for where their headspace is, and then if I were a doctor that would definitely help me deliver the news differently, right?"

- **Get to the point**

  "Although the clinician or the doctor or whoever has only been doing this for three sessions, the parents have been waiting, because they've suspected something, for years. So the longer you take, the more they're just looking and going, "Okay. Okay. Yeah, great. Go, go, go. Tell me. I need to know."

  "Don't frontload the conversation with everything that you know about autism."

  "I think I would say maybe start with the diagnosis at first. I think going through the criteria -- Everybody's going to react a little differently, but I was like okay get through it, get through it, like I was waiting [to hear] so does he have it or does he not"

  "Be upfront and don't pussyfoot around issues, don't give somebody a stupid photocopied picture of an umbrella saying this is how we approach autism these days. I don't know, like maybe start with we've found that your child has autism and here's why."

  "Start right off like here it is and here's what we're going to do."

  "Try not to delay too long telling you. But it was good that she went over the test, but she didn't have to go into such detail to prolong the wait to find out."

- **Explain how the diagnosis pertains to this child and what it means for the family**

  "[The clinician] has to give them clearly how she made the diagnosis and what is it and how it's going to affect that individual and the family then socially and what we can do further."

  "Maybe the doctor needs to explain from a list. 'I diagnose your kid with autism because he had this one, this one, this one.'"

  "Tell me exactly how this pertains to my child."

  "Clear explanations of what that means. Like what does it mean for your family."

- **Communicate in simple, understandable ways**

  "Try to use simple words, like explain it in English compared to doctor-speak. Make sure that who you're telling understands what you're saying."

  "Explain things that are very much in a simple language, so parents understand."

  "Some type of visual to go along with the fact base might help."

- **Explain what autism is**

“They should be aware that people aren’t aware of what autism is because they think of Rain Man. I did.”

“Explain social and communication disorders just basically mean this, and that's what autism is. And this is what we've determined your son or daughter is. And I think that takes the -- it takes the threat away.”

- **Be neutral**

“Neutrality is a big part, stay as neutral as you can.”

- **Inspire hope**

“You have to know how to break the news. Like break the news and give them hope at the same time.”

- **Have another professional in the room to provide emotional support**

“Having a second person there, not on my end, even on their end besides just the doctor to be like kind of the person -- The supporting person instead of saying well you're going to see a social worker in three weeks, [already have a] social worker there to provide the kind of more emotional -- You know the doctor can just deliver the diagnostic criteria and maybe someone else is there that’s there to provide the emotional support.”

- **Highlight child’s strengths**

“Pointing out the strengths of the child. Every parent likes to know what their kid’s good at. They want to hear what their kid is good at, right. So, when they showed us the areas of what they took into-- when they made their diagnosis, like, their behaviour, the social. It was like you know, yes, he's like really good at here. He's was really great at here. Like this is where we needed like some. It's like a sandwich: information where it is good-bad-good.”

“Point out the good points [about the child] as well as the bad points.”

- **Provide clear next steps**

“The big thing is the next steps, because when you leave the room and you don't have those next steps you're like, ‘Okay, what does this mean? What am I going to do?’”

“Give the parents their prioritised treatments, what he needs first.”

“There is a lot that can be done to empower the parents quickly, right. And I mean, I think it should be clear that now that you've got the diagnosis, as soon as the letter comes out, you should register with the – you know, it’s almost like, even a checklist of things for us to do with the flow of events – that will be very useful.”

“Give a future plan – at least an overview what we can do. He may not have enough time to give it in detail, so he could -- Reassure the parents that there is something they can do.”

"Being prepared when the parents ask, 'What do we do now?' "

"Give them, like, different types of treatment that is possible. Like, just a generic, right, is … okay, he has … your child has autism, like, whatever level it is and just a brief explanation, like we mentioned, of what does that involve and possible options according to that. Like, you know, there's the [Denver] model, there's this model. So, look at those three, something that you can start looking and see your options, so as parents you can start preparing."

- **Do not rush the meeting**

"The result that was given back to us, and I think it's rather too short, like, about that one hour. I know it's not [the clinician] that dictates this, but it needs another structure of this, kind of, diagnosis. We would like to have a little bit longer time, you know, to discuss. One of them, you know, rush everything. That's basically giving the shrug, but we don't have time. We don't have enough time to really - our concerns are not respected. Yes, we would like to have a little bit longer time."

"I think making sure they have enough time, as much time as the family needs and not feeling like you're being rushed."

"It's a message that I think no matter how it gets delivered, you need a lot of time, because people are going to need to react to it. So, if you are going to deliver the message, I think they've got to be conscious about the fact that most of what they say for probably the next five minutes aren't going to be absorbed by the people when they're sharing the diagnosis."

- **Do not highlight inexperience**

"Maybe not talk about, like, patients or a group of people that you haven't seen. Just talk about, like, your -- I think for me that's like the worst thing that you can do, is just to say, oh, I haven't done this before, I don't really see kids this age."

- **Offer follow-up contact and support**

"A follow-up appointment or a follow-up phone call to say, you know, hey, a week ago you had this, that – you know, your child had this diagnosis. Where are you in terms of – I think that would be very helpful."

"Saying okay now with this diagnosis, this is what we can do for you. This is where we can direct you to. This is who you will be seeing. Start with a social worker, that kind of thing, because I think the family really needs that. Especially if there's other children involved, right. Like having someone there who can like talk to the whole family. Maybe not right away. Because people have to go home and adjust for a duration. But, like a week or so, and like having like somebody that could help the parents, or the family members on, okay, 'How has your week been? Like, what have you…' you know, just to kind of touch base."

"It would be nice if they see us. Because this- like, continuing. They tell us improvement stages, or what to expect. Once you're diagnosed what to expect. That part, I think we don't know. And that's big."

- **Connect parents with other parents**

  "Whether [the clinician] could connect the parents to some other parent who have the same child, so they can share the experience"

- **Be aware of cultural differences**

  "Be aware of cultural differences, because I notice that talking to different parents with their issues with their kids, as a parent there are cultural, different cultural views of autism. So I think it's really important to be versed in that and at least prepared even if that reaction doesn't happen. Be prepared."